

# Handbook of Health Social Work

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Edited by  
Sarah Gehlert and Teri Arthur Browne



John Wiley & Sons, Inc.



Handbook of Health  
Social Work



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*This book is dedicated to the memory of my beloved son  
Matthew Gehlert who had the soul of a social worker.*





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# Foreword

**T**HIS BOOK IS a compendium of the history, roles, domains, and contemporary practice issues of social work in health care and health settings. This volume provides a comprehensive and effective overview to contemporary social work practice in health care. It begins with an examination of the historical roots and evolution of social work practice in health care during its first 100 years. It connects the dots for social work health practitioners in understanding the origins of many practice issues and the ways the profession has developed and advanced in the context of these practice issues and the larger milieu in which health issues emerge. Using that foundation, the authors build a comprehensive conceptualization of biopsychosocial health social work in the context of human health, behavior, and psychological functioning, shaped by the social and public health policy in prevailing political and economic contexts.

The myriad social work roles, functions, and models are examined in the context of the current design and delivery of health care as well as social work traditions. Critical differences and alliances between the medical and biopsychosocial models of health are examined. Ethical issues, the profession's code of ethics, social work research, and contemporary issues such as access to health care, reproductive rights, genetics, and practice conflicts related to bureaucratic policies such as managed care are examined and provide the foundation and practical tools to navigate not only the challenges of today, but also evolving technologies and health frontiers of tomorrow.

The authors in this *Handbook* cover the spectrum of settings in which health social work practitioners work. In doing so, they provide the practitioner cutting-edge information on practice fundamentals and best practices in settings with children, older adults, and families; in health and mental health; and in hospital and community arenas. Specific skill sets in team development, communication, data management, negotiation, problem solving, and biopsychosocial interviewing and interventions are presented. In these practice settings, the authors clarify the role of social work as a change agent, counselor, negotiator, service provider, manager, and leader. The *Handbook* provides both a foundation for social work practice in health care and also a guide for strategy, policy, program, and practice development in proactive and actionable terms.

The *Handbook of Health Social Work* is a remarkable resource for the practitioner and will greatly facilitate the understanding and practice of students or practitioners early in their practice. It places current practice in context,

provides cutting edge practice information, and connects practice to theory. It's "a must read" for social work educators, administrators, students, and practitioners. Anyone who reads this book will be better prepared for social work practice in health as an educator, administrator, policymaker, problem solver, leader, and clinician.

JAY CAYNER

# Acknowledgments

THE PREPARATION OF this *Handbook* involved the efforts of a number of people. First and foremost was Jerrod Liveoak, a very talented young man who helped us organize and edit the *Handbook*. We could not have done it without his assistance. Isabel Pratt and Tracey Belmont of John Wiley & Sons' behavioral science division were supportive throughout the process. The 29 contributors to the *Handbook*, some of whom were friends and others only known to us by reputation prior to the collaboration, worked hard and were patient with our edits. Our spouses Roy Wilson and Lyle Browne were always willing to listen to our fledgling ideas and provide feedback. Finally, we would like to thank Jeanne Marsh, dean of the School of Social Service Administration, for her encouragement and seemingly endless support of our work.



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# Introduction

**I**N A FACULTY meeting a few years ago, a colleague from another profession referred to the “lower level skills” of social workers in health care. She distinguished these skills from the “higher level skills” of social workers in mental health settings. I addressed her comment by citing the broad array of information that social workers in health care must possess and be able to access quickly to assess client situations and devise optimal plans in the limited time available to them in health-care settings. I characterized the process as highly challenging, requiring skills at least as well-developed as those of social workers in other arenas.

As health care becomes increasingly more complex, social workers have much to know. Current federal approaches to addressing complicated health conditions like HIV/AIDS and cancer argue strongly for simultaneous attention to factors operating at the social, psychological, and biological levels (see, e.g., Singer & Ryff, 2001). As members of health-care teams that take these approaches, social workers must possess sufficient knowledge at the social, psychological, and biological levels to converse productively with other members of the teams and work in concert with them constructively. In addition, to be effective, social workers must be aware of how these factors operate with individuals, families, groups, communities, and societies.

The *Handbook of Health Social Work* was developed to prepare students to work in the current health-care environment in which providers from a number of disciplines work more closely together than was ever the case in the past. Health care in the United States has moved from being multidisciplinary to being interdisciplinary, with the ultimate goal of being transdisciplinary. In multidisciplinary environments, professionals from different disciplines work on the same projects but speak their own languages, view health care through their own disciplinary lens, and share knowledge with one another after the fact. Interdisciplinary teams interact more closely, but each discipline continues to operate within its own boundaries. Because an interdisciplinary approach almost never provides a broad enough view of health-care conditions to capture their inherent complexities, transdisciplinary teamwork has become the exemplar. Here, health-care professionals work so closely together that they must develop a shared language and pool the best of their separate disciplinary theories. Absent of this new, more interdependent approach, the team is reminiscent of the old cartoon of a roomful of blindfolded people touching different parts of an elephant, with each describing the beast based only on the part that she is touching. One might base his description on the trunk, another on the ears, and a third on the tail. To effectively address complex health conditions like HIV/AIDS, we must recognize the elephant in the room.

The *Handbook of Health Social Work* considers social workers in health care to be active problem solvers who must draw from a variety of germane bodies of information to address the issues and problems faced by individuals, families, groups, communities, and societies. Its authors and layout reflect this approach. Learning exercises at the end of each chapter are designed to stimulate discussion and help readers process the information provided and consider it analytically. The book's chapters are sandwiched between a Foreword by Jay Cayner and an Afterword by Candyce Berger, both of whom have broken ground as social work leaders in health care and done much to raise the profile of the profession.

The book is divided into three sections. Part I, *The Foundations of Social Work in Health Care*, provides information that we consider basic and central to the operations of social workers in health care. "The Conceptual Underpinnings of Social Work in Health Care" discusses the principles that underlie the development of social work in health care and follows its course through time to determine any changes in principles and activities that may have occurred. "Social Work Roles and Health Care Settings" carefully outlines the wide array of roles performed by social workers in health-care settings today. "Ethics and Social Work in Health Care," after providing a framework for ethical decision making, considers some key issues confronting social workers in health care in a variety of arenas, from practice with individuals to policy development.

Because social work has played an integral role in public health in the United States and other parts of the world, a chapter titled "Public Health and Social Work" was included to orient readers to the public health perspective. The chapter introduces readers to the concepts of primary, secondary, and tertiary health care and considers health from a wider lens than is often used to view health care, including global patterns of health and disease. "Health Policy and Social Work" presents basic information on the interplay between clinical, administrative, and policy issues in health care. Although it is beyond the scope of this book to cover all possible health policies and considerations, an overview of the most pertinent policies and issues is provided. Because individuals and families do not operate independently, but rather as parts of communities, an overview of the relationships between health and community factors is included in Part I. "Community and Health" reviews significant evidence-based information and provides information about how knowledge about community factors can be accessed and included in social work activities in health care.

Part II is titled *Health Social Work Practice: A Spectrum of Critical Considerations*. Although cases and questions confronted by social workers in health care vary widely, certain critical issues should always be considered. The seven chapters in this part represent critical issues that should be considered in approaching cases or pursuing the answers to health-care questions, even though they may not prove in time to be germane to those cases or questions. Failing to consider issues such as religion, sexuality, or substance use may lead to incomplete understandings of cases or consideration of health-care questions. It was only after considering health beliefs, for instance, that Matsunaga and colleagues (1996) were able to understand why native Hawaiian women did not participate in breast cancer screening despite their high rates of breast cancer.

"Theories of Health Behavior" outlines five key theories and methods that can help guide social work practice and research in health care. Empirical evidence for their use in certain situations is provided. The complex interplay of physical

and mental health is addressed in “Physical and Mental Health: Interactions, Assessment, and Intervention.” The chapter carefully outlines how to assess for mental health concerns and reviews a variety of interventions. Because communication is central to the effective provision of health care, a chapter titled “Communication in Health Care” is included in Part II of this *Handbook*. The chapter provides a basic framework for understanding the dynamics of health-care communication; reviews interventions for improving communication; considers the effect of culture, gender, race, and other salient factors on patient and provider communication; and provides guidelines for the use of interpreters. It also addresses the dynamics of health-care teams and social workers’ position on teams.

“Religion, Spirituality, and Health” reviews the ways in which religion and spirituality affect health and individual and group responses to health care. Ways of incorporating religious and spiritual considerations into practice and policy are reviewed. Chapter 11, “Families, Health, and Illness,” presents a framework for understanding the interplay between family structure and dynamics and health and addresses its implications for social work practice and policy in health care. Chapter 12, “Human Sexuality and Physical Intimacy,” addresses the relationship between sexuality and health and provides ways to incorporate sexual and other intimate considerations into practice and policy. The author makes the point that sexual and other intimate issues are more likely to be faced by social workers in health care than in other areas of practice.

Because substance use is widespread today and can negatively affect health and response to treatment, it is important that social workers consider the topic in practice and policy. “Substance Use Problems in Health Social Work Practice” carefully outlines the importance of considering substance use and abuse and provides guidelines for incorporation into practice and policy.

Part III, titled Health Social Work: Selected Areas of Practice, contains nine chapters by social workers with extensive practice and academic experience. Selecting the areas to include was difficult, and the list is not meant to be exhaustive. Our aim was to present a range of examples of good social work practice in sufficient detail to provide a reasonable overview of social work practice in health care. Chapter 14, “Social Work with Older Adults in Health-Care Settings,” for example, outlines the issues central to practice with older adults and challenges faced by social workers. Chapter 15, “Social Work Practice and Disability Issues,” carefully frames social work practice with individuals and groups with disabilities and provides suggestions for practice. After providing background on end-stage renal disease and its psychosocial sequelae, Chapter 16, “Nephrology Social Work,” reviews evidence-based social work interventions, policies and programs, and resources and organizations available to nephrology social workers. Chapter 17, “Oncology Social Work,” similarly reviews psychosocial issues faced by patients with cancer and their families. Practice considerations are outlined and suggestions for interventions provided.

Issues of chronic illness are addressed in Chapter 18, “Social Work and Chronic Disease: Diabetes, Heart Disease, and HIV/AIDS.” Chronic conditions present a number of unique challenges to social workers, such as how to improve adherence to treatment recommendations. The authors outline these challenges and make suggestions for practice. Chapter 19, “Social Work and Genetics,” considers the role of social workers in helping patients and families learn and make decisions about genetic testing and to cope with its results. Chapter 20, “End-of-

Life Care," discusses how social workers can assist patients and families in dealing with these end-of-life issues effectively.

The management of pain in acute and chronic illness increasingly has become the domain of social workers in health care. Chapter 21, "Pain Management and Palliative Care," orients readers to the effect of pain on behavior and functioning and reviews roles for social workers in pain management and palliative care teams. Complementary and alternative treatments are reviewed in the last chapter, "Alternative, Complementary, and Integrative Medicine in a Conventional Setting." The author provides information on the extent of alternative and complementary treatments in the United States and reasons for their use. She reviews a number of treatments and their histories and addresses the importance for social workers of being familiar with complementary and alternative techniques.

Our aim in preparing the *Handbook of Health Social Work* was to provide a source of information for social workers that would help them to be active problem solvers rather than followers of routines and existing protocols. The book allows social work students to learn the foundations of practice and policy in health care (Part I), critical considerations in implementing practice and policy (Part II), and the ways in which social work is practiced in a number of arenas and with a number of health conditions (Part III).

We hope that the book will also be useful in professional education, allowing those already in practice to learn about issues such as pain management and alternative and complementary medicine that they might not have been exposed to while in school or had the opportunity to learn after graduation. It also is a valuable source of information on evidence-based practice in a variety of areas of health care.

Social workers in health care today face a number of challenges, some new and some that have always been with the profession. We hope that readers will use the 22 chapters of the *Handbook of Health Social Work* as a set of tools to help them better address the health-care needs of the individuals, families, groups, communities, and societies with whom they work.

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PART I

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THE FOUNDATIONS  
OF SOCIAL WORK IN  
HEALTH CARE





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## CHAPTER 1

# The Conceptual Underpinnings of Social Work in Health Care

SARAH GEHLERT

**T**HE WRITING OF this text coincides with the centennial of the hiring of the first medical social worker in the United States, Garnet Pelton, who began working at Massachusetts General Hospital in 1905. It seems an appropriate time to consider the history of social work in health care and to assess the degree to which the vision of its founders has been met in its first 100 years. Ida Cannon (1952), the second social worker hired at Massachusetts General Hospital, whose tenure lasted for 40 years, wrote, “basically, social work, wherever and whenever practiced at its best, is a constantly changing activity, gradually building up guiding principles from accumulated knowledge yet changing in techniques. Attitudes change, too, in response to shifting social philosophies” (p. 9). How, if at all, have the guiding principles of social work in health care changed over the century?

This chapter focuses on the development of the profession from its roots in the nineteenth century to the present. This longitudinal examination of the profession’s principles and activities should allow for a more complete and accurate view of the progression of principles through time than could have been achieved by sampling at points in time determined by historical events, such as the enactment of major health-care policies.

### CHAPTER OBJECTIVES

- Discuss the historical underpinnings of the founding of the first hospital social work department in the United States.
- Describe the forces and personalities responsible for the establishment of the first hospital social work department in the United States.
- Determine how the guiding principles of social work in health care have changed from the time of the founding of the first hospital social work department to the present time.
- Determine how the techniques and approaches of social work in health care have changed from the time of the founding of the first hospital social work department to the present time.

Frequent references to other chapters in this book capture the current conceptual framework of social work in health care.

### THE HISTORICAL FOUNDATION OF SOCIAL WORK IN HEALTH CARE

Social work in health care owes its origins to changes in: (a) the demographics of the U.S. population during the nineteenth and early twentieth centuries; (b) attitudes about how the sick should be treated, including where treatment should occur; and (c) attitudes toward the role of social and psychological factors in health. These three closely related phenomena set the stage for the emergence of the field of social work in health care.

A number of events that began in the mid-1800s led to massive numbers of persons immigrating to the United States. In all, 35 to 40 million Europeans immigrated between 1820 and 1924. The Gold Rush, which began in California in 1849, and the Homestead Act of 1862 added to the attractiveness of immigration.

About 5.5 million Germans immigrated to the United States between 1816 and 1914 for economic and political reasons. Over 800,000 arrived in the 7-year period between 1866 and 1873, during the rule of Otto von Bismarck. The Potato Famine in Ireland in the 1840s resulted in the immigration of two million persons during that decade and almost a million more the following decade. Between 1820 and 1990, over five million Italians immigrated to the United States, mostly for economic reasons, with peak years between 1901 and 1920. A major influx of Polish immigrants occurred between 1870 and 1913. Those arriving prior to 1890 came largely for economic reasons and those after for economic and political reasons. Polish immigration peaked again in 1921, a year in which over half a million Polish immigrants arrived in the United States. Two million Jews left Russia and Eastern European countries between 1880 and 1913.

The United States struggled to adapt to the challenge of immigration. The Ellis Island Immigration Station opened in 1892 to process the large number of immigrants entering the country. By 1907, over one million persons per year were passing through Ellis Island. The massive waves of immigration presented new health-care challenges, especially in the Northeastern cities where most of the new arrivals settled. Rosenberg (1967) wrote that 723,587 persons resided in New York City in 1865, 90% on the southern half of Manhattan Island alone. Over two-thirds of the city's population at the time lived in tenements. Accidents were common, sanitation primitive, and food supplies were in poor condition by the time they reached the city. One in five infants in New York City died prior to their first birthday, compared to one in six in London (Rosenberg, 1967). Adding to the challenge, the vast majority of immigrants had very limited or no English language skills and lived in poverty. Immigrants brought with them a wide range of health-care beliefs and practices that differed from those predominant in the United States at the time.

In the late 1600s and early 1700s, persons who were sick were cared for at home. A few hastily erected structures were built to house persons with contagious diseases during epidemics (O'Conner, 1976, p. 62). These structures operated in larger cities and were first seen before the Revolutionary War. As the U.S. population grew, communities developed almshouses to care for persons who were physically or mentally ill, aged and ill, orphaned, or vagrant. Unlike the

structures erected during epidemics, almshouses were built to operate continuously. The first almshouse, which was founded in 1713 in Philadelphia by William Penn, was open only to Quakers. A second almshouse was opened to the public in Philadelphia in 1728 with monies obtained from the Provincial Assembly by the Philadelphia Overseers of the Poor. Other large cities followed, with New York opening the Poor House of the City of New York (later named Bellevue Hospital) in 1736 and New Orleans opening Saint John's Hospital in 1737 (Commission on Hospital Care, 1947). Although called a hospital, St John's is classified as an almshouse because it primarily served persons living in poverty who had nowhere else to go.

By the mid-1700s, persons who became ill were separated from other almshouse inhabitants. They were at first housed on separate floors, in separate departments, or other buildings of the almshouse. When these units increased in size, they branched off to form public hospitals independent of almshouses. Hospitals eventually became popular among persons of means, who for the first time preferred to be treated for illness by specialists outside the home and were willing to pay for the service.

A number of voluntary hospitals were established between 1751 and 1840 with various combinations of public and private funds and patients' fees (O'Conner, 1976). The first voluntary hospital was founded in Philadelphia in 1751 with subscriptions gathered by Benjamin Franklin and Dr. Thomas Bond and funds from the Provincial General Assembly of Philadelphia. The New York Hospital began admitting patients in 1791 and the Massachusetts General Hospital in 1821. In 1817, the Quakers opened the first mental hospital, which began admitting anyone needing care for mental illness in 1834.

A third type of medical establishment, the dispensary, began to appear in the late 1700s. Dispensaries were independent of hospitals and financed by bequests and voluntary subscriptions. Their original purpose was to dispense medications to ambulatory patients. In time, however, physicians were hired to visit patients in their homes. The first four dispensaries were established in Philadelphia in 1786 (exclusively for Quakers), New York in 1795, Boston in 1796, and Baltimore in 1801.

#### NINETEENTH-CENTURY EFFORTS TOWARD PUBLIC HEALTH REFORM

The last half of the nineteenth century saw efforts to reform hospitals and dispensaries, many of which were led by women physicians. Dr. Elizabeth Blackwell, unable to find employment in hospitals because of her gender, established a dispensary for women and children in New York's East Side in 1853. The East Side had seen a massive influx of immigrants from Europe and was becoming increasingly crowded. Blackwell's dispensary provided home visits and by 1857 had secured a few hospital beds for its patients. The dispensary, which later became the New York Infirmity for Women and Children, provided home visits to 334 African American and White American patients in 1865 (Cannon, 1952). The following year, Dr. Rebecca Cole, an African American physician, was hired as a "sanitary visitor." When visiting families, Cole discussed topics such as hygiene and how to select and cook food and addressed issues of education and employment. In 1890, Mrs. Robert Hoe provided funds to the New York Infirmity for Women and Children to employ a full-time home visitor to work under the direction of Dr. Annie

Daniels. Dr. Daniels kept records of family size, income, and living expenses in the manner of social workers of the time such as Jane Addams, who founded Hull House in Chicago in 1889.

The first medical resident to work with Dr. Blackwell in New York, Marie Zakrzewska, moved to Boston and in 1859 became the first professor of obstetrics and gynecology at the New England Female Medical College. Dr. Zakrzewska established a dispensary and 10-bed ward in Boston in 1862, the New England Hospital for Women and Children. It was the first hospital in Boston and the second in the United States (after the New York Dispensary for Women and Children) to be run by women physicians and surgeons. As had the New York Dispensary for Women and Children, the New England Hospital for Women and Children featured home visiting, with increased attention to social conditions. For many years, home visits were part of the education of nurses and physicians in training.

In 1890, Dr. Henry Dwight Chapin, a pediatrician who lectured at the New York Postgraduate Hospital and the Women's Medical College of the New York Infirmary for Women and Children, established a program in which volunteers visited the homes of ill children to report on conditions and ensure that medical instructions had been understood and implemented. In 1894, he appointed a woman physician to do the job but soon replaced her with a nurse. Chapin's efforts led to a foster-care home for ill and convalescing children whose parents were unable to care for them adequately (Romanofsky, 1976). He founded the Speedwell Society in 1902 to encourage foster care. The Speedwell Society would have ties to the social work departments later established in New York hospitals.

A close partnership between the Johns Hopkins Hospital and Baltimore's Charity Organization Society at the turn of the century served as a breeding ground for ideas about how to merge social work and medicine. Four persons involved in these discussions were instrumental to the establishment of formal social work services in hospitals. Mary Richmond, Mary Wilcox Glenn, Jeffrey Brackett, and Dr. John Glenn, who became the director of the Russell Sage Foundation, were actively involved in the application of social work to medicine.

#### HOSPITAL ALMONERS IN LONDON

The first social worker, called a *hospital almoner*, was hired by the Royal Free Hospital in London in 1895. This occurred when the Royal Free Hospital came together with the London Charity Organization Society through Charles Loch. Loch was a very religious man who had served in the Secretarial Department of the Royal College of Surgeons for 3 years. He was appointed Secretary of the London Charity Organization in 1875 and brought with him a strong interest in the social aspects of health. While on the Medical Committee of the Charity Organization Society, Loch addressed a growing concern that patients might be misrepresenting their situations to receive free care. In 1874, the Royal Free Hospital asked the Charity Organization Society to screen patients to determine how many were indeed poor. They found only 36% to be truly eligible for services. Loch thought that individuals requesting care should be screened by "a competent person of education and refinement who could consider the position and circumstances of the patients" (Cannon, 1952, p. 13). Loch fought for many years to have an almoner appointed. He addressed the Provident Medical Association in 1885 and was called to testify before a committee of the House of Lords in 1891.

In 1895, Mary Stewart was hired to be the first social almoner at the Royal Free Hospital. Prior to assuming the position, Mary Stewart had worked for many years for the London Charity Organization Society. She was stationed at its entrance because her principal function at the hospital was to review applications for admission to the hospital's dispensary and accept those who were deemed suitable for care. Her secondary duties were to refer patients for services and determine who should be served at dispensaries (Cannon, 1952).

Stewart was given 3 months of initial funding by the London Charity Organization Society. Although by all accounts her work was considered productive, the Charity Organization Society refused to renew her contract until the Royal Free Hospital agreed to pay at least part of her salary. Ultimately, two of the hospital's physicians agreed to pay half of Stewart's salary for a year and the Charity Organization Society covered the other half. From that point on, social almoners were part of hospitals in England. By 1905, seven other hospitals had hired almoners.

In 1906, the Hospital Almoners' Council (later the Institute of Hospital Almoners) took over the training of almoners. The Institute for Hospital Almoners was responsible for the expansion of the almoner's repertoire to include functions such as prevention of illness. The first years of its operation saw the development of classes for prospective fathers, a hostel for young women with socially transmitted diseases, and other programs (Cannon, 1952).

#### THE FIRST SOCIAL SERVICE DEPARTMENT IN THE UNITED STATES

Garnet Pelton began work as a social worker in the dispensary of the Massachusetts General Hospital, 10 years after Mary Stewart was first hired to work at the Royal Free Hospital in London. Ida Cannon, who replaced Pelton after she became ill 6 months into her tenure and who held the position for 40 years, described "a special bond of fellowship between the English almoners and the medical social workers of our country" (Cannon, 1952, p. 20). She also described her own 1907 visit with Anne Cummins, an almoner at London's St. Thomas Hospital.

Garnet Pelton, Ida Cannon, and Dr. Richard Cabot were central to the establishment of the social work department at Massachusetts General Hospital. Relatively little has been written about Pelton or her short tenure at the hospital. Cannon (1952) briefly described Pelton's nurse's training at Massachusetts General Hospital and her contribution to the Denison House Settlement. While at the settlement, she brought Syrian immigrants from her South End Boston neighborhood to the hospital for treatment. Pelton was hired by Dr. Richard Cabot to work at Massachusetts General Hospital and began on October 2, 1905. She worked from a desk located in a corner of the corridor of the outpatient clinic at Massachusetts General Hospital and resigned after 6 months when she developed tuberculosis. The poor received treatment for tuberculosis in the outpatient department because they could not afford the sanitarium treatment. There is some question about whether Pelton contracted tuberculosis through her work in the outpatient department. At any rate, Cabot arranged for her treatment at Saranac Lake, New York, and later at Ashville, North Carolina.

Pelton was succeeded by Ida Cannon, who published two books and several reports on medical social work and about whom a fair amount of biographical information is available. Cannon was born in Milwaukee into a family of means. She was trained as a nurse at the City and County Hospital of St. Paul and worked as

a nurse for 2 years. She then studied sociology at the University of Minnesota, where she heard a lecture by Jane Addams and became interested in social work. She worked as a visiting nurse for the St. Paul Associated Charities for 3 years prior to enrolling in Simmons College of Social Work. Cannon met Richard Cabot through her older brother, a Harvard-educated physiologist, at the time that Cabot was organizing social services at Massachusetts Hospital. She was hired to replace Pelton in 1906, began working full-time after graduating from Simmons College in 1907, and was named the first Chief of the Social Service Department in 1914. She retired from Massachusetts General Hospital in 1945.

Dr. Richard Cabot was an especially prolific writer and has himself been the subject of scholarship over the years (see, e.g., Dodds, 1993; O'Brien, 1985). Cabot was a Harvard-educated physician who had a great deal to do with the establishment of social work and other helping professions in U.S. hospitals. He was active professionally from the 1890s through most of the 1930s, a time when professions were being defined (see, e.g., Flexner, 1910) and medicine was the standard for what it meant to be professional.

Cabot's paternal grandfather, Samuel (1784 to 1863), made his fortune in trading after first going to sea at 19 years of age. Samuel Cabot married Eliza Perkins, daughter of Boston's most successful trader, and eventually took over his father-in-law's firm. He is described as a practical man who believed primarily in action and hard work and favored commerce over culture (Evison, 1995).

Cabot's father, James (1821 to 1903), studied philosophy in Europe, trained as a lawyer, taught philosophy at Harvard, and was a biographer and friend of Ralph Waldo Emerson. He considered himself a transcendentalist, holding that, "the transcendental included whatever lay beyond the stock notions and traditional beliefs to which adherence was expected because they were accepted by sensible persons" (Cabot, 1887, p. 249). The transcendentalists questioned much of the commercialism of their parents' generation and were particularly critical of slavery. The Civil War, which began when James Elliott Cabot was 40 years old, was in part waged due to the sentiments of this generation. Cabot's mother, Elizabeth, bore most of the responsibility of raising the couple's seven sons, yet shared with her husband the transcendentalist's questioning of stock notions and traditional beliefs. Elizabeth Cabot said of women, "it seems to me that very few of us have enough mental occupation. We ought to have some intellectual life apart from the problems of education and housekeeping or even the interests of society" (Cabot, 1869, p. 45). O'Brien describes Elizabeth Cabot as "warmly maternal and deeply religious" and "tirelessly philanthropic" (O'Brien, 1985, p. 536).

The Civil War demoralized the nation and spawned a new conservatism and materialism. The publication of *Origin of the Species* by Darwin in 1859/1936, which brought an appreciation of the scientific method, and growing concern about the number of immigrants arriving in the country, added to a shift to realism from the idealism of James Elliott Cabot's generation. In the wave of social Darwinism that ensued, charity was seen as naïve and potentially harmful to its recipients. It was into this post-transcendentalist atmosphere that Richard Cabot was born in 1868.

The tension between his generation and that of his parents shaped Richard Cabot's vision. He took a radical centrist position based in philosophical pragmatism, taking two opposing views, and helped to locate a middle ground between the two. Rather than considering either side as right or wrong, he held that a



greater truth could emerge through creating a dialogue between the two sides. Throughout his career, Cabot saw himself as an interpreter or translator, able to find the middle ground between extremes.

Cabot first studied philosophy at Harvard and then switched to medicine. He rejected philosophers who observed rather than acted and for that reason was drawn to the philosophy of John Dewey. Evison writes, "action drew him; Jane Addams and Teddy Roosevelt appealed to him because they did something" (1995, p. 30). Cabot held that knowledge was gained through problem solving, even when hypotheses were not supported. Like Addams before him, he believed that people can learn from failure.

Cabot's senior thesis used epidemiologic methods to examine the efficacy of Christian Science healing (Dodds, 1993). By the time he had completed medical school in 1892, the germ theory of the 1870s and 1880s had taken hold, and the roles of technology and laboratory analysis had gained in salience. Cabot initially followed the trend by completing postgraduate training in laboratory research and a Dalton Research Fellowship in hematology. He turned down an appointment as the first bacteriologist at Massachusetts General Hospital, and in 1898, 4 years after completing his fellowship, accepted a much less prestigious appointment in the outpatient department.

Patients were treated in the outpatient department at Massachusetts General Hospital rather than in the wards when their cases were considered uninteresting or hopeless (Evison, 1995). Because no treatment existed for conditions such as tuberculosis, typhus, and diabetes, patients with these conditions usually were treated in the outpatient department, especially if they were poor. Medicines prescribed were largely analgesic (antibiotics were not developed until the 1940s). Many patients were immigrants who presented with language barriers and infectious diseases such as typhus. Adding to the bleakness of the situation was the depression of 1893, the worst that had been experienced to that date.

Cabot described the speed with which physicians saw patients when he first arrived in the outpatient department: Referred to by some physicians as "running off the clinic" (Evison, 1995, p. 183), a physician pulled a bell to signal a patient to enter the room. The physician would shout his questions while the patient was still moving and have a prescription written by the time the patient arrived at his desk. He would then pull the bell for the next patient.

Cabot began to see that social and mental problems often underlay physical problems and that purely physical afflictions were rare (Cabot, 1915). He held that it was not possible to restore patients to health without considering what he called the nonsomatic factors, such as living conditions. He described one case as follows:

One morning as I was working in the out-patient department, I had a series of knotty human problems come before me . . . that morning I happened to wake to the fact that the series of people that came to me had pretty much wasted their time. I had first of all to deal with a case of diabetes. That is a disease in which medicine can accomplish practically nothing, but in which diet can accomplish a great deal. We had worked out very minutely a diet that should be given such patients. We had it printed upon slips which were made up in pads so that we could tear off a slip from one of these pads and give the patient the best that was known

about diabetes in short compass. I remember tearing off a slip from this pad and handing it to the patient, feeling satisfaction that we had all these ready so that the patient need not remember anything. . . . The woman to whom it had been given did not seem satisfied. I asked her what was the matter. . . . She looked it over and among the things that she could eat she saw asparagus, Brussels sprouts, and one or two other things, and she called my attention to the fact that there was no possibility of her buying these things. We had, in other words, asked her to do things that she could by no possibility do. (Cabot, 1911, pp. 308–309)

Cabot's exposure to social work came first from his relationship with Jane Addams. In 1887, he took a course at Harvard entitled "Ethical Theories and Social Reform" from Francis Greenwood Peabody. Many who took the course went on to work for the Boston Children's Aid Society, as did Cabot when he became a director there in 1896. It was there that he was exposed to the case conference approach.

Cabot viewed the relationship between medicine and social work from his radical centrist perspective. He thought that each profession possessed the element that the other most needed. For medicine this was empiricism and for social work it was breadth. Cabot thought physicians' enthusiastic acceptance of empiricism had made them far too narrow in scope, ignoring social and psychological factors in health. Social workers possessed the breadth that physicians lacked, but relied too heavily on good intentions. They needed to become more scientific and systematic to ensure that their methods were effective and to develop a theoretical base for their work. Each profession could gain from association with the other.

Cabot set about reforming the treatment process in the outpatient clinic. He hired Garnet Pelton to fulfill three functions: (1) to critique while helping to socialize medicine, (2) to act as a translator between the physician and patient and family, and (3) to provide information on social and mental factors. Cabot described the critical role by saying, "she will not be there primarily as a critic, but nevertheless she will be far better than the average critic because she will be part of the institution and will be criticism from the inside, which I think is always the most valuable kind" (Cabot, 1912, pp. 51–52). Pelton kept records of every case, which were used for instruction and to identify trends that would be published in regular reports. Prior to Pelton, no records of patient visits to the outpatient department were kept at Massachusetts Hospital.

Cabot viewed social workers as translators of medical information to patients and families in a way that they could understand. He said, "the social worker . . . can reassure patients as to the kind of things that are being done and are going to be done with them. There is no one else who explains; there is no other person in the hospital whose chief business is to explain things" (Cabot, 1912, p. 50).

Cabot also saw social workers as translators of information about patients and families to physicians. Social work's role in providing social and psychological information to physicians is described in a quote from Ida Cannon:

While she must have an understanding of the patient's physical condition, the physical condition is only one aspect of the patient to which she must take account. As



the physician sees the disease organ not isolated but as possibly affecting the whole body, so the hospital social worker sees the patient not merely as an isolated, unfortunate person occupying a hospital bed, but as a member belonging to a family or community group that is altered because of his ill health. Physician and nurse seek to strengthen the general physical state of the patient so that he can combat his disease. The social worker seeks to remove those obstacles, either in the patient's surroundings or in his mental attitude, that interfere with successful treatment, thus freeing the patient to aid in his own recovery. (Cannon, 1923, pp. 14–15)

Cabot thought that social work could best fulfill this role because nurses had “lost their claim to be a profession by allowing themselves to become mere implementers of doctor’s orders” (Evison, 1995, p. 220). He defined social work’s expertise as diagnosis and “treatment of character in difficulties,” which he saw as encompassing expertise in mental health.

The hospital did not initially support Pelton’s hiring, so Cabot paid her salary with his own funds. To convince the hospital’s superintendent Frederic Washburn that Pelton was a good addition, Cabot set about documenting that her hiring was cost-effective. He calculated that the hospital had spent \$120 on a baby with gastrointestinal problems whose mother brought her to the hospital on four occasions over a short period of time because the family was unable to provide the nutrients prescribed for her. Cabot did not want administrators to view social work’s primary role as preventing misuse of hospital services but instead to save money by helping to make treatment more effective. He viewed medical social workers as distinct from hospital almoners.

Ida Cannon took over for Garnet Pelton in 1906 when Pelton went to Saranac Lake, New York, to receive treatment for pulmonary tuberculosis. Cannon was named the first chief of social work in 1914. She shared status with the chief of surgery and the chief of medicine. Cannon developed training programs for social workers at Massachusetts General Hospital, including medical education. Cannon hired Harriett Bartlett to be the first educational director in the Social Work Department. Other programs begun during her tenure included a low-cost lunch counter for patients and staff; a committee to investigate the social correlates of tuberculosis, which produced the first comprehensive analysis of tuberculosis in the United States; interdisciplinary medical rounds with social workers; and clay modeling classes for psychiatric patients. Cannon and Cabot together developed systems for evaluating the effectiveness of social work interventions and included this information in medical records.

Cannon did not take the same radical views of hospital social work that were espoused by Pelton and Cabot, with whom she clashed often during their first years of working together. Cannon thought social workers should accommodate hospital mechanisms rather than being critics or reformers of medicine, as Cabot had advocated. Nevertheless, the two worked together until Cabot accepted a commission of major in the Medical Reserve Corps in 1917. He returned to the outpatient department of Massachusetts General Hospital in 1918, but he then left to chair Harvard’s Department of Social Ethics in 1919. Shortly before he left the hospital, its board of directors voted to make the Social Service Department a permanent part of the hospital and to cover the full cost of its functioning. Prior to that, Cabot had covered the cost of up to 13 social workers with his personal funds.

Ida Cannon was named director of the new Social Work Department in 1919. She retired from Massachusetts General Hospital in 1945. At the time, the hospital employed 31 social workers. Several former social workers at Massachusetts General Hospital went on to direct departments in other hospitals, such as Mary Antoinette Cannon (the University Hospital of Philadelphia) and Ruth T. Boretti (Strong Memorial Hospital of the University of Rochester School of Medicine and Dentistry).

### THE GROWTH OF HOSPITAL SOCIAL WORK DEPARTMENTS

In 1961, Bartlett described the course of social work in health care as spiraling, "in which periods of uncertainty and fluidity alternated with those of clarity and control" (Bartlett, 1961, p. 15). She said that in its first 30 years, growth was linear as social work spread from one hospital to another. Methods were simple because social work in hospitals "almost alone carried the responsibility for bringing the social viewpoint into the hospital" (p. 15).

The success achieved at Massachusetts General Hospital eventually drew the attention of the American Hospital Association and the American Medical Association. Johns Hopkins Hospital hired Helen B. Pendleton, who had worked with the Charity Organization Society as its first social worker in 1907. As had been the case with Garnet Pelton at Massachusetts General Hospital, Pendleton remained on the job for only a few months. The position remained vacant for 4 months, then she was replaced by a graduate nurse. At Johns Hopkins, social workers were initially housed in a room that was also used for storing surgical supplies. They were not allowed on the wards, which were controlled by nurses (Nacman, 1990). Social workers, however, controlled access to medical records by physicians and nurses and had to approve all free medical care and prescriptions for medicine that was to last longer than 1 week (Brogen, 1964). The department prospered, as had the department at Massachusetts General Hospital, and by 1931 had a staff of 31.

Garnet Pelton completed a survey of social service in hospitals in the United States in 1911 at the behest of John M. Glenn, the first director of the Russell Sage Foundation and a strong proponent of social work in health care. She was able to locate 44 social service departments in 14 cities, 17 of which were in New York City alone. These departments provided a range of services, all focused on the provision of assistance to the patient (Cannon, 1952).

New York City, which housed nearly 40% of the country's hospital social service departments, organized the field's first conference in 1912, which was called the New York Conference on Hospital Social Work. The conference was held regularly between 1912 and 1933. A quarterly report entitled *Hospital Social Service* documented conference findings and highlighted the progress of various hospital social service departments.

By 1913, 200 U.S. hospitals had social workers. Ruth Emerson, who left Massachusetts General Hospital in 1918, established the social service department at the University of Chicago. Edith M. Baker, who left Massachusetts General Hospital in 1923, established the social service department at Washington University in St. Louis.

## THE PROFESSIONALIZATION OF THE FIELD

The first training course in medical social work was held in 1912. Cannon (1932) wrote that the growth of such courses was slow and lacked coordination until 1918, when the American Association of Hospital Social Workers was established in Kansas City. The association, which employed an educational secretary, had a two-fold purpose: to foster and coordinate the training of social workers in hospitals and to enhance communication between schools of social work and practitioners. Although the American Association of Hospital Social Workers was the first national organization of social workers in health care, it was preceded by local organizations in St. Louis, Boston, Philadelphia, Milwaukee, and New York. Stites (1955) says that prior to the establishment of the American Association of Hospital Social Workers, medical social workers in health care for some time had congregated at meetings of the National Conference of Social Work (formally called the National Conference of Charities and Corrections). The burning question at the first meeting of the American Association of Hospital Social Workers in 1918 was whether the group should orient more closely with social work or medicine. Eight of the 30 women who signed the association's first constitution were graduate nurses.

The American Association of Hospital Social Workers published a study of 1,000 cases from 60 hospital social work departments in 1928. According to the report:

The social worker's major contributions to medical care, gauged by frequency of performance, are: (1) the securing of information to enable an adequate understanding of the general health problem of the patient; (2) interpretation of the patient's health problem to himself, his family and community welfare agencies; and (3) the mobilizing of measures for the relief of the patient and his associates. Briefly then, the basic practices of hospital social work exhibited in the study under consideration can be described as discovery of the relevant social factors in the health problems of particular patients and influencing these factors in such ways as to further the patient's medical care. (American Association of Hospital Social Workers, 1928, p. 28)

This description does not differ appreciably from the way that hospital social work was conceptualized by Cannon and Cabot at Massachusetts General Hospital.

A survey of schools of social work published in 1929 (Cannon, 1932) listed 10 schools that offered formal courses in medical social work and 18 that were in the process of planning medical social work curriculum:

- The University of Chicago
- The New York School of Social Work
- Tulane University
- Washington University
- The University of Indiana
- The University of Missouri
- Simmons College
- Western Reserve University
- The Pennsylvania School of Social and Health Work
- The National Catholic School of Social Work

In all, medical social work was considered to be graduate-level work. A second survey that year was sent to social service department heads in hospitals asking them to query their workers about their training and experience. Of the 596 respondents, 70% had taken at least one course in general social work, and 48% of those had received a diploma or certificate between 1899 and 1930. Interestingly, 38% of respondents had completed at least one course in nursing and 86% of those had received a certificate or diploma in nursing. The survey listed six activities of medical social workers:

1. Medical social case management,
2. Securing data,
3. Health teaching,
4. Follow up,
5. Adjustment of rates, and
6. Medical extension of transfer to convalescent home, public health agency, or medical institution.

In 1954, the year before the American Association of Medical Social Workers merged with six other specialty organizations to form the National Association of Social Workers, 2,500 persons attended its annual meeting. The American Association of Medical Social Workers was the largest of all social work membership organizations. The current major specialty organization for social workers in health care on the national level, the Society for Leadership in Health Care, boasts 1,300 members (Society for Social Work Leadership in Health Care, 2005). This organization, which changed its name from the Society for Social Work Administrators in Health Care in the 1990s and is affiliated with the American Hospital Association, was founded in 1965. Other current national organizations include the American Network of Home Health Care Social Workers, the Association of Oncology Social Work, the Council of Nephrology Social Workers, the National Association of Perinatal Social Workers, and the Society for Transplant Social Workers.

#### DEFINING MEDICAL SOCIAL WORK

By 1934, the American Association of Medical Social Workers (the American Association of Hospital Social Workers changed its name that year) published a report prepared by Harriet Bartlett (1934). The report defined medical social work as a specific form of social case work that focuses on the relationship between disease and social maladjustment. Bartlett wrote, "it is an important part of the social worker's function to concern herself with the social problems arising directly out of the nature of the medical treatment. In this way, she facilitates and extends the medical treatment" (p. 99). Emphasis was placed on surmounting social impediments to health, "providing some occupation or experience for the person jolted out of his regular plan of life by chronic disease, to offset what he has lost and to make him feel that he has still a useful place in the world" (p. 99).

A series of problems was highlighted in the American Association of Medical Social Worker's 1934 report as requiring particular attention. They were: (a) the integration of psychological concepts, defined in part as needing to know more about human motivation in general and in relation to illness; (b) problems of

functional and mental disease, specifically the need to integrate the study of the organism with that of the personality; and (c) problems of methods of thinking, which had to do with balancing the study of personality with a consideration of the person in his social situation.

This competition for attention between personality and social environment gained salience with the advent of psychiatry and psychoanalysis in the United States. Although popular in Europe in the 1880s and 1890s, mental treatment in hospitals did not at first take hold in the United States. Courses in psychotherapy began appearing in medical schools in 1907, and Freud made his first tour of the United States 2 years later.

The emergence of psychiatry and psychoanalysis into medicine had two major effects on social work in health care. First, psychiatry's emergence into medicine is tied to the appearance of other professionals in hospitals, such as psychologists and social scientists. Their presence meant that the social and mental domains of health were no longer exclusive to social work and that medical social work for the first time had significant competition for a role in health care.

A second effect of psychiatry's emergence into medicine was the impact of psychoanalytic theory on how social workers in health care approached cases, namely, from a more person-centered perspective. The confusion between a focus on personality and on social environment remained after psychiatric social work separated from medical social work. The separation is often attributed to 1919, when Smith College developed a course for psychiatric aides attached to the U.S. Army during World War I (Grinker, MacGregor, Selan, Klein, & Kohrman, 1961), although the Psychiatric Social Service Department was not established at Massachusetts General Hospital until 1930. Mary Jarrett (1919), the associate director of the Smith College Training School for Social Work, argued for a more psychiatric approach to case work in her address to the Conference of Social Work in 1919:

One by-product of the psychiatric point of view in social case work is worth consideration in these days of overworked social workers, that is, the greater ease in work that it gives the social worker. The strain of dealing with unknown quantities is perhaps the greatest cause of fatigue in our work. . . . More exact knowledge of personalities with which we are dealing not only saves the worker worry and strain but also releases energy which can be applied to treatment. . . . Another result is that impatience is almost entirely eliminated. No time is wasted upon annoyance or indignation with the uncooperative housewife, the persistent liar, the repeatedly delinquent girl. . . . I know of social workers who looked with suspicion upon the careful preliminary study of personality, because they feared that all the worker's interest might go into the analysis, and that treatment might be neglected. I believe that fear has been something of a bugaboo in social work. (p. 592)

The implication of Jarrett's address is that a focus on personality allows the social worker to get at the client's problem with ease, thus saving time for treatment.

Another possible source of social work's attraction to psychoanalytic theory was Abraham Flexner's 1915 address to the National Conference of Charities and Corrections, in which he said that social work was not a profession. Flexner defined professions as: (a) involving essentially intellectual operations, (b) having large individual responsibility, (c) deriving their raw material from science and learning, (d) working up their material to a practical and definite end, (e) possessing

educationally communicable techniques, (f) tending to self-organization, and (g) becoming increasingly altruistic in motivation. He said that although social work had a professional spirit, it failed to meet all of the criteria for a profession because its members did not have a great deal of individual responsibility and lacked a written body of knowledge and educationally communicable techniques. Flexner's address had a profound effect on the field. Some social workers viewed medicine as a model profession and an intrapersonal approach as more professional than one focused on social and environmental factors.

Nacman (1990) notes that, by the 1940s, psychosocial information was increasingly being used by medical social workers to make medical diagnoses and treatment plans. This was in contrast to its use, in Ida Cannon's words, "to remove those obstacles, either in the patient's surroundings or in his mental attitude, that interfere with successful treatment, thus freeing the patient to aid in his own recovery" (Cannon, 1923, pp. 14-15). The work of Helen Harris Perlman countered the tendency to use information primarily to make medical diagnoses and plans by emphasizing social science concepts over psychoanalytic and refocusing on society and environment. A focus on environment was reinforced in the 1950s by the community mental health and public health movements (see Chapter 4 of this text) and the civil rights movement of the 1960s.

#### SOCIAL WORK IN HEALTH CARE: BEYOND THE HOSPITAL

After World War II and the passage of the Social Security Act, social work in health care began to branch out from its hospital base. Social work programs were established in the U.S. Army and Navy and the Veterans Administration. The advent in the mid-1960s of Medicare and Medicaid, and titles XVIII and XIX of the Social Security Act, provided coverage for persons who might otherwise not have been treated. These two programs further increased the need for social work services.

The number of social workers in health care increased with the variety of work settings. Between 1960 and 1970, the number of social workers in health care nearly doubled (Bracht, 1974). By 1971, social workers were employed in a wide range of settings. A Medicare report from that year reported 11,576 social workers in 6,935 participating hospitals, 2,759 in 4,829 extended-care facilities, and 316 social workers in 2,410 home health agencies (U.S. Department of Health, Education, and Welfare, 1976). Social workers also could be found in state and local health departments and in federal agencies such as the Department of Defense. Social workers entered new health-care arenas such as preventive and emergency services. Techniques were added to the social work repertoire to address these new settings and arenas. Interventions appeared based on behavior, cognitive, family systems, crisis, and group work theories. Because health costs were growing at an alarming rate, the federal government began to institute measures to control costs. In 1967, utilization review measures were enacted that required Medicare providers to demonstrate that care was necessary and that its costs were reasonable. In 1972, Congress enacted the Peer Standards Review Act (PSRO), which required the peer review of medical billing to ensure that services had been utilized appropriately.

Neither utilization review nor peer standards review proved as effective as was hoped. Another attempt to control costs took its cues from a long history of prepaid health-care arrangements provided to workers around the country, the



first of which was a rural farmers' cooperative in Elk City, Oklahoma, in 1929. The best known of these arrangements was the Kaiser Permanente Health Plan. In 1973, the Health Maintenance Organization (HMO) Act was passed by the Nixon administration. The Act authorized \$375 million in federal grants to develop HMOs. Initially, employers saw HMOs as a less expensive way of providing insurance to their employees. In recent years, state governments have used managed care in their Medicaid programs. By 1993, 70% of Americans with health insurance were enrolled in some form of managed care. Cornelius (1994) distills the perils of managed care for social workers by saying, "the social worker becomes an agent of managed care and agrees to serve the public within the corporate guidelines and not necessarily according to the assessed needs of the client. . . . If the social worker practices outside the protocols, . . . the client is denied coverage and the social worker is denied reimbursement; money becomes the carrot and the stick" (p. 52).

Another major cost containment effort had a profound effect on hospital care. The prospective payment system, based on a set of 500 diagnostic-related groups (DRGs), each with its own specific payment rate, was instituted in 1983 to replace traditional retrospective reimbursement for hospital care. The rates were developed based on the nature of the illness, accepted treatment procedures, whether the hospital was a teaching facility, local wage scales, and the hospital's location (Reamer, 1985, p. 86). This standardization was intended to provide an incentive for hospitals to become more efficient.

Under DRGs, patients entered the hospital sicker and left sooner (Dobrof, 1991). This impacted hospital social work services in two major ways: Hospitalization was seen as a failure of the system and every effort was made to avoid it; thus, those who were admitted were quite ill. Also, because hospitals were paid a specified rate, it was in their best interests to keep stays as short as possible. Because patients entered more ill and stayed for a shorter time, less comprehensive care could be provided in hospitals. Although there is debate about the extent to which social workers were cut from hospitals (see e.g., Coulton, 1988), many social work forces in hospitals were downsized or reconfigured during this period. Some were merged with other departments, others self-governed, and in other cases, social workers and other professionals were organized by service rather than by department.

It is clear that hospital social workers found less opportunity to spend time with patients because patients were there for less time, and much of the social worker's time was taken by helping to prepare sicker patients and their families for recuperation at home or in other facilities, such as extended care facilities. Dobrof (1991) describes "hospital-based social workers confronting larger caseloads of sicker patients with increased need for home care services or placement in nursing homes" (p. 44).

Both HMOs and DRGs affected how social workers in health care practiced. HMOs restricted social workers ability to practice based on their own assessment of needs. DRGs limited the time that social workers in hospitals had to work with patients and forced an emphasis on discharge planning. This limited social workers' ability to perform in the manner outlined by its founders, such as Bartlett's, "to concern herself with the social problems arising directly out of the nature of medical treatment" (1934, p. 99), or Cannon's, "to remove those obstacles . . . that interfere with successful treatment" (1923, pp. 14-15).

New techniques have been developed in response to time limits on treatment. Task-centered case work (Reid & Epstein, 1972) emphasizes the goals of treatment, and a number of brief treatment techniques have been developed (see, e.g., Mailick, 1990). Social workers have helped to adapt intervention theories for use in health settings, such as stress inoculation from cognitive theory (see, e.g., Blythe & Erdahl, 1986).

Claiborne and Vandenburg (2001) define a new role for social workers as disease managers. As patients live longer with disease conditions or survive conditions once considered fatal, such as cancer, issues of quality of life arise. Survivors of cancer, previously expecting to die, need assistance with learning how to live. Those with long-term health conditions, such as rheumatoid arthritis, require guidance on how to live a full life with their condition. As a rule, disease management entails "a team of professionals that integrates and coordinates care across an array of services to maintain optimal patient functioning and quality of life" (Claiborne & Vandenburg, 2001, p. 220). These teams often operate across facilities. Claiborne and Vandenburg see social workers as key members of disease management teams due to their ability to work across health systems and managed care settings. Chapters 8 and 18 of this text discuss mental health issues in chronic illness.

#### CHANGES IN TECHNIQUE AND APPROACH THROUGH TIME

The settings in which social work is practiced in health care have changed through time. From 1905 until 1930, medical social workers practiced almost entirely in hospitals. Harriet Bartlett (1957) described the course of change during that period as linear, with the number of social service departments increasing steadily and their claim to the social and mental domains largely unchallenged by other disciplines. With the advent of psychotherapy, however, professionals such as psychologists and other social scientists began to work in hospitals, and for the first time social workers had to compete for roles.

The period of linear growth was followed by an expansion into previously unimagined settings. Federally imposed cost containment, beginning in the late 1960s, posed challenges to social workers in health care and forced a great deal of flexibility and creativity. In some respects, the competition with other disciplines that social work experienced in its most recent 70 years in health care and its failure to define a niche that was exclusively its own since that time (see, e.g., Lister, 1980), prepared social workers to remain viable in a changing health-care environment. They have adapted well to these changing environments.

How do the visions of Ida Cannon and Richard Cabot hold in the current health environment in which social workers practice? At a time when the changing demographics pose problems of communication in health care, Cabot's idea of social worker as translator or interpreter seems modern and as salient today as it was in 1905. In 2000, 1 in 10 U.S. residents, over 28.4 million persons, was born outside the country (Lollock, 2001). These figures do not include persons born in other countries who are living in the United States without benefit of legal residency.

The current 10% of U.S. residents who were born outside the country compares to a high of 15% between 1890 and 1910, the years during which Mary Stewart



was hired in London and Garnet Pelton and Ida Cannon were hired in Boston. The percent born outside the country in 2000 is higher than it was for the decades that immediately preceded 2000. According to U.S. Census Bureau records, 7% of the population was born outside the United States in the 1950s, 5% in the 1970s, and 8% in the 1990s (Lollock, 2001).

As outlined in Chapter 9 of this text, communication is the key to the provision of effective health care. Clinical encounters are more problematic when providers and patients are from different racial or ethnic groups or different socioeconomic statuses. A report by the Institute of Medicine (2002) implicated physician behavior in health disparities in the United States, and researchers (see, e.g., Johnson, Roter, Powe, & Cooper, 2004) have noted different communication patterns among White American physicians when they are dealing with African American versus White American patients. It is unlikely, however, that these biases are limited to physicians. Although empirical studies to date have centered on the behavior of physicians as the time that providers are able to spend with patients decreases, the opportunity for mental shortcuts that can lead to bias increases (Burgess, Fu, & von Ryn, 1990). Clearly, the translator or interpreter role first defined by Richard Cabot in 1905 remains important in health care today. Likewise, the idea that social workers are in the best position among professionals in health care to interpret information from patients and families to providers and to interpret and explain information from providers to patients and families holds true.

Cannon's dictum that the social worker see the patient "as a member belonging to a family or community group that is altered because of his ill health" (Cannon, 1923, p. 15) also seems germane to the current challenge of disease management. Cannon was writing at a time prior to the development of treatment advances such as antibiotics, chemotherapy, and radiation therapy, when patients did not live for long periods of time with chronic health conditions. Her words seem even more salient today when a growing number of patients face living with chronic conditions.

Cabot's belief that social workers should become more scientific and systematic was evidenced with the advent of research in social work in the late 1960s and early 1970s. He and Cannon would be heartened by the success of evidence-based practice and the active incorporation of research in social work practice in health care. Social workers with health-care backgrounds now head research teams and serve as program directors and other key positions at the National Institutes of Health and other federal agencies.

Although they initially disagreed about the role of social workers as critics or agents of socialization within hospitals, both Cabot and Cannon would doubtless be impressed by the growing number of social workers who serve as administrators of hospitals and health-care agencies and institutions across the United States.

Ida Cannon's statement that social work, when practiced at its best, "is a constantly changing activity, gradually building up guiding principles from accumulated knowledge yet changing in techniques" (1923, p. 9), still holds true. Social work in health care has been through a great deal in 100 years and has weathered seemingly insurmountable challenges through time. Nevertheless, its guiding principles remain in force and are as strong today as they were in 1905.

## SUGGESTED LEARNING EXERCISES

## LEARNING EXERCISE 1.1

The persons involved in establishing the first Social Service Department at Massachusetts General Hospital (Ida Cannon, Garnet Pelton, and Richard Cabot) were all White Americans and came from families without financial difficulties. Cabot was from a very privileged background. Cannon's father was a railroad administrator in Minnesota. That Pelton was able to obtain nurses' training at the turn of the century suggests that she had means. The subsequent century of social work's involvement in health care has seen the inclusion of persons from a number of racial, ethnic, and socioeconomic backgrounds. How do you think the narrowness of the backgrounds of the founders of social work in health care affected its guiding principles and approach, if at all? Have changes in the diversity of persons involved in social work in health care had a demonstrable influence on how the guiding principles and techniques of social work in health care have changed through time?

## LEARNING EXERCISE 1.2

The first hospital almoner in England (Mary Stewart) and the first hospital social worker in the United States (Garnet Pelton) were both women whose hiring was championed by men with influence in medicine (Charles Loch and Richard Cabot). Who should be credited for the development of social work in health care? To what extent do you think that the development of social work in health care is attributable to the vision of Loch and Cabot? Were Loch and Cabot necessary catalysts for the development of social work in hospitals rather than pioneers? To what extent was the development of social work in health care due to the vision and efforts of women like Pelton, Cannon, and Stewart? Would social work in health care eventually have developed on its own absent the vision of influential men?

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## CHAPTER 2

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# Social Work Roles and Health-Care Settings

TERI ARTHUR BROWNE

**N**CESSARILY, THE ROLE of health social workers through time has changed to accommodate federal, state, and local policy changes, trends in health and disease, and the changing roles of other health-care professionals. As discussed in Chapter 1, however, the basic function of social work remains, and social workers' roles today reflect their responsibility to treating the whole person by taking a biopsychosocial approach to intervention and care.

Health social workers operate in a variety of environments and assume numerous roles in the design, delivery, and evaluation of care. Social workers facilitate linkages across organizational systems and professions to improve health care for both individuals and populations. This occurs in myriad settings, in a number of different ways, and with various levels of interdisciplinary collaboration. Health social workers need to be aware of these factors to most effectively provide services to individuals and communities.

### CHAPTER OBJECTIVES

- Describe a biopsychosocial approach to health care and the professionals who deliver it.
- Define the role of the social worker on the health team.
- Outline the tasks of health social workers related to the delivery and design of health care.
- Discuss professional issues and challenges related to team work and recommendations for effective collaboration.

### SOCIAL WORK'S BIOPSYCHOSOCIAL APPROACH TO HEALTH CARE

Increasingly, the recommended approach for health-care service delivery today is *biopsychosocial*. Proposed by Engel in 1977, the biopsychosocial model addresses the

biological, social, environmental, psychological, and behavioral aspects of illness. This expands the traditional medical model of health care that focuses primarily on the biological causes of disease. The biopsychosocial model considers the nonmedical determinants of disease in collaboration with the purely biological components. For example, a biopsychosocial model of health service takes into account a patient's ability to purchase recommended medicine for diabetes when creating a treatment plan for the patient rather than focusing only on her laboratory results and physical status, as a medical-model approach would do. Lindau, Laumann, Levinson, and Waite's (2003) interactive biopsychosocial model expands Engel's model to include general health status rather than illness alone and consideration of the important role of social networks and cultural contexts in health. For the purposes of this chapter, the term *biopsychosocial* is used to indicate an approach to health service delivery that addresses the psychological and social aspects of health and treatment that includes behavioral and environmental factors.

Intervention that considers biopsychosocial issues related to health requires the use of an interdisciplinary team of professionals to address medical problems and concerns in a variety of settings. In addition to social workers, professionals may include physicians, physician assistants, and residents; nurses and nurse practitioners; dietitians; psychologists; patient care technicians; nurse and home health aides; physical, occupational, and speech therapists; administrators; chaplains; and pharmacists.

#### THE LIMITS OF THE MEDICAL APPROACH: PSYCHOSOCIAL ISSUES RELATED TO HEALTH

Prior to the introduction of Engel's biopsychosocial model, Nason and Delbanco (1976) recommended that providers of medical services attend to patients' psychosocial issues and advocated for the inclusion of social workers on health care teams. Health social workers directly address the social, behavioral, and emotional concerns of individuals and their social support network as well as develop and administer policies and programs and conduct research that are attuned to the psychosocial needs of individuals.

On an individual level, people may not be able to understand illness and recommended treatment due to developmental disabilities; low literacy levels; or language, hearing, or vision barriers. Many medical conditions and treatments are very complex, and social workers may be required to explain these issues to patients and their families. Socioeconomic disadvantage can greatly impact a patient's ability to receive medical care. If she lacks adequate health insurance, transportation to medical appointments, prescription coverage, or money to buy nutritional supplements and special dietary products, her health may be compromised. Patients may need myriad services from a number of agencies, such as meal delivery, homemaker services, or physical therapy. Arranging and coordinating community services can be confusing or overwhelming for patients, especially for those with additional social, psychological, or medical burdens. Environmental factors also directly impact individuals' social functioning and health status (see Chapters 4 and 6 for models of how environmental factors influence health and functioning).

Emotional problems can be caused by and result from health problems (see Chapter 8). After a major medical procedure such as open-heart surgery, a pa-

tient's anxiety may increase (Ben-Zur, Rappaport, Ammar, & Uretzky, 2000). Among people with cardiovascular disease, untreated depression has been found to increase the risk of heart attack (Monster, Johnsen, Olsen, McLaughlin, & Sorenson, 2004). A person who is depressed may be less motivated to follow up with medical appointments. If he is not coping well with his diagnosis and treatment regimen, he may do less well physically (Livneh, 2000). Effective coping, enhanced self-efficacy, and optimism have been associated with enhanced quality of life in the chronically ill (Rose, Fliege, Hildebrandt, Schirop, & Klapp, 2002).

Patients' social support networks can influence their health status significantly. As discussed in Chapter 11, families can provide important support and assistance during times of health crisis, or they can also represent barriers to optimal care. For example, the husband of a breast cancer patient who does not support the doctor's recommendation for a double mastectomy may confound and even further harm the patient's health status by causing her to become reluctant to have the necessary surgery. Family structure and the availability of social support impacts the health of patients across their life course (Thompson, Auslander, & White, 2001).

Conversely, illness may exacerbate existing psychosocial problems; for example, a woman in a troubled marriage who becomes ill may lose her primary social support when her partner leaves because he cannot cope with the stress of her illness and its treatment. This may leave her with no transportation to medical appointments in addition to coping with issues related to role adjustment and loss, both of which can negatively impact her health.

If a child has supportive family members to help him with the challenges of medical problems and hospitalizations, he will likely fare better than a child who does not. Likewise, a woman recovering from heart surgery who has neighbors or family to help with household chores and child care may recuperate better and be more likely to attend weekly cardiac rehabilitation appointments than someone who has no help. Psychosocial issues like these, which occur outside hospitals and doctors' offices, greatly influence individuals' abilities to maintain their health.

Many individuals who seek medical care also have what Rehr (1982) refers to as "social illnesses and problems." These illnesses and problems are psychosocial rather than biological in nature such as child or elder abuse, violence (including sexual assault and family violence), substance use, other harmful behaviors such as "cutting" or bulimia, and suicide attempts. All are factors that require social work attention and intervention to improve biopsychosocial status and, consequentially, health status.

The current health-care environment in the United States (see Chapter 5) emphasizes cost containment through shorter hospital stays, briefer medical interventions, and the provision of fewer comprehensive services with fewer personnel. For example, decades ago, individuals may have spent a number of weeks in a hospital recuperating from hip replacement or kidney transplant surgery. Many surgical procedures that were once done on an inpatient basis are now performed in outpatient, same-day facilities. Lengthy hospital stays are now the exception rather than the rule due to fixed reimbursement for medical procedures, and an individual who has a hip replaced or receives a kidney transplant may be discharged from the hospital a few days after her surgery.

The trend toward shorter hospital stays and greater reliance on outpatient care may exacerbate patient psychosocial problems. Bateman and Whitaker



**Box 2.1**  
**Health Social Work Profile**

Mildred Williamson, MSW, PhD, is the director of programs and research for the Ambulatory and Community Health Network of the Cook County Bureau of Health Services in Chicago. In this capacity, she creates health programs based on the community's needs. She previously was the administrator of the Woodlawn Health Center in Chicago and the Women and Children HIV Program at the Cook County Hospital. Williamson is a recipient of many local, state, federal, and private foundation grants for health research. She has served as a member of the Centers for Disease Control and Prevention's Advisory Council on HIV/AIDS Prevention and Care and is on the boards of directors of two Chicago HIV-related organizations: Vision House and the Families' and Children's AIDS Network. Williamson currently serves on the board of the AIDS Alliance for Children, Youth, and Families, a national organization of HIV family and youth-centered care providers, advocates, and consumers that she helped to found in 1994. She served as president of the organization's board from 1997 to 2001.

(2002) assert that social workers are needed in medical settings to address increased home-care needs in part because they can provide discharge planning that links patients to necessary home-health services. The authors also suggest that social workers should play a greater role in primary care settings, addressing medical issues on a preventive level to decrease morbidity and the need for hospitalization. (See Box 2.1.)

Related to an emphasis on medical cost containment is an increase in community health programs. Aimed at preventing illness or health issues, programs that confront issues such as prenatal care and cancer screening employ social workers in their orchestration and day-to-day functioning.

#### HEALTH SETTINGS AND THE SOCIAL WORKER'S PLACE WITHIN THEM

Direct health services are provided in various settings and include public and private hospitals, outpatient clinics, neighborhood health centers, ambulatory surgery centers, physician's offices, mobile care units, skilled nursing facilities, military settings, correctional facilities, schools, and health maintenance organizations. Care may be provided in centers devoted to specific diseases such as kidney failure (dialysis centers), cancer (chemotherapy clinics), and HIV/AIDS (community health clinics), or in multipurpose organizations that address numerous health issues.

Other practice settings might specifically treat acute medical needs (including outpatient services or services provided on an ad hoc basis) or chronic medical needs where patients are admitted and receive services for a period of time. Indirect health services, such as program and policy planning and health programming, may be overseen by professionals working on interdisciplinary teams via local, state, and federal agencies; community organizations; government offices; or schools and research institutions. Health is considered across the life course in micro- and macrolevel settings, from prenatal and infant care to older adult and end of life care.



Health is a critical practice area for all social workers, both clinically and on the macrolevel, and social workers play an important role in each of these care settings. In 2004, 22% of all social workers were employed as medical and public health social workers (U.S. Department of Labor, 2004). Regulatory standards for social work in health care vary by state in the United States with each state having a different set of licensing rules for social workers. Also, health organizations differ in how they recommend and regulate the inclusion of social workers on health care teams. As noted in Chapter 1, social workers have been involved in medical settings for over a century and are essential to the implementation of biopsychosocial models of health service delivery.

Empirical evidence indicates that approaches to health care that include social workers and nurses in addition to physicians result in better patient outcomes than do approaches involving physicians alone; such evidence also suggests that social worker and nurse interventions are less costly. For example, Sommers, Marton, Barbaccia, and Randolph (2000) conducted an experimental research study on the effectiveness of an interdisciplinary team model in the provision of primary care. In this study, the intervention group received care from a primary care physician, registered nurse, and social worker while the control group received care from the primary care physician alone. The researchers found that the group cared for by the interdisciplinary team experienced significantly lower rates of hospitalization and hospital readmission, fewer follow-up physician visits, and increased participation in social activities. They estimated that the interdisciplinary approach saved at least \$90 per patient (including the cost of the additional personnel), not including the savings from fewer physician visits.

## THE SOCIAL WORKER'S ROLE ON HEALTH TEAMS

Social workers are essential to the delivery and design of optimal health care. Social workers contribute via direct clinical contact with patients and their families as well as through roles in macrolevel settings. They work on health teams comprised of direct patient-care professionals and as administrators overseeing program planning and implementation. Health social work tasks are congruent with the goals of the profession of social work and include helping clients problem solve and cope with life stressors; linking individuals with resources, services, and opportunities; promoting effective and humane service systems; and developing and improving social policy (Gambrill, 1997).

## HANDS-ON PRACTICE: SOCIAL WORKERS AS PART OF HEALTH-CARE DELIVERY

A wide variety of health social work tasks exist in direct patient-care settings. These include interventions with patients and members of their social support networks, collaborations with members of interdisciplinary teams, coordination of services within the community and entitlement agencies, advocacy with governmental bodies for patient needs, and supervision or administration in health facilities. Activities of the health social worker in direct patient-care settings include careful assessment of patient situations and the design and implementation of interventions.

*Health Social Work Assessment* Social workers conduct an evaluation of the strengths and needs of individuals and members of their social support network as part of a social work assessment to identify assets and potential barriers to care. These efforts are specific to practice settings and influenced by organizational or regulatory requirements and the type of services offered by the organization. For example, a hospital may have a standard social work assessment tool used in all departments. Oncology social workers may use a standardized tool with cancer patients that is specific to their needs, whereas rehabilitation social workers will likely use a different type of assessment tool. For an example of a disease-specific assessment tool, see the Appendix of Chapter 16 in this book. Such assessment tools aren't limited to disease, and social workers also help health-care teams assess psychological and social issues, such as domestic violence (Danis, 2003) and socioeconomic barriers to the attainment of quality health care, among other issues.

*Health Social Work Intervention* Based on a careful assessment of needs, social workers provide assistance and develop and implement interventions to address identified needs. This process may include explaining the disease and its treatment to patients in a manner that is sensitive to their literacy levels; developmental stages; and language, visual, or hearing barriers. Facilitating communication between providers and patients is a key health social work role further discussed in Chapter 9. (See Box 2.2.)

Social workers are familiar with the eligibility requirements of local and federal entitlement programs and can assist patients and their families in accessing and learning more about these resources. Social workers are the health professionals who possess “the knowledge necessary to assess social services needs [and] to secure and coordinate community-based services” (Berkman, 1996, p. 545). Health social workers can help patients gain needed resources by providing case management services that refer and link patients and their families to services and other resources.

Furthermore, health social work has a dual focus of enhancing social institutions' responses to human needs and enhancing the social functioning of individuals (Dhooper, 1994). Health social workers use their clinical skills to help

**Box 2.2**  
**Health Social Work Profile**

Kay Ammon, MSW, LCSW, QSW, is a social worker in the intensive care nursery at Santa Clara Valley Medical Center in San Jose, CA. Working with critically ill infants and their families, Ammon orients families to the nursery, which is highly technical and can be overwhelming, and discusses its policies and procedures. Ammon provides emotional support, grief counseling, coping with guilt and anxiety, end-of-life care, and information, referral, and linkages to resources for ill children and their families. As a Spanish-speaking health care provider working with many Hispanic families, she considers herself a “key link” between families and the health care team. She translates sophisticated medical communications to patients' families and coordinates family care conferences. She helps families understand complex medical terminology and discharge recommendations.

patients and their families cope with illness and treatment recommendations. Many diagnoses, such as Amyotrophic Lateral Sclerosis (ALS; also called Lou Gehrig's disease), are very difficult for patients to accept. ALS is a progressive neuromuscular disease that is very debilitating and ultimately fatal. A person given an ALS diagnosis may be depressed, angry, and fearful. A health social worker is trained to provide counseling to assist the patient cope with his diagnosis, provide grief counseling for the losses that he will experience as a result of his disease, and encourage him to follow up with medical care to maximize his quality of life.

Additionally, recommended treatment regimens can be difficult for patients to follow. A teenage boy diagnosed with diabetes may find that the need to test his blood glucose levels several times a day, self-administer insulin shots while at school, and avoid dessert to be very cumbersome. He may choose not to follow medical advice because it conflicts with his preferred lifestyle. A health social worker can help him by empathizing with the intrusiveness of the diabetic treatment regime, providing supportive counseling, and helping him to find ways to cope with the difficult aspects of his treatment regimen. She may also collaborate with the school nurse to explore the possibility of the boy testing his blood glucose level and self-administering insulin in her office. This would afford him greater privacy than if he were to use a public space. Another lifestyle intervention might include the social worker discussing with the boy's parents the types of food or refreshments served at home or at parties to ensure that these foods conform to his diet. Some children and adolescents face stigma or misunderstanding about their illness from their peers and classmates, and, in this case, the social worker might offer a class presentation to educate the patient's peers about his disease and dispel any myths or misinformation about diabetes that they may possess, making them more familiar with the disease and demystifying the boy's unique diet requirements and need for insulin injections during the school day.

For older individuals, social workers in health care are able to provide couples and family counseling. A couple grieving over the death of their newborn daughter may see the hospital social worker for grief counseling. The social worker may work with an entire family to discuss their adjustment after a father's leg amputation. Likewise, interventions related to end-of-life care often require family conferences and intervention using a range of theory- and evidence-based intervention strategies. Health social workers often run support groups for patients and their families to provide education and support on a variety of health issues.

Health social workers may see patients referred by other professionals. Patients may be referred because of psychosocial issues that represent a barrier to effective treatment. For example, a hospital social worker may not see all patients who come to the emergency room but will be called to assess and provide services to victims of sexual assault or family violence or refer these victims to appropriate services. Likewise, a social worker employed in a primary care setting may be asked to work only with patients and families who have identified psychosocial needs, such as problems coping with vision loss that preclude follow-up with recommended referrals or a lack of insurance to pay for needed medications.

Conversely, some social workers see every patient who passes through their particular setting. For instance, transplant social workers evaluate the psychosocial issues that affect every patient in need of a transplant. The goal of the evaluation is to help the team decide if the patient should be accepted into the program.

The social worker addresses the psychosocial issues that might interfere with a successful transplant and that must be resolved before a patient is scheduled for transplant surgery. Case management services are provided by social workers to patients while they are being worked up for transplant. Such services include referrals for community resources, financial counseling, and family and caregiver preparation and education for their post-transplant caregiving roles.

A common trend in social work today is having patients, their families, and community members actively participate on health teams or act as advisors to programs. Underlying this trend is the ideal that patients have a voice equal to that of professionals in their health-care planning. The Center for Interdisciplinary Health Disparities Research at the University of Chicago, led by Sarah Gehlert, MSW, PhD, is part of a multisite federal program to develop centers for the study of population health and health disparities. Each project includes community members as stakeholders, along with scientific investigators with specialties in the biological, social, and psychological aspects of health. Gehlert's team conducted 49 intensive focus groups with 503 community residents to determine community beliefs, concerns, and attitudes about breast cancer and its treatment. Social workers in clinical, administrative, and research roles are instrumental in helping health-care teams incorporate community members and consumers in planning and serve as advocates for them throughout the process.

On a health-care team or in an administrative role, social workers ensure that the social context of health is addressed in patient care and program planning. Miller and Rehr (1983) refer to social workers in health care as mediators between the health-care system and consumers. This also involves advocating at the systems level for improvements in the delivery of care.

#### SOCIAL WORK AS PART OF THE DESIGN OF HEALTH CARE

The profession of social work has a dual focus on enhancing the social functioning of individuals and social institutions' responses to human needs (Dhooper, 1994). A wide variety of health social work tasks exist in nondirect patient-care settings such as community, university-based, and government agencies. These tasks might include public health social work, policy development, program planning, community education and screening, or research. In these macrolevel settings, social workers collaborate with other professionals and with policymakers, elected officials, and university faculty, administrators, and community members.

Health social workers design and implement community health programs and initiatives. For example, a social worker may work on a team that is planning a program to improve prenatal care. The social worker must then ensure that psychosocial barriers to prenatal care, such as a lack of child care at a prenatal clinic, are addressed in the initiative. Social workers may also provide education to individuals, groups, and communities on different health issues. Health social workers are involved in preventive services such as health screening and immunizations. They can help identify individuals in need of services and providing linkages to such services via outreach programs. (See Box 2.3.)

At an even broader level, many social workers are involved in research that directly and indirectly influences policy, community and public health, and direct clinical practice. Routinely, health social workers perform quality assurance and outcome measurement on the services they provide to track psychosocial issues

**Box 2.3**  
**Health Social Work Profile**

Rose Popovich, MSW, LCSW, is the 2001 recipient of the Ida M. Cannon Award for Distinguished Leadership from the Society for Social Work Leadership in Health Care. Popovich serves as the practice administrator for the family medicine residency program at Community Hospitals in Indianapolis. The residency program provides outpatient maternal, child, and family medicine as well as school-based health care involving over 30 physicians and staff. Popovich says that her social work background is essential to the creation of the community health program she oversees in that it helps her to better understand the needs of the population they serve.

Popovich also facilitates the Consortium of Health Care Social Work Organizations. Consortium members include representatives from the following organizations: the American Case Management Association, the American Network of Home Health Care Social Workers, the American Public Health Association, the Association of Oncology Social Work, the Association of Pediatric Oncology Social Workers, the Association of State and Territorial Public Health Social Workers, the Council of Nephrology Social Work, the Council on Social Work Education, the National Association of Children's Hospitals and Related Institutions, the National Association of Perinatal Social Workers, the National Association of Social Workers, the National Council of Hospice and Palliative Professionals, the Society for Social Work Leadership in Health Care, and the Veterans Health Administration. This group meets regularly so that its members can share interests, information, and projects common to social workers in various health-care practice settings.

and the impact of social work intervention on alleviating these issues. Social workers also perform research at the community or university level with individuals or as it relates to health-care issues in general. Social workers have an active voice in large funding organizations such as the National Institute of Health and make sure that research is conducted that is psychosocially relevant.

### A SURVEY OF SOCIAL WORK PROFESSIONALS

As discussed in this chapter, social workers' roles are diverse and aspire to achieve total patient health and well-being as well as provide community and public service to bring about positive health status on a larger scale. Social workers entering the field today have innumerable opportunities to affect the quality of individual patients' lives, the health of myriad communities, and the field in general. To illustrate the many and varied responsibilities and opportunities with which social workers are faced as they prepare to enter the field today, consider actual professionals currently contributing to the field.

#### CASE MANAGEMENT AND PATIENT ADVOCACY

Jennifer Schlinger, MSW, LCSW, is a hospital social worker at MedCenter One Health Systems in Bismarck, North Dakota. She primarily works in the rehabilitation department, collaborating daily with physicians, physical and occupational therapists, dietitians, nurses, and other professionals. Although most of

her patients are adults, she occasionally works with pediatric patients and provides services to all individuals who are admitted to the rehabilitation department. Patient stays are limited to 6 weeks while patients receive medical treatment and are assisted with recuperation surgery or medical crises. Schlinger performs case management activities on a daily basis, helping patients plan their discharge and arrange follow-up care. This is particularly challenging for patients living in rural areas of the state in which no local home-health or other health-care services are available. Schlinger spends a great deal of time advocating for patients, especially those on Medicaid who are burdened with an annual 30-day limit for rehabilitation services. Schlinger helps patients to obtain entitlements, access community resources, and create and nurture social support systems. She acts as a liaison between patients and the medical team as well as community organizations.

Health social workers may also serve as supervisors in their practice settings by providing clinical supervision, or they may hold a position as a liaison between the department of social work and the administration of the agency or organization for which they work. Sharon Mass, MSW, PhD, is the director of case management and hospice at Cedars-Sinai Medical Center in Los Angeles. In this position, she oversees an interdisciplinary group of over 110 physicians, nurses, social workers, data analysts, and administrative support staff. She is a founding member of the board of directors of the American Case Management Association and has published in the areas of case management and end-of-life care. She is an adjunct professor of the School of Social Work at the University of Southern California and has received many awards for her work in social work in health care. Mass attends daily administrative and medical staff meetings about health-care delivery in which she advocates for patients from the social work and case management services departments. She provides supervision for social work licensure and to guide social workers' professional development at the hospital. She is also active in committees on patients' rights and institutional review.

#### ASSESSMENT OF NEED: THE FIRST STEP OF CARE

Some social workers in health care see all patients in the clinical settings in which they work. Jeff Harder, MSW, LICSW, is a transplant social worker at the University of Washington Medical Center in Seattle. In his work with the kidney and pancreas transplant program, Harder conducts psychosocial evaluations on all patients referred for a kidney or pancreas transplant. Harder assists patients and their caregivers find needed resources, such as local housing for follow-up outpatient care after transplant, if necessary. He provides counseling, education on what to expect after a transplant, and discharge planning. Harder assists patients and their families with coping, information, referrals, assessment of further needs, and assists patients with vocational rehabilitation. He continues to assist patients who previously received transplants when they lose insurance coverage or have questions about returning to work.

#### NEEDS-BASED CARE: ASSISTING THE CLIENT IN NEED

Some health social workers see only those patients in their health-care setting that require their services. Additionally, other health social workers may work on



a freelance basis. For example, Mary Raymer, MSW, ACSW, is a psychiatric social worker and licensed marriage and family therapist who has worked with terminally ill patients and their families for 25 years. An early hospice leader, she was the social work section leader for the National Hospice and Palliative Care Organization and is one of the originators of the Social Work End-of-Life Education Project. She has her own private practice and specializes in complicated grief reactions, stress, and terminal illness. The majority of her practice involves counseling individuals and families who are coping with grief.

#### PUBLIC HEALTH SOCIAL WORK

Marvin R. Hutchinson, MSW, LISWAP, CP, is the director of public health social work for the South Carolina Department of Health. He participates regularly in legislative, policy, and program meetings (assuring a psychosocial emphasis to the proceedings) and oversees the public health social work program. His staff includes regional public health social work directors and state program public health social work consultants with whom he works to develop new initiatives for more than 225 master's level public health social workers. These social workers are employed in clinical, community, and management positions across the state in programs such as maternal health, child health, family planning, tuberculosis treatment, school health, children's rehabilitative services, AIDS, and home health services. Hutchinson teaches at the College of Social Work of the University of South Carolina. He directs violence and suicide prevention initiatives and oversees the MSW/Master's in Public Health internship program. He presents workshops and papers to interagency staff, as well as to audiences at state, regional, national, and international conferences. In addition, Hutchinson serves on national level committees (representing the Association of State and Territorial Public Health Social Workers, the National Council on Aging, the Public Health Foundation, and the National Association of Social Workers) and legislative committees regarding issues such as school health, violence, systems, and integration. He received recognition from the Surgeon General for Public Health Services and is the 2005 South Carolina NASW Social Worker of the Year.

#### MULTILEVEL INTERVENTION: DIVERSIFYING RESPONSIBILITY

Social workers can intervene both on an individual and systems level in health care. Patricia Ann Gibson, MSW, ACSW, is the director of the comprehensive epilepsy program at the Wake Forest University School of Medicine in North Carolina. She is involved in (and received many awards from) numerous organizations including the American Epilepsy Society, the Epilepsy Foundation, the International Bureau of Epilepsy, and International Epilepsy Congress. Gibson is also on the Professional Advisory Board of the National Tuberos Sclerosis Association and has authored numerous publications for patients and professionals. In 1976, she developed and continues to run a nationwide telephone information line for epilepsy. She speaks with patients and their families about their concerns. After learning of parents' inability to afford their children's medicine, she spent 8 years developing an epilepsy medication fund for the state of North Carolina and supplements this fund with a variety of fund-raising efforts (including a chili cook-off, yard sales, and selling snacks at their office). Gibson sees patients for patient

education as well as individual, family, and group counseling. Much of her time is spent speaking and conducting workshops, conferences, and symposia. These include providing education to primary and secondary schools, parents, physicians, nurses, medical students, hospitals, and community organizations about epilepsy and organizing several national conferences, such as *Advances in the Management of Epilepsy*, the *Pediatric Neurology Symposium*, and the *International Conference on Epilepsy Care*. In these trainings, she presents a multidisciplinary approach to the treatment of epilepsy.

Rick Russo, MSW, CSW, is the coordinator of consumer relations and community development for the End Stage Renal Disease (ESRD) Network of New York, Inc., and is another example of a health social worker involved in direct-patient and community-level service. A major part of his job entails organizing and presenting at workshops for dialysis unit staff members about challenging patient situations and increasing staff sensitivity to patient needs. At the ESRD Network, Russo also provides assistance to renal patients and their families, assists with rehabilitation promotion for ESRD patients, and facilitates the state's Patient Advisory Committee that addresses dialysis patient concerns and encourages patients involvement in their care.

#### ADMINISTRATION AND SOCIAL WORK IN THE DESIGN OF HEALTH CARE

Social workers play an important role in the design of health-care delivery through administrative roles in clinical settings, overseeing both social workers and other professionals. Polly Jones, MSW, MSM, LCSW, CPHQ, is the director of clinical excellence for Ascension Health in Burlington, Indiana. She is responsible for the coordination of accreditation activities for the 70 plus Ascension hospitals, including educational initiatives, individual consultations, and quality improvement activities, and facilitating the Joint Commission on Accreditation of Health Care Organizations (JCAHO) system survey each year. She also oversees programming and projects for all of the hospitals. In these capacities, she advocates for the social work profession by encouraging social work involvement in activities, programs, and teams at a local level. On a daily basis, she travels to different hospitals across the country to work with multidisciplinary teams on various projects. As a project manager, she facilitates team interaction and promotes improved patient outcomes. She reports that her social work training is invaluable as it relates to knowledge of group dynamics, change theory, and how systems work. Jones frequently publishes and speaks about various topics related to health social work and is the 2005 president of the Society of Social Work Leadership in Healthcare. As president of this organization, she networks with social work leaders across the country to provide education, advocacy, and other support to social workers in myriad health-care settings.

#### FILLING THE HEALTH-CARE VOID: SOCIAL WORK'S MYRIAD RESPONSIBILITIES

As discussed, social workers sometimes have health-care specific responsibilities. Others, however, are responsible for a variety of roles within the setting in which they work. Douglas Kirk, MSSW, LCSW, for example, is the program director for mental health intensive case management at the Veterans Hospital in Madison, Wisconsin. He works with veterans at the hospital who require inten-



sive mental health case management. In describing his various tasks in this role, Kirk stated:

On any one day, I might be in with a client in a medical examination for hepatitis, helping both the physician understand the patient (not all doctors have patience for the mentally ill) and the patient to understand the doctor. I might then be on the phone with the district attorney (DA) advocating for probation rather than jail, helping the DA understand that jail may be counterproductive for this mentally ill person or explaining to the group home how to care for the edema in this man's legs. Later that day, I might be showing someone else how to operate a washing machine and observing him to see if the recent increase in medication has resulted in any side effects. While doing the wash, we might discuss how to cope with his voices. Afterward, we may rework his budget to reflect his wish to have more money for fun on the weekends. Later that day, I might be meeting with the family of a patient who are trying their best but instead are enabling the patient to be stuck and not move forward. I help them see that their son has skills and strengths and is more than his mental illness. I might take that patient to the store to teach him how to shop more independently and eat more nutritiously. Earlier, I cleaned diarrhea off the floor for a dehydrated person who lives alone, hugged another who is having a particularly lonely day, and spent time with a very psychotic person who has exercised his right to decline medication but is suffering as a result. (personal communication, March 25, 2005)

In treating each individual case, Kirk is faced with an unusual collection of responsibilities that fall under his area of expertise as a health social worker. In this role, he must work multilaterally in order to provide the best care for his patients, addressing microlevel needs for one patient and macrolevel issues in order to ensure that another is treated appropriately and in his or her best interest.

Dawn Romano, MSW, LMSW, LCSW, is a clinical social work supervisor at Children's Mercy Hospitals and Clinics in Kansas City, Missouri. She serves as another example of a social worker who performs a multitude of tasks. Her daily clinical responsibilities include crisis intervention, child abuse and neglect assessment, and trauma counseling to patients and families. As a supervisor, she oversees the hospital's social workers, providing child abuse orientation and clinical supervision. She serves on a variety of committees, including the trauma and domestic violence committees. The majority of her work centers on child abuse and neglect assessments, and she meets with children and families to complete psychosocial assessments for child abuse and neglect. Working closely with her team, she completes hotline reports and works with the Child Protection Services agencies to assess the immediate safety of children. She advises law enforcement officials on the reporting and investigation of child abuse and neglect, provides support and education to families, and connects families to community support services. Romano is also a part of the trauma and hospital emergency response teams. She is the social worker representative on a team including a chaplain and nursing supervisor that provides crisis intervention, education, emotional support, and grief counseling to families whose children have been injured in motor vehicle accidents, shootings, drownings, falls, suicides, and other tragedies. She also provides case management services.

### THE INTERDISCIPLINARY APPROACH: COLLABORATING WITH OTHER PROFESSIONALS

In the various health settings described, social workers are called on to collaborate with other health-care professionals. Social workers may work on teams that are *multidisciplinary* (each professional works autonomously with little interaction), *interdisciplinary* (professionals interact with one another to provide services but maintain clear professional boundaries dictated by distinct terminology and interventive preferences), or *transdisciplinary* (close collaboration among the professionals, including sharing a common language and approach to programming and intervention planning).

The level of collaboration within a team is specific to individual health settings and their norms and practices. At one end of the spectrum, collaborating with other professionals might occur indirectly. For example, physicians may read social work notes in a patient's chart yet never discuss the patient's care directly with the social worker. Social workers may be employed at health settings on a per diem or consultant basis and not be active members of teams. At the other extreme, professionals may work directly with one another on a daily basis, confer frequently about patient issues, visit patients as a team, and make all care planning decisions based on group meetings and group feedback, with all members having an equal voice in the process.

#### CHALLENGES TO PROFESSIONAL COLLABORATION

Professional collaboration can be challenging in a health setting. Even if the team interacts frequently, professionals may not have equal voices in the care planning process, professional roles may not be clear, and professional perspectives and ethics may clash. The execution of team collaboration varies significantly. At care planning meetings, the social worker may be a passive observer and not encouraged to participate unless necessary. Alternatively, social workers may organize and run such meetings.

Workplace change represents a significant challenge to health social workers. Health-care provision increasingly is focused on reducing costs and decreasing hospital stays. Professional departments, including counseling services and community education, have been reduced in size or eliminated (Sulman, Savage, & Way, 2001). Another challenge to health social work is the cooptation by other professions of tasks that historically have fallen under the rubric of social work. This is notably true in case management, with nurses and other professionals performing case management activities. Hospital social work departments are being replaced by nurse-led case management departments, and nursing professionals increasingly are supervising health social workers (Alveo, 2001; Globerman, White, & McDonald, 2003). In a study of discharge planners, Holliman, Dziegielewski, and Teare (2003) found nurse case managers to be paid more than social work case managers. The authors found that private hospitals were more likely to hire nurses as discharge planners although federal and state hospitals were more likely to hire social workers as discharge planners.

Collaboration may be hampered by ambiguity of roles and tasks, and different disciplines may not understand one another's lexicon and procedures. Health professionals have unique training, education, and perspectives toward practice.

Physicians, nurses, and social workers (along with the other members of the interdisciplinary team) view and frame patient's problems and their solutions to those problems through separate lens. Carlton wrote that, "social work is a profession whose purpose, logic, and underlying rationale differ from those of other professions" (1984, p.xiii). Rolland asserts:

Clinicians from different disciplines bring their own assets and liabilities to the interaction of family and illness and disability. Physicians and nurses have a surplus of technical medical information. They can have trouble seeing the psychosocial forest through the technological lens they need to use to help the patient medically. And if they can switch lenses, often they have trouble deciding which trees in the medical forest are psychosocially important. They may have difficulty taking the 1001 facts about diabetes and distilling from them the essence of the psychosocial meaning of the disorder. (1994, pp. 20–21)

Social workers are both trained and ethically obligated to advocate for their patients. This may lead to interprofessional strain, because other professionals may be annoyed by patient and family behavior that does not fit neatly with the policies and procedures of health-care agencies or institutions. Physicians and nurses may get frustrated with the parents of an infant in an intensive care nursery who only visit late at night. They may view the parents as negligent because they do not spend the entire day with the ill child and awaken the baby when they do visit. While empathizing with the staff's need to cope with visitation beyond the "normal" visiting hours, the social worker can inform the team about the parents' work schedules that preclude daytime visits. The social worker can also advocate for these parents, pointing out the fact that despite working during the day, the parents visit every day, spending several hours with the infant and are indeed very devoted parents. Social work advocacy can also play a role when issues arise regarding nontraditional families. In situations in which the medical team does not view a same sex partner as legitimate, social workers can advocate for inclusion of such partners in care planning.

#### HEALTH SOCIAL WORK RECOMMENDATIONS

Many recommendations can be made to maximize health team collaboration. Professional differences in health settings can be reframed as assets rather than liabilities. A biopsychosocial model of health requires the perspectives of a number of professionals to most effectively deliver health services. Cowles (2003, p. 21) lists specific objectives that are essential to maximal team collaboration:

- Role clarity and flexibility
- Mutual respect and trust
- Consensus on group norms, values, commitment, and purpose
- An egalitarian attitude; a sense of equal importance
- A sense of group bond and interdependence, rather than autonomy
- Open communication and sharing
- Flexible leadership and decision making; shared power
- Flexible membership composition based on case needs
- A stable core membership

- A sense of both group and professional identity
- Ability to negotiate and reach consensus
- Goal focus and goal clarity
- Record keeping of meetings
- Attention to both the task and maintenance functions of the team
- A systems perspective

Health social workers need to remember that clients do not normally present to the health-care system for social work services specifically; rather, they present with medical needs that have psychosocial components. As such, it is the social worker's responsibility to be familiar with the biological aspects of the biopsychosocial care model. Social workers should enhance their understanding of medical issues and terminology so that they are knowledgeable when talking to patients and their families and can participate fully on health-care teams.

Health social workers can support and reinforce other team members' roles rather than engage in turf wars and provide staff education on psychosocial issues to other members of the team (Nason & Delbanco, 1976). Globerman, White, Mullings, and Davies (2003) recommend that social workers minimize role conflict with other members of the health team by proactively defining and promoting their unique roles and tasks, continuously updating their knowledge base related to the relevant practice area, and acknowledging the expertise of other professionals. They also advise that social workers evaluate and track the impact of their services. This allows social workers to identify areas in which they specialize, establish a niche on the team, and show the effectiveness of their unique contribution to health care. Social workers should play an active role on quality assurance or continuous quality improvement committees.

As Kayser, Hansen, and Groves (1995, p. 498) state, "to obtain resources and the commitment from hospital administrations to provide comprehensive services, social work departments need to continually collect the data that substantiates that they are the professionals best trained for such responsibilities and can deliver the services in the most cost-effective manner." This is particularly true in the era of managed care, for which medical spending is limited and cost containment is mandated by health organizations (Segal, 2002). If social workers can show that they reduce medical costs by reducing hospital stays, increasing patient satisfaction and quality of life, and reducing morbidity and mortality, they can maintain their presence in health organizations. Social workers also need to equip themselves with the skills to effectively intervene with patients on a short-term or ad hoc basis.

Simmons (1989) reviewed the fiscal advantage of social work services in health-care settings and noted that social workers conserve institutional resources in several ways. They link patients with insurance and resources and thus increase reimbursement, reduce hospital stays through effective discharge planning and linkages to outpatient resources, increase service provision through outreach and program planning and mediating conflicts between patients and providers, enhance revenue through the creation of new programs and services, and improve the productivity of the medical team by participating in employee assistance programs that support team members.

Health social workers must also advocate for themselves as active members of health teams. Lee (2002) and Globerman (1999) recommend that health social

workers create literature that informs other professionals and consumers about the role of health social workers, provide team training about the social work activities and roles, provide evidence of the effectiveness of social work services, and be visible parts of health settings by volunteering to be part of task forces and committees. Social workers must document their interventions with patients and their families. Brief, quickly completed forms may suffice to achieve this aim if social workers are burdened by high caseloads and time constraints.

Changes in health-care delivery and organizational constraints affect all members of the health team. Just as they help clients cope with illness, its treatment, and the changes that illness entails, social workers can use those skills to help the health-care team adapt to hospital and program restructuring (Globerman, 1999). Social workers can provide professional support to their colleagues when they face challenging patient situations, such as when patients die (Roberts, 1989). These efforts allow health social workers to help minimize role conflict with other team members as well as demonstrate that social work is effective.

### TREATING THE WHOLE PERSON: SOCIAL WORK'S PRIMARY ROLE

Health social workers fill various roles, work in myriad settings, and perform a broad collection of tasks on the clinical and administrative levels. Social work fulfills a critical function in the biopsychosocial approach to health care. As Romano wrote, "social work occupies a unique position in that it has its feet in health and mental health, its hands in the social sciences, its viscera in clinical intervention skills, and its head and heart in a commitment to the issues of the quality of life of disabled persons in society" (1981, p. 15). Although fiscal, organizational, and professional challenges exist in providing health services that fully incorporate the biological, social, and psychological determinants of health, social work is a vital component to health teams in order to explain and significantly affect the complex pathways through which variables at different levels influence health (Keefler, Duder, & Lechman, 2001).

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### SUGGESTED LEARNING EXERCISES

#### LEARNING EXERCISE 2.1

Using the profiles of health social workers throughout this chapter, compare and contrast the different roles in health-care settings—what is it exactly that health social workers do? How are these roles similar? How are they different? What are the differences and similarities between clinical health social workers and those who work in an administrative or policy level capacity?

#### LEARNING EXERCISE 2.2

Using information from this chapter, discuss the differences between social workers and the rest of the health-care team. What are some fundamental differences? What does social work uniquely bring to the care of patients? What are differences in the code of ethics among different professionals? How may these differences

manifest themselves in a health setting (in both a microlevel and macrolevel capacity)? What are some examples of professional challenges/clashes? How can social workers most effectively collaborate with other professionals on a team, agency, or policy level setting? How might you as a health social worker make a case for why case management or patient education is your domain and not another discipline? (You may also incorporate content from Chapter 1 and social work history course(s) to consider these questions.)

### SUGGESTED RESOURCES

The National Association of Social Work (<http://www.socialworkers.org>) has numerous resources for health social work, including: a health specialty practice section, social work summits that include health social work organizations, continuing education modules (available online) regarding social work and various health-care settings (such as oncology and end of life), and social work clinical indicators for various health settings.

### ADDITIONAL RESOURCES FOR SOCIAL WORKERS

- American Case Management Association (<http://www.acmaweb.org>)
- American Lung Association (<http://www.lungusa.org>)
- Institute for the Advancement of Social Work Research (<http://www.iaswresearch.org>)
- American Network of Home Health Care Social Workers (<http://www.homehealthsocialwork.org>)
- American Public Health Association (<http://www.apha.org>)
- Association of Oncology Social Work (<http://www.aosw.org>)
- Association of Pediatric Oncology Social Workers (<http://www.aposw.org>)
- Association of State and Territorial Public Health Social Workers (<http://www.astho.org>)
- Council of Nephrology Social Work (<http://www.kidney.org/professionals/CNSW/index.cfm>)
- Council on Social Work Education (<http://www.cswe.org>)
- Epilepsy Foundation (<http://www.epilepsyfoundation.org>)
- National Association of Children's Hospitals and Related Institutions (<http://www.childrenshospitals.net>)
- National Association of Perinatal Social Workers (<http://www.napsw.org>)
- National Council of Hospice and Palliative Professionals (<http://www.nhpc.org/templates/1/homepage.cfm>)
- National Multiple Sclerosis Society (<http://www.nationalmssociety.org>)
- Society for Social Work Leadership in Health Care (<http://www.sswlh.org>)
- The Society for Transplant Social Workers (<http://www.transplantsocialworker.org/index.cfm>)
- Veterans Health Administration (<http://www1.va.gov/socialwork>)



## INTERNATIONAL SOCIAL WORK ORGANIZATIONS

- Australian Association of Social Workers (<http://www.aasw.asn.au>)  
 British Association of Social Workers (<http://www.basw.co.uk>)  
 Canadian Association of Social Workers (<http://www.casw-acts.ca>)  
 International Federation of Social Workers (<http://www.ifsw.org>)  
 Irish Association of Social Workers (<http://iasw.eire.org>)
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## CHAPTER 3

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# Ethics and Social Work in Health Care

JARED SPARKS

If this is the best of all possible worlds, what are the others like?

Voltaire, 1759/2003

**W**HEN CONFRONTED WITH the harsh reality of illness and suffering that existed in the eighteenth century, the French author and philosopher Voltaire expressed his feelings of incredulity that such conditions were tolerated. Even now, as the tools of science and technology have advanced society's understanding of biology and the human condition, mankind continues to feel a sense of astonishment and vulnerability in the face of unresolved modern health-care issues and ethical dilemmas.

Today, lives are increasingly influenced by human invention even prior to conception, through genetic counseling and intervention. As a person progresses through each developmental stage of his or her life, choices must be made regarding available health options. These can be especially difficult at the end of life.

The purpose of this chapter is to facilitate discussion and understanding of health social work ethics in a changing health care environment. Toward this end, some of the philosophical foundations of ethics are reviewed and the history of social work ethics is discussed, as are decision making, theoretical frameworks, and other special topics.

### CHAPTER OBJECTIVES

- Discuss the development of social work ethics, medical ethics, and bioethics within a historical and cultural context.
- Define ethical terminology and theory as these relate to the Social Work Code of Ethics.

- Outline decision-making models and theoretical applications as they relate to social work ethics in health care.
- Discuss particular ethical issues related to dual relationships, managed care, and research ethics.
- Outline ethical challenges in the twenty-first century and beyond.

### AN OVERVIEW OF ETHICAL ISSUES IN SOCIAL WORK

Within each chapter of this book and the concomitant practice areas in social work reside compelling ethical issues and questions. Social workers play an important role in addressing these issues and answering these questions. In health social work, practitioners inform patients of their treatment and discharge options, advocate for patients within a transdisciplinary team, serve on ethics committees, and shape policy. These experiences provide a unique and valuable opportunity to gain both a micro- and macroperspective of health social work ethics. The ability to clearly articulate a position and effect change depends on understanding the ethical issues involved. Today, more than at any time in history, social workers must have a working knowledge of ethical dilemmas in health care and how health social work ethics may be employed to address these dilemmas.

Social workers and other health-care professionals may prefer to think of themselves discretely as completely homogeneous groups, each profession holding a unique value system and set of beliefs. All social workers may have an idea of what health social work ethics constitute and suggest. In reality, however, not everyone shares the same concept of exactly what that may be. The eighteenth-century French author Diderot described an appreciation of separateness of understanding from person to person in his work *D'Alembert's Dream*.

For the obvious reason that no two of us are exactly alike, we never understand exactly and are never exactly understood. There is always an element of “more or less”—our speech falls short of the real sensation or overshoots it. We realize how much variety there is in peoples’ opinions, and “there is a thousand times more that we don’t notice and fortunately cannot notice” (Diderot, 1769, p. 222).

Diderot reveals some trepidation in considering the possibility of understanding exactly how someone else experiences or interprets a certain phenomenon. It does seem fortunate that individuals experience life differently. In the study of health social work ethics, consensus may be reached fairly easily. That will not always be the case, and care should be taken to respect different opinions.

Throughout the course of a career, most social workers encounter situations for which no completely desirable solutions can be found because each alternative has its own set of undesirable outcomes. Proctor, Morrow-Howell, and Lott (1993, p. 166) further define *ethical dilemmas* as situations “when a social worker cannot adhere to professional values or when adhering to one ethic requires behaving counter to another.”

Reamer (1987, pp. 801–809) identified eight areas of importance when considering ethical dilemmas in social work: (1) confidentiality and privileged communication; (2) truthfulness; (3) paternalism and self-determination; (4) laws, policies, and regulation; (5) whistle-blowing; (6) distributing limited resources; (7) personal and professional values; and (8) ethical decision making. Some of these topics are discussed throughout this chapter.

In contemplating ethical dilemmas, the point of ethical discourse is not necessarily to arrive at an immutably “right” solution. Value lies in thoughtful review and discussion. Through the process of ethics discourse, a more complete understanding may be reached, alternative courses of action may appear, and, if not, there may be at the very least an appreciation that whatever decision was reached was the result of informed and thoughtful consideration rather than the singular expressed preference of a party involved in the patient’s care.

Ethics codes provide some direct guidance for practice. Lowenberg and Dolgoff (1996) identify four other purposes of codes of ethics. They:

1. Protect the public.
2. Protect the profession. (Self-regulation is a hallmark of a profession and ideally more effective than governmental involvement.)
3. Prevent internal strife.
4. Protect practitioners from lawsuits. (The rationale for why a specific course of action was taken provides some defense against lawsuits.)

Prior to discussing individual cases in which some of the purposes of codes of ethics may be made clear is a review of the philosophic underpinnings of social work ethics. This review should not be considered comprehensive. You are encouraged to read on your own in this area to develop a more complete understanding as well as to prepare yourself to use the code of ethics in your social work practice.

## ETHICS TERMINOLOGY AND THEORY

Some social work schools provide classroom instruction on ethics. In fact, some states now have licensure laws requiring ongoing ethics education. The inclusion of content on ethics in curricula will undoubtedly provide much needed guidance. Terminology found in the National Association of Social Work (NASW) code of ethics provides a solid foundation to any review of this subject matter. Much of the vocabulary used in this chapter requires clear definition and distinction because terms such as values, morals, and even ethics are used interchangeably by some, though each informs very different aspects of social work practice and codes of ethics.

### VALUES

A discussion of values is fundamental to the study of professional ethics. While they have specific meaning as they relate to social work ethics, values exist in personal, professional, and societal contexts. Confusion may arise from explanations of this notion because a multitude of definitions for the term *values* exists depending on the branch of philosophy or social theorist making reference to it. Further, the term values has been co-opted by a variety of political influences, each claiming to have a more correct grasp of what values are. Nonetheless, through all this contention, values have specific and significant meaning in a code of ethics.

Value is derived from the Latin word *valere*, which means “be worthy, be strong” (Angeles, 1992). The *Harper Collins Dictionary* (1992, p. 329) defines value as “worth; the quality of a thing that makes it desirable, desired, useful, or an object

of interest," as well as, "of excellence; that which is esteemed, prized or regarded highly, or as a good." As value relates to human behavior, Rokeach (1973, p. 23) provided this definition: "an enduring belief that a specific mode or end state of existence is personally or socially preferable to an opposite or converse mode or end state of existence." Values serve as ideals of what is right. Within professions, values constitute what is unique and good that sets one profession apart from others.

As a profession, social work holds the following core values: service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence (NASW, 2000). According to Reamer (1995, p. 3), "Social work is among the most value-based of all professions."

Before attempting to identify, understand, and comment on ethical dilemmas, health social workers should examine their personal values. Each person has personal values that have been shaped by family, friends, culture, and prior life experiences. These personal values influence how dilemmas are viewed and whether or not a practitioner accepts the profession's core values. Understanding differences in individual value bases has special relevance as practitioners interact with patients operating from value positions different from their own. Hodge (2003, p. 107) underscored this in an article providing data to suggest that master's level social workers' "values were more to the left of working and middle class clients."

#### MORALS

*Morals* is a term derived from the Latin word *moralis*, meaning custom, manners, or character. Morals have been defined as consisting of "principles or rules of conduct which define standards for right behavior" (Lowenberg & Dolgoff, 1996, p. 22). Morals encompass widely accepted notions of right and wrong. While morals are not necessarily outlined in the NASW Code of Ethics, they do shape how social workers develop professional and personal values.

#### LAWS

*Laws* have also been defined in different ways. Some definitions point to concerns with protection from abuses of power by authorities as well as individuals. Other definitions refer more to social control and welfare, and yet others emphasize more consideration of social justice.

Laws, ethics, and values all have unique meanings. Simply passing legislation does not change individuals' deep-seated beliefs and ideas regarding a particular issue. For example, passing laws proscribing assisted suicide will not change people's personal perspectives. Simply attending to the law does not protect social workers from behaving in a professionally unethical way. When laws are passed that are unjust, social workers have an obligation to work through the courts to address social injustice. For example, NASW is active in addressing legislation affecting health-care issues, such as prescription drug coverage.

#### PRINCIPLES AND STANDARDS

*Principles* in a code of ethics may be thought of as a stage in the formation of values. In their own right, principles can serve as an ideal of sorts. Principles inform social work practice (Reamer, 1995) and offer a reference point for the develop-

ment of even more specific standards. *Standards* in a code of ethics specifically outline how social workers should conduct themselves.

## ETHICS

Ethics is a term derived from the Greek word *ethos*, which means a person's character or disposition (Angeles, 1992). There are several ways of defining ethics. For the purposes of this chapter, ethics will be divided into three branches: metaethics, normative ethics, and applied ethics.

*Metaethics* Metaethics asks the questions: What does something really mean? What does it really mean to be "good" or "bad"? Metaethics refers to the study of the "methods, language, logical structure, and reasoning used to arrive at and justify moral decisions and knowledge" (Angeles, 1992, p. 183).

*Normative Ethics* In contrast to metaethics, normative ethics is concerned with identification of the morals, values, principles, or standards that might be relevant in addressing a dilemma. In developing a normative ethical response to this situation, several values and principles might be relevant. The NASW 2000 Code of Ethics wisely reflects that there are situations in which values, standards, and principles conflict. In these situations, two reasonable and informed practitioners may disagree on what constitutes an ethical response to a clinical situation.

*Applied Ethics* Applied ethics is a third branch of ethics and is concerned with the application of normative ethics (a relevant set of morals, values, principles, and standards) to specific situations. This would be the stage at which decisions are actually made. Social workers should consider if the ethical standard speaking to legal obligations supersedes the principles of autonomy and self-determination, or if they feel that they should act to have the law changed.

Ethics can be defined within each of the three contexts—metaethics, normative ethics, and applied ethics. That is, ethics can be considered as: (a) a branch of philosophy interested in value-based reasoning and human conduct; (b) a framework of morals, values, principles, and standards; or (c) the actual decision-making process derived from that specific framework. As it relates to social work in health care, Joseph and Conrad (1989) provide a definition of ethical behavior as "social workers' professional behaviors in relation to biomedical ethical choices" (p. 23). The following section provides a discussion of ethical issues related to a topic that health social workers may encounter related to end-of-life care.

## THE RIGHT TO DIE

The right-to-die debate resurfaced in 2005 with the case of Terri Schiavo, whose husband had her feeding tube and hydration removed against her parents' wishes. This case provides an example of just how divisive ethical dilemmas can become. Schiavo's case was not the first to capture national attention. Two other women, Karen Quinlan and Nancy Cruzan, similarly faced the court's involvement in their right-to-die cases. Both women suffered brain damage and never regained consciousness to the point that they were able to verbalize their wishes. Karen Quinlan's breathing tube was ultimately removed but she lived another 10

years. Nancy Cruzan's parents won a lengthy court battle to have her feeding and hydration stopped. Nancy Cruzan died 2 weeks after her feeding tube was removed. Both Quinlan and Cruzan died in the 1980s. Amid even more controversy, Terri Schiavo died on March 31, 2005, 13 days after her feeding tube was removed. These cases all reflect fundamental moral, ethical, and religious differences in this country. They also point to a strong need for health social workers to be attentive to their patients' wishes and advocate for completing advance directive documents specifying such wishes.

When responding to challenging situations such as the ones just described, the practitioner should first examine his or her own values as they relate to the wishes of the patient. A social worker's values may differ from the patient's and interfere with the ability to engage in a meaningful discussion. In a study of 110 hospice social workers, Csikai (2004) found that among the least discussed issues in hospice care were those of euthanasia, assisted suicide, and thoughts of suicide by a patient, even though 34% of the social workers had been approached by their patients about assisted suicide. Under no circumstance should the social worker fail to address the patient's concerns. In situations in which a social worker's values conflict with those of a patient, it may be necessary to refer the patient to another colleague.

One of the first responses to a patient requesting to die should be a careful screening for depression and review of any other possible health treatment modalities. It may be that after careful consideration and review of options, the patient will still wish to die. However, it also may be that she would like reassurance from her family that she would be cared for and not be a burden or abandoned (Csikai, 1999). She might also be concerned about what options her life could hold. Once these issues are addressed adequately, the patient might not continue to wish for euthanasia or assisted suicide.

Metaethics would be imposed in situations in which social workers believe that suicide is wrong. Questions considered in metaethical analysis include why it is wrong and if it is wrong in all situations. The definition of suicide influences any subsequent conversation. Metaethics would be involved in understanding whether suicide is wrong in the case of a suffering patient. Metaethics would also be concerned with questions about what suicide is. Is it suicide when it is physician-assisted, that is, a doctor gives a competent patient the medications or other means to end his life? Is suicide somehow different from active voluntary euthanasia when a physician injects a competent patient who requests a lethal amount of an opiate-based pain killer? Is foregoing recommended medical treatment suicide?

In contrast to metaethics, normative ethics is concerned with the identification of the morals, values, principles, or standards that might be relevant in addressing a dilemma. In the Bouvia case (see Box 3.1), a normative ethics dilemma may be whether or not one should support assisted suicide or euthanasia. Normative ethics is also concerned with assembling a framework out of those identified morals, values, principles, and standards that could be used in contemplating a specific instance of assisted suicide or euthanasia.

From a medical standpoint, the principles of beneficence and nonmalfesance apply. The principle of beneficence basically instructs the practitioners to "do good." The principle of nonmalfesance instructs the practitioner to "do no harm." From the social work code, the value in question could be dignity and worth of



**Box 3.1**  
**The Bouvia Case**

One prominent right-to-die case that created an ethical dilemma was that of Elizabeth Bouvia. In 1983, Ms. Bouvia asked to be admitted to the psychiatry ward of Riverside General Hospital in California because she was having thoughts of death (Munson, 2000). Ms. Bouvia had overcome a great deal in life. Despite the fact that she had cerebral palsy, since age 18, she had lived on her own, completed a bachelor's degree, and studied to become a social worker. She dropped out of her MSW program due to problems with a field placement (Pence, 2004). At the time of her hospital admission, she was mostly paralyzed, with the partial use of one arm. She only had the ability to speak and to swallow food that was fed to her. Ms. Bouvia was also in constant pain from arthritis. She was wakeful, aware, and able to express her wishes.

During admission, she decided that she did, in fact, wish to die and asked to be allowed to starve to death. Her physician did not agree with this course of action and informed Ms. Bouvia that he felt obligated to see that she was fed by tube because she had become a danger to herself. She alerted the local media and, ultimately, with the assistance of the American Civil Liberties Union, sued the facility. The judge agreed that she could commit suicide, but only if unassisted. She was fed by a tube until 1986, when she returned to court asking to be fed only a liquid diet. The court ruled in her favor. However, she soon agreed to be fed more than liquid. Over the next few years, she tried eating and then again expressed a desire to starve herself. At one point, she revealed that starving would take too long and expressed a desire to have a quicker method to end her life. Ms. Bouvia was ultimately moved to a private apartment with twenty-four-hour care provided by Medicaid at a great cost.

the person. The principles of autonomy and self-determination seem to also have bearing. However, the ethical standard of commitment to clients takes into account that social workers may have legal obligations falling into the realm of standards, as discussed earlier, that would preclude facilitating euthanasia or assisted suicide. Also relevant would be evaluating whether patient autonomy supersedes preserving life in such a case.

A variety of broad philosophical theories exists within an ethics code to inform and influence decision making. Both social work and medicine have been influenced by a number of philosophies over the years. Modern medicine, as a profession, owes more to the positivist model than does social work. Positivism is the notion that reality exists, is based on fixed laws, and is thus understandable (Guba, 1990). Science in this framework is the mechanism by which we can determine what constitutes this reality and ultimately manipulate it in our interest. This thought came about during the Enlightenment Period in the late seventeenth and throughout the eighteenth centuries when the world was being viewed more and more in the context of a clockwork universe that was ultimately understandable and subject to our control (Spurlin, 1984).

Health social work may at times be seen as a profession struggling to emulate the positivistic approaches that have led medicine to its present status in society. However, it would be difficult to argue that social work has not paid heed to a constructivist model. In contrast to a clockwork universe, constructivism proposes that

society is not “a system, a mechanism, or an organism” (Parton, 2003, p. 5). Rather, it is a symbolic construct relying on collaboration between the observer and observed, together creating a novel and fluid meaning.

As it relates to social work in health care, constructivism asks that a practitioner step outside the imposed work environments (in thought) and engage his patient on her own terms in order to develop a more thorough understanding of the patient, what she is experiencing, and what she would desire. The social work injunction to “start where the patient is” and not where the social worker is or where the social worker wants the patient to be would be a step in the right direction toward constructivism. Social workers may better provide relevant services if they understand the meaning imposed by a patient on his disease and its available treatments.

### BASIC NORMATIVE THEORIES

Some ethics theories are more concerned with outcomes of actions. Others are more concerned with identifying principles, standards, and rules that can guide behavior before any action is taken. Hence, most normative ethical theory falls into the category of deontological or teleontological.

#### DEONTOLOGICAL AND TELEONTOLOGICAL THEORIES

Deontological theory places primacy on the ethical value, standard, or principle in determining the correct action without consideration of the outcome. For example, with the principle of confidentiality, deontological theory would dictate that a social worker should under no circumstances violate the principle.

Teleontological theory is more concerned with the outcome of a particular action than with values, principles, or standards. Teleontological comes from the Greek word *telos*, which means end or goal (Angeles, 1992, p. 369). For example, a teleontological consideration of confidentiality would be more concerned with what would happen if this confidentiality were violated.

Deontology and teleontology often clash, as do the values, principles, and standards of an ethical code. One example of this is the 1976 case of *Tarasoff v. Board of Regents of the University of California* (Kagle & Kopels, 1994). In this case, a patient informed his psychologist at the University of California that he was having homicidal ideations, with Tatiana Tarasoff as the target. The patient even went so far as to inform his psychologist of his plans. The psychologist contacted the campus police, who detained the patient for a brief time and later released him with a warning not to go near Tarasoff.

Later, the psychologist’s supervisors told him to destroy his case notes surrounding this incident, which by law is illegal and by the NASW standards would be a clear violation of the principles surrounding client records, deception, and fraud. Several months later, the patient murdered Tatiana Tarasoff. Tarasoff’s parents ultimately successfully sued the university. The California Supreme Court indicated that the University had a duty to protect, which superseded the patient’s privacy and confidentiality.

This controversy falls within the realm of “duty to protect” or “duty to warn.” The deontological consideration in this case would be to attend to the ethical standard of confidentiality regardless of the outcome. This obviously falls apart



when the outcome seems much more harmful than the violation of confidentiality, as was affirmed by the court. A teleontological consideration to protect the intended victim may ultimately have more of a positive benefit in the sense that a life is saved.

In addition to framing ethical dilemmas via teleontological and deontological perspectives, other concepts such as utilitarianism, Kantian ethics, ethics of care, and virtue ethics can be applied in health social work.

*Utilitarianism* Utilitarianism was strongly influenced by British philosophers Jeremy Bentham and John Stuart Mills. This theory is premised on the principle of utility. Utility is the doctrine that a person ought to do that which brings about the greatest happiness to the greatest number of people or to the community as a whole. The determination of right or wrong is teleontological in utilitarianism.

Utilitarianism has two main divisions: act and rule. Act utilitarianism focuses exclusively on the outcome. A classic example would be the experiments conducted by the Nazis during World War II. This “research” violated a host of ethical considerations and resulted in the torture and death of many. The question an act utilitarian might pose would be, “Could the research have some utility in providing usable data?” The act utilitarian might insist that the data be made available to provide insight into certain human conditions, treatments, or diseases because there might be value in these data.

Rule utilitarianism, however, defers to established standards within an ethical framework to make the decision of what produces the most good. Research ethics has informed consent as a cornerstone for its foundation. This was clearly violated by the Nazi experiments. With regard to these experiments, a rule utilitarian would suggest that the use of these data might generate more harm than good by setting a precedent for using data obtained unethically.

*Ethics of Duty (Kantian Ethics)* In contrast to most utilitarian thought, especially act utilitarianism, stands ethics of duty. This concept was espoused by the German philosopher Immanuel Kant who felt that the outcome of an act was not relevant to determining whether it was right or wrong. Kant believed that actions were right only if they were consistent with a particular standard, fitting within a categorical imperative. One way of determining what a categorical imperative was would be to pose the question, “Would everyone benefit if everyone participated in a particular act?”

Kant believed that there were basically two types of duties—perfect and imperfect. Perfect duties are duties of omission, or clear duties of things one should not do, such as steal, lie, or kill. These duties are primarily “black and white” in terms of conduct. Imperfect duties are not as clearly defined. They are duties of commission, such as be a good person. These duties are more difficult to identify, as they are difficult to clearly extrapolate in every instance.

*Ethics of Care* Gilligan’s (1982) study of morality and purported differences in male and female moral reasoning brought Kant’s arguments to a new audience. She believed that there were differences, but they were not necessarily indicative of moral superiority. Gilligan held that females attended more to the ethics of care than the ethics of rights and justice. The ethics of care dictates that a more

constructivist approach might be taken in speaking to patients and their families. Carse (1991) identified seven applications of care ethics in health settings:

1. A shift from principle-ism and institutional rules and emphasis on a more responsive relationship with the patient
2. An emphasis on self-awareness as a part of understanding others
3. Placing value on ethical discourse and not focusing exclusively on outcomes
4. A review of gender-based differences in health care
5. An emphasis on the nature and dynamics of relationships as particularly important in ethical deliberation
6. Acknowledgment of the reality of *moral ambivalence*
7. Consideration of what traits or virtues one should develop to further competency in ethical decision making

*Virtue Ethics* Virtue is a translation of the Greek word *arête*, which means excellence (Lacey, 1996). Both ethics of care and virtue ethics have been referred to as “theories without principles,” because they do not arise from specific principles (Munson, 2000). While the ethics of care theory may use principles during application, virtue ethics may rely on principles even less. Virtue ethics refers to the positive attributes of a particular type of person. Carse (1991) considered virtue ethics valuable in the sense that contemplating a virtue may result in a better-developed sense of professional self as it relates to others.

Virtue ethics may be problematic. For instance, ideas about what attributes a virtuous doctor must possess may vary from person to person. They might include patience, empathy, and intelligence. It may be more difficult to come up with an agreed on definition of what attributes a virtuous social worker might have, especially as it relates to particular practice areas, even within health social work. For example, a hospital-based social worker in a case management department might be perceived as virtuous because she is able to contain costs by discharging patients quickly. Another hospital-based social worker may be perceived as virtuous because he advocates for longer hospitalizations for his psychiatric patients.

## DEVELOPMENT OF MEDICAL ETHICS, SOCIAL WORK ETHICS, AND BIOETHICS

### MEDICAL ETHICS

“If anyone conceal more than a single lunatic without a license, he becomes liable to a penalty of five hundred pounds” (Percival, 1803, p. 69).

Western medical ethics can be traced to 477 B.C.E. and the Oath of Hippocrates. However, Thomas Percival’s 1803 Code of Ethics will serve as the starting point of this review. While the language and perspective of this code may seem antiquated, as evidenced in the above passage, it intimates modern dilemmas. For example, licensing and credentialing of health-care institutions and practitioners continue to be relevant today.

Percival was a physician in England during the late eighteenth and early nineteenth centuries. In addition to being a physician, he was a writer of morality stories for the middle class. People sought his help resolving disputes at the local

Manchester Hospital. He was also familiar with larger societal forces causing unrest in England; namely, the introduction of spinning mills, the English slave trade, and treatment of the poor (Baker, Porter, & Porter, 1993). Much of his awareness of larger societal concerns can be seen in his 243-page *Medical Ethics* (1803) which was progressive and thorough. Unfortunately, the publication has been criticized as more involved with professional etiquette than professional ethics. This criticism, though, seems to miss the mark since topics covered are cogent even by today's standards and include abortion, rape, medical malpractice, and the purpose of charity. To be fair, the codes of both medicine and social work have components of trade etiquette as well as more value-based considerations. Percival's code eventually appeared in America in the early 1800s in a much-abridged version of the original and influenced the American Medical Association's (AMA) first code of ethics in 1847.

#### SOCIAL WORK ETHICS

Abraham Flexner may have provided some impetus for the field of social work developing a unique code of ethics by posing the question of whether social work was, in fact, a profession. Flexner was one of the most influential figures of his day in medical education, and he imposed many changes in how education was conceptualized and delivered (Bonner, 2002). Flexner also commented on the profession of social work in his 1915 article, "Is Social Work a Profession?" published by the New York School of Philanthropy. In this article, he outlined the necessary criteria for a profession. According to Flexner, social work had not yet met all the criteria of a profession; however, Flexner posited that in some ways it was closer to doing so than law and medicine. One of the most important requirements of a profession, according to Flexner, was that it should have "spirit" or values:

In so far as accepted professions are prosecuted at a mercenary or selfish level, law and medicine are no better than trades. . . . In the long run, the first, main and indispensable criterion of a profession will be the possession of a professional spirit, and that test social work may, if with will, fully satisfy. (p. 24)

The social work community began a conversation about ethics shortly after Flexner's report. Reamer (1998) identified five distinct periods of development for the social work code of ethics: the morality period, the values period, the ethical theory and decision-making period, and the ethical standards and risk management period (p. 488).

The morality period for social work occurred in the late nineteenth century and lasted until the 1950s. Individuals receiving care from social workers were often viewed as defective in some way. In the early twentieth century, social workers began to attend more to social justice concerns. External influences of society, such as poverty, disease, and educational opportunities were appreciated. The settlement house movement reflected this concern with attempts to provide newcomers to America with some basic skills and understanding of how to better integrate into their new country.

Mary Richmond has been credited with drafting an early social work code of ethics in the 1920s (Reamer, 1987). This was during what was likely the beginning of the end of the morality period. During this time, articles were written on the need for social work ethics, and in 1923 the American Association for Organizing

Family Social Work (AAOFSW) began work on a code of ethics (Lowenberg & Dolgoff, 1996). The American Association of Social Workers adopted a formal code of ethics in 1947, 100 years after the AMA's code was adopted (Reamer, 1999). AAOFSW merged with others to form the National Association of Social Workers (NASW) in 1955. NASW published its first code of ethics in 1960 consisting of a set of 15 "I" statements, such as "I respect the privacy of the people I serve." Shortly after the interest in settlement houses declined, social work focused more on developing a domain-specific knowledge base and area of practice that would set it apart from other professions. In the 1940s and 1950s, social work moved into the values period (lasting until the 1980s) during which there continued to be a shift away from focusing on the client's morality to identifying ethical standards and guidelines.

In social work, the 1980s ushered in the ethical theory and decision-making period. In both the medical and social work communities, this period was largely influenced by conferences and center and commission work in developing a normative ethical response to bioethical dilemmas. Lowenberg and Dolgoff (1996) and Reamer (1995) wrote on the importance of ethical theory and decision-making models in resolving health-care and social justice issues. Malpractice concerns as well as the introduction of managed care also helped direct ethics in this period.

Social work ethics is now in a period of ethical standards and risk management according to Reamer (1998). The 1990s through the beginning of the twenty-first century have seen a number of increasingly public scandals. Companies have been caught engaging in ethically unsound accounting practices that have impacted thousands. The Catholic Church has been beset as inappropriate sexual relationships have been made public. Also, as a consequence of some new Homeland Security initiatives, concern regarding confidentiality and privacy has increased. Social work has a role in treating and advocating for the victims of abuses by powerful organizations. Clearly understanding the ethical principles involved allows practitioners to more easily identify and address misconduct.

Recent abuses of power by large corporations, institutions, and the government suggest an ongoing need to set clearer standards for social work practice in more ethically unambiguous situations, such as when social workers enter into dual relationships with patients. Because standards for behavior in ethically challenging situations may prove elusive, social workers need to continue to update their knowledge base and learn decision-making skills that will protect their clients against harm and themselves against litigation. As a consequence of a litigious society and challenging practice environments, many social work ethics experts agree that all social workers should purchase malpractice insurance. The touchstone for guiding practice, however, remains the latest code of ethics. The revised 1999 NASW Code of Ethics clearly articulates social work's mission and values base. This code is the best developed and refined to date and reflects an increasing sophistication in social work theory and practice.

## BIOETHICS

During the late 1940s and early 1950s, there were significant advances in medical technology (Jonsen, 1998). In 1949, the polio vaccine was discovered. In 1950, antihypertensive medications were discovered. In 1952, antipsychotic medications

for the treatment of schizophrenia were developed. Medical ethics of that time echoed a sense of accomplishment and security that the profession was respected. In what may have been medicine's self-satisfaction, thoughtful review and analysis of ethical dilemmas may not have seemed necessary. This supposition may be supported in the slimming down of the medical ethics code of the 1950s. In 1957, a revision cut the code down to 10 statements, and to seven in 1966.

This self-assuredness waned in the 1960s as biotechnology ushered in unforeseen difficulties. Albert Jonsen traces the birth of bioethics to the point in time at which technology made hemodialysis available on a chronic basis with the development of the Scribner Shunt, which allowed for external access to the bloodstream. This marked the first time that a terminal illness—end-stage renal disease—moved from 100% fatal to 100% treatable by mechanical means. The ethics relevance of this was the subsequent development of dialysis selection committees. These committees had to make decisions regarding what nonmedical criteria should be used in determining who lives and who dies. This called into question individual social worth and what this constitutes. On the social front, the 1960s and 1970s were a period of growth in awareness and activism. The Nixon administration's Watergate scandal and the unpopular Vietnam War collaborated to bring ethics and social justice concerns to the public consciousness. Biotechnological realities and consequent real-life dilemmas presented the public with seemingly impossible ethical situations.

The 1960s also bore witness to conferences in America and other countries that addressed bioethical issues. These conferences acknowledged and reviewed dilemmas in areas such as genetics, eugenics, and transplantation. In addition to dialysis, heart transplantation became a feasible intervention. The discussion at the conferences ultimately resulted in the generation of scholarly papers on ethics. As these collections began to develop and several bioethics centers appeared to house these collections, further bioethical conversations developed. Some of these centers were the Hastings Center, the Kennedy Institute of Ethics at Georgetown, and the Society for Health and Human Values.

As bioethics centers were developing, the bioethical conversation moved to the realm of government. The Mondale Hearings of 1968, for example, raised important questions about end-of-life issues, behavior control, and experimentation with human participants. Ultimately, the hearings gave birth to the National Bioethics Commission that exists today. The 2003 Commission was made up of 17 individuals appointed by the president. These individuals include scientists, doctors, ethicists, social scientists, lawyers, and theologians. The purpose of this committee is to advise the president and help shape policy.

As discussed in the research ethics section that follows, the Tuskegee story first appeared in the media in July of 1972. Peter Bruxton, who had training as a social worker, was essential in exposing this story. He learned of the study from colleagues after he was hired to work with patients who had venereal disease. He attempted to work within the system to intervene, through contacting superiors. Ultimately, he became a "whistle-blower" and went to the press in 1972 to expose the study (Jones, 1981). Partially in response to the public outrage, the Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was established in 1974. As its name suggests, the Commission's imperative was to develop guidelines for protecting participants in research.

This marked the development of one of the first governmental bodies to consider ethics and develop recommendations for policy and legislation. The Commission for the Protection of Human Subjects of Biomedical and Behavioral Research consisted of 12 individuals from science, law, ethics, and the public. Its mandate was to publish guidelines for medical research, an example of which is the 1975 "Recommendations on Research with the Fetus." Several other important documents followed: The 1975 report on "Research involving Prisoners" and 1979s "Report and Recommendations on Institutional Review Boards." Finally, in 1979, the National Commission issued the Belmont report in an effort to fulfill its mandate to identify basic ethical principles that could guide research. Albert Jonsen, who served on the Commission wrote:

As a commissioner I participated in the formulation of that (Belmont) Report. Today, I am skeptical of its status as serious ethical analysis. I suspect that it is in effect a product of American Moralism prompted by the desire of congressmen and of the public to see the chaotic world of biomedical research reduced to order by clear and unambiguous principle. (Jonsen, 1991, p. 125)

His commentary on the Commission he was part of foreshadows the difficulty to find clear guidelines in right-to-die cases. Following the Belmont Report, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research was established in 1979. This Commission had a broader mandate than the National Commission for the Protection of Human Subjects. It addressed topics such as how death should be defined. One of the important documents to come out of this Commission was "Deciding to Forego Life-Sustaining Treatment," which suggested that a competent patient should have priority over others in decision making. Prior to disbanding in 1983, the Commission recommended that ethics committees should have a role in dilemmas involving life or death care and reviewed the concept of durable power of attorney. These committees are appointed to fulfill a specific mandate and are appointed for a specific period of time.

The Los Alamos National Laboratory, Lawrence Livermore National Laboratory, and Department of Energy Laboratories began producing DNA clone libraries of single chromosomes in 1983, marking the beginning of a process that would ultimately result in the mapping of the human genome. The Human Genome Project began in 1990, and by April 2003, the human genome had been mapped.

The National Bioethics Advisory Commission established in 1995 and the President's Council on Bioethics created in 2001 and renewed in 2003 have both had to address the implications of Human Genome Research. In addition to the governmental oversight in the form of commissions, the Human Genome Project also developed its own ethics program. This is the world's largest bioethics program and it is a model for other programs throughout the world.

## DECISION-MAKING MODELS

Social workers routinely make key decisions in a variety of settings. One of the most visible settings for social work decision making is on health-care policy and/or ethics committees. Social work presence may have changed somewhat with the advent of managed care, but historically organizations have felt that so-



cial work input is essential (Mulvey, 1997). As these decisions become more transparent and subject to scrutiny, it becomes increasingly important to make them in an orderly and informed fashion. This is in contrast to what Goldmeier (1984) believes was, in the recent past, a “tendency to resolve ethical dilemmas on a case-by-case basis without systematic grounding in ethical principles.”

Developing a sound ethical decision can be a daunting task, and currently a variety of models exist to help guide decision making. These models assume various geometric shapes; some square, some triangular, some two-dimensional, others three-dimensional. It is not the appearance of the model, however, that is important. Rather, it is the number of elements and complexity of ties that is important. Sound decision making involves consideration of a variety of factors and variables and not necessarily in a formulaic or linear fashion. For an informed decision to be made, the practitioner must be aware of many factors, such as:

- Personal values and collegial, institutional, and societal influences
- Ethical theory and decision-making models
- Social work theory, research, and practice standards
- Social work ethical codes, as well as other professional codes
- Relevant agency policy
- Federal and state laws and other regulations
- Impact on patients and, in some cases, impact on practitioner (as in whistle-blowing)

Identifying and attending to all of these factors is challenging. For example, Mattison (2000) reflects that identifying specifically what social work practice standards are may be somewhat difficult as a standard of practice is often not well defined. Also, most social workers in health care do not work in isolation. Rather, they are part of larger transdisciplinary teams. In considering institutional influences, the relationships with and perspectives of others on the health-care team have a significant impact on the contribution social workers have in ethical decision making (Landau, 2000).

After the social worker has developed understanding of the dilemma, the social worker should first look to the social work code of ethics to identify values, principles, and standards that may be relevant in resolving the problem. In addition to the areas identified previously, there should be an added effort to identify sources of feedback. These may be colleagues, agency committees, local state boards of social work examiners, professional social work organizations including NASW, or legal council.

Models of decision making often share components. They may differ at times in some fundamental areas, such as how principles are ordered hierarchically. In this sense, models may represent different schools of thought in much the same way that models of treatment in health care vary and treatment theories differ from one another. Murdach (1995), Lowenberg and Dolgoff (1996), Mattison (2000), Jonsen, Seigler, and Winslade (1997), and Netting, Kettner, and McMurtry (1993) all review different models and decision-making approaches relevant to health social work practice.

According to Netting et al. (1993, pp. 411–412), the steps to decision making are as follows:

- Recognize the problem
- Investigate the variables
- Get feedback from others
- Appraise the values that apply to the dilemma
- Evaluate the dilemma
- Identify and think about possible alternatives
- Weigh the pros and cons of each alternative
- Make your decision

Part of the difficulty in completing the last task in the list, actually making the decision is weighing one principle against another, or even rank ordering a series of principles (such as freedom over well-being). Reamer (1990) proposes comparing principles to one another and deciding which one is more important. For example, "an individual's right to freedom takes precedence over his or her own right to well-being" Reamer (1990, p. 63). In the case of a patient's decision to continue to engage in self-destructive behaviors, however, this ordering would allow an alcoholic to continue to drink. In considering other principles, Reamer does make provision for an attempt at intervention to determine "voluntariness and informed choice," as well as preventing harm to others (p. 63). However, in this example, the ontological considerations of freedom supersede the teleontological considerations such as impact on family, friends, and work, as well as long-term health consequences such as cirrhosis. In other words, protecting individual freedom may be seen as a more important principle than forcing someone to live a healthy lifestyle.

Lowenberg and Dolgoff (1996, p. 414) propose a rank ordering of principles from which an individual should be able to:

- Exist with basic needs
- Receive treatment that is fair and equal
- Have free choice and freedom
- Have injury that is minimal or nonexistent
- Cultivate a good quality of life
- Secure privacy and confidentiality
- Understand the truth
- Receive available information

## SPECIAL TOPICS RELATED TO HEALTH SOCIAL WORK ETHICS

### DUAL RELATIONSHIPS

Dual Relationships in health social work practice may be loosely defined as a violation of the practitioner and patient relationship. Injunctions against dual relationships in health care have been in evidence since the time of Hippocrates. "Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves" (Hippocratic Oath, 400 BC).

After an examination of NASW code violations, Strom-Gottfried (2000) found most to be boundary violations in dual relationships. The largest areas were sex-



ual relationships and other nonsexual dual relationships. Current definitions of dual relationships are varied. Craig (1991) describes them as “ambiguous relationships in which the goals and boundaries are tailored to meet the needs of the counselor” (p. 49). Hill and Mamalakis (2001) define dual relationships as “any concurrent or sequential relationship between a therapist and client that is distinct from the therapeutic relationship” (p. 200).

Early work on the topic of dual relationships focused on absolute contraindications in dual relationships, such as a practitioner having sex with a client. Obviously, a variety of nonsexual dual relationships exist. Recently, the paradigm has shifted to consideration of when dual relationships are appropriate. Reamer (2003a) has recently divided dual relationships into those that are boundary crossings and those that are boundary violations.

Boundary crossings may not be inappropriate in all cases, but remain controversial. One example might be a hospital social worker serving on a fund-raising board with a current or former patient. Determining if this situation would be appropriate would greatly depend on the social worker’s ability to make appropriate judgments in what could potentially become an ethically compromising environment. Some would caution social workers to completely avoid these potentially dangerous and libelous situations.

On the other hand, we could argue that failing to collaborate with the patient would result in more harm than good for him. Recently, social work licensing specialists in Louisiana who were making a presentation on ethics advised nephrology social workers to refrain from engaging in dual relationships with patients no matter what the situation. This certainly seems an outdated and perhaps alarmist position that might place patients at greater risk if it jeopardized potential collaborations between social workers and patients. Threatening the ability to collaborate on boards or planning committees, for example, might mean that social workers and patients would not engage in dialogues to establish the needs of end-stage renal patients.

How would one go about ordering principles and standards in this instance? Does the slippery slope argument have the final say in whether to proscribe potentially beneficial interactions? The slippery slope metaphor is a very prominent argument in the field of ethics. It is also called the “thin edge of the wedge or wedge argument.” (Pence, 2004, p. 111). According to Pence, these arguments are most prominent at the beginning or end-of-life ethical dilemmas. While colloquial in common parlance, it does speak to some important considerations, such as conceptual or empirical trajectories. Would allowing dual relationships to occur in this area result in an ongoing reduction of standards in more clearly defined inappropriate relationships?—conceptual. Or, is there something about human nature that will ultimately take advantage of these situations?—empirical. Lazarus would respond by saying that “one of the worst professional violations is that of permitting current risk management principles to take precedence over humane interventions” (1994, p 260).

The careful consideration of the appropriateness of potential dual relationships is especially relevant to rural social workers who may encounter multiple dual relationships. In response to the misleading information provided by the licensing specialists, the author of this chapter contacted by phone the Louisiana State Board of Social Work Examiners (LSBSWE), NASW, and the Council of Nephrology Social Workers (CNSW) for input. Additionally, the NASW code of ethics was

consulted for guidance. No board expressly prohibited all dual relationships. However, it was suggested by the state board that guidelines be developed to address this issue.

Boundary violations, alternatively, are clearly inappropriate. These involve "exploitative, manipulative, deceptive, or coercive" actions (Reamer, 2003a). The 2000 National Association of Social Workers Code of Ethics proscribes social workers' engagement "in dual or multiple relationships with clients or former clients in which there is a great risk of exploitation or potential harm to the client" (Standard 1.06).

Clear dangers are inherent in the example of a social worker serving on a board or committee with a patient. If the social worker was not sensitive to the dynamics of the situation, the board role could devolve and several untoward outcomes could be possible. For instance, the relationship could devolve into a more collegial or friendship related relationship and even possibly to a sexual relationship, or the patient might feel he has more access to the social worker and attempt to use this time to address more clinical concerns. This access to the health-care provider beyond the provider/patient relationship may become increasingly problematic, as social workers are responsible for more and more patients with less time to provide clinical services.

The issue of confidentiality could pose a problem if the social worker was not careful. For example, one scenario that could conceivably cause problems might be if the patient was sick and other board members asked the social worker about specifics of his illness. The social worker could abuse power in the relationship to stifle the patient's voice on the board or in the patient's health-care environment. Further, the social worker and patient could manipulate decisions and available resources for economic or other gain.

Other potential dangers are possible serving on boards with patients and a simple risk management strategy of weighing the benefits of the relationship against its potential costs would not be sufficient to justify participation. In applying utilitarianism to this example, it becomes apparent that both courses of action may be defensible. Act utilitarian thought and care ethics may dictate that the potential benefits take precedence over the risks. Rule utilitarianism or Kantian ethics might suggest that more harm would be done to the profession if these rules were not maintained.

Arguments for considering dual relationships in light of the service provided may also be relevant. For example, Hardinia (2004) points out that direct clinical social work practice is substantively different from community social work. With this in mind, some would argue that collaboration takes on more of an ethical imperative in community work than it does in clinical. Does this hold true for social work in health care? Strom-Gottfried (2003) provides data to suggest that private practitioners have a higher rate of ethical violations than do social workers in agencies. This was measured by reviewing 894 of 901 ethics complaints filed with NASW in 1986 to 1997. More work should be undertaken to determine why this is the case, as the study questions how the data was gathered. One possible explanation would be that there is more oversight and thus fewer opportunities for violation in agency settings such as hospital social work as opposed to private practice. Another explanation might be that the nature of the client and social worker relationship is different and in nonpsychotherapeutic settings and therefore lends itself less easily to abuse.

When inappropriate dual relationships do occur it may have less to do with the nature of the relationship and more with intrapsychic features of the practitioner. Schoener (1995) suggests that clinicians who engage in sexual or other inappropriate relationships with clients may have underlying mood or personality disorders. In addition, Simon (1999) identified the egregious occurrence of impairment and incompetence as possible triggers of inappropriate dual relationships.

#### MANAGED CARE AND WHISTLE-BLOWING

As discussed in Chapter 5 of this book, managed care has dramatically changed the dynamics of health-care provision in the United States. Neuman (2000) describes the new environment as one with decreased reimbursement for health-care providers, decentralization of services, a decrease in staff credentialing and expertise, and the emergence of standards of care. These conditions increase the possibility that ethical violations will occur, as explained next.

Possible abuses that might occur more frequently in a managed care environment include the exaggeration of patients' symptoms in order to ensure or increase reimbursement. This may be well intentioned from the practitioner's perspective. It may assume the form of changing diagnoses from an adjustment disorder to a more severe psychiatric illness in order to secure or extend needed treatment in a psychiatric hospital. Employees may be encouraged to seek treatment from in-network providers. These providers, especially in health care, may also be colleagues, vendors, or consumers of the patient. This places an employee in a potential dual relationship with the provider.

Historically, managed care has threatened informed consent through facilities' use of nondisclosure, or gag, clauses. These gag clauses prevented social workers or other practitioners from discussing the limits of services available as mandated by third-party payers, or of discussing other available options beyond those offered by a particular managed care organization (Strom-Gottfried, 1998). Social work, specifically through NASW, was one of the first professions to specifically address the ethics involved in informed consent as it relates to nondisclosure clauses.

Confidentiality may also be more threatened in a health-care environment that relies on outsourcing services. The availability of electronic data and transfer of data from one facility to another may pose an ethical risk. However, this may be more a function of technology than managed care specifically. With the vast amount of data available electronically, this information has become a target of computer hackers and other criminals. There have been recent cases where tens of thousands of individual's personal credit information has been accessed by criminals. It is not inconceivable for this to happen to personal health information. Personal health information in the wrong hands could affect a person's employment potential, finances, and interpersonal relationships.

Practitioners in managed care and other health-care environments may witness unethical practices. One decision is whether to inform authorities of these practices. *Whistle-blowing* refers to the act of notifying authorities of harmful deviation from standards of care or unethical practices within an organization. From a microperspective, this may take the form of notifying superiors of a colleague's malpractice in terms of violations of the NASW Code of Ethics, law, or

agency policies. From a macroperspective, this may involve a practitioner notifying people outside the agency of problems within the agency. While the best policy generally is to follow a chain of command within an agency, this may not provide the appropriate results. For example, retaliation is a real concern in a corporate work environment.

If the identified problem is with the policies set by the management and these have been brought to the attention of the management with no effect, it may be necessary to pursue other options outside the company. For example, local media, or the American Civil Liberties Union have been accessed in the past by whistleblowers. However, Reamer (1999, p. 162) recommends that prior to notifying authorities within or outside an agency of ethical violations, a practitioner should take time to consider:

- The severity of harm and misconduct involved
- The quality of evidence of wrongdoing
- The effect of the decision on colleagues and agency
- Viability of alternative courses of action

It may be important to realize that no agency is perfect, and employees cannot be functional if they whistle-blow every time they encounter a problem. If a social worker comes across a problem with a colleague or an agency, there should be an effort to directly address the colleague or follow the chain of command. Careful documentation of the event and the efforts taken by social worker to resolve the problem should be made.

The NASW Code of Ethics includes several references to situations where reporting violations might be appropriate. However, lock step/formulaic responses to this type of dilemma, as in all other ethical dilemmas, may prove incomplete. Decision making during the reporting process should be made in a reflective and orderly fashion and documented. For any claim to be taken seriously, documentation must be provided. This also serves to protect the social worker, especially if the court becomes involved.

Consideration should be made to what effect any accusations by the reporter might have. It could ruin the reputation of a coworker or undermine the mission of an agency. As a consequence, clients could be harmed if there is an interruption or end to services. Finally, great care should be taken to consider other options. There are some governmental guidelines protecting a person who reports possible wrongdoing, but he is placed at great risk from the beginning. This may result in damage to the social worker's reputation. Still, when it is clear that there is harm to others, all reasonable efforts should be taken to remedy the situation.

## SOCIAL WORK RESEARCH ETHICS

The ethics of social science are situation ethics. (Humphreys, 1975, p. 170)

This quote from Humphreys can be seen as somewhat morally ambiguous, depending on how it is interpreted. Fortunately, safeguards exist today that protect ethical analysis from devolving into an argument used to justify a desired protocol (Lacey, 2003). For example, all universities and health-care facilities should

have their own institutional review boards (IRBs) that provide some safeguard against potentially harmful research and ensure that research does not exploit human participants. IRBs ensure that there is informed consent, confidentiality consideration, policies regarding data storage, and other safeguards.

Unfortunately, problems occur even with these safeguards in place. While conducting research, social workers may deviate from ethical practice for a variety of reasons. One of the most seductive motives may be that the researcher believes the benefit from the results or knowledge accrued by bending rules for research on human subjects or other deviations from research protocols outweighs any harm done to participants. Deviations from ethically sound research, regardless of how seemingly innocuous or, conversely, compelling can have serious consequences to the researcher, participants, and society at large. Within the realm of research the areas of most importance are:

- Voluntary participation or consent
- No harm to participants or nonmaleficence
- Anonymity and confidentiality
- Deception
- Analysis and reporting
- Justice and beneficence

Many people trace the development of research ethics to the Nuremberg Code. Following World War II, in 1946, the United States, France, the United Kingdom, and Russia participated in an 8-month trial in which 16 German physicians were convicted of crimes against humanity. These physicians had participated in research on prisoners without their consent often inflicting great pain and death. Some of this wartime research in Nazi Germany involved shooting prisoners to study wounds and purposefully injecting prisoners with live viruses to study disease.

The Nuremberg Code was developed in response to these violations. Attention to voluntary consent was the center point the Nuremberg Code. In all, the Nuremberg code identified 10 principles designed to protect research participants. This was a great step forward in research ethics but its principles have not always been followed. In a sense, this marks the beginning of a cyclical phenomenon in which a crisis involving research occurs, a response is made in the form of legislation addressing the crisis, and the conditions preceding the crisis eventually reappear.

America was not immune from this phenomenon. In 1929, the U.S. Public Health Service with the local departments of health of Mississippi, Tennessee, Georgia, Alabama, North Carolina, and Virginia were involved in what is called the Tuskegee Study, whose aim was to control syphilis. In 1932, syphilis treatment was withheld from approximately 400 African American men in Macon County, Georgia. The fact that African American men were used exclusively was reflective of the racist attitudes of the time. This marked the beginning of the study that would span some 40 years despite the fact that penicillin became available to treat syphilis in the 1940s (Jones, 1981). The study was made public in the 1970s as an example of misuse of research on human subjects.

A common theme in both the Nazi atrocities and the Tuskegee Study is the use of vulnerable populations. These often take the form of the disenfranchised,

minorities, and women. In both situations, one of the primary violations of research ethics was in the lack of voluntary participation.

Millgram's obedience study provides an example of violation of the "no harm to participants" principle (Miller, 1986). Millgram conducted this study in the early 1960s. He was researching the phenomenon of obedience. For this study, he recruited participants via a newspaper advertisement. He then instructed the participants to assume the role of a teacher who would inflict punishment through an electric shock to a learner. An actor assumed the role of the learner and had an electrode strapped to his arm. The teacher was instructed to give the learner a shock with each incorrect response. The teacher was then instructed to increase the voltage incrementally. The actor would respond to each shock.

Disturbingly, the teachers continued to administer the shocks even when the voltage meter indicated that the shocks registered in the dangerous and severe range. Throughout this experiment, the teachers appeared to suffer psychological trauma while administering the shocks, yet they continued to follow Millgram's commands. A common criticism of Millgram is that he relied on the ends to justify the means or attended to only teleontological considerations. This experiment did reveal valuable information. It has been viewed by some as shedding light on why people were able to commit violent acts while under the direction of an authority, such as in Nazi Germany. This is still considered an egregious violation of research ethics for a variety of reasons including the possible long-term psychological trauma to the participants.

Project Camelot was an attempt by the U.S. government in the 1950s to investigate how governments were overthrown and reformed in Latin America (Howoritz, 1967). The underlying intent was to gain information that would allow some control over how governments in volatile political climates developed. This type of research has clear problems. While this example may come from the macro practice, it serves to illuminate the misuse of research in politics. This type of research immediately calls into question justice and beneficence.

It also speaks to a clouded purpose of the research. The danger that health social workers should remember from this is that the true nature of research is not always apparent. Health social workers involved in their own and institutional research endeavors are wise to carefully reflect on the previously discussed research considerations. Many social workers, especially those working in teaching hospitals, will either be approached to participate in research or will have patients who are in research studies. Learning the funding source and the premise behind the research will help social workers assess its value to the patients and better inform them.

#### ETHICAL CHALLENGES IN THE TWENTY-FIRST CENTURY

As is apparent in some of the examples in this chapter, ethical challenges evolve in ways that at once demand and escape satisfying solutions. In the twenty-first century and beyond, ethical dialogue is inexorably tied to science. Health social work has an obligation to provide a voice to individuals and to existing culture as sciences provide an ever-broadening array of ethically ambiguous choices. Health social workers providing direct care to patients, serving on ethics committees, shaping policy, and those active legislatively must all have the ability to redirect attention to ethical and interpersonal considerations. From a micro to macro per-



spective, this will be challenging because new health-care dilemmas have profound societal meaning.

Compelling health dilemmas have the potential to draw reasonable discourse and action away from the issue at hand. These dilemmas may be used as rallying cries for agendas far removed from the welfare of the patient. An inadequate and depersonalizing health-care industry further threatens ethical care in this country. Health social workers can effect change, however. Through remaining grounded in an understanding of the profession's mission, values, and ethics, health social workers have the ability to avoid losing focus. With a clear sense of purpose, health social workers can help redirect health care to an ethical best fit with patients.

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## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 3.1

Consider a former football linebacker turned NFL broadcaster named Spencer. Spencer is a transplant recipient who prides himself on his heterosexual identity. While preparing for an NFL Monday night broadcast, he receives a call from the family of the individual who donated the heart that he received. The donor's mother read about the recipient in the newspaper and deduced that Spencer was the recipient of her child's heart. She called his television network and somehow persuaded one of Spencer's colleagues to give her his phone number. Spencer, immediately after getting off of the phone with her, calls the transplant center, obviously shaken. He and the donor's mother have made plans to meet and talk.

But, something the mother said made Spencer think that the donor was female. This would be quite a blow to him as the transplant surgeon had assured him that the donor was a male. He asks the transplant social worker to confirm the recipient's gender. The social worker and a physician review the donor's chart and find that the donor was, in fact, a male. However, although the donor was biologically male, he had been taking female hormones for years and had been living as a woman; the donor was transsexual. Obviously, the social worker could not reveal these details over the phone. As a metaethical consideration, is an omission of detail in this instance a lie? The individual may, in fact, have a male genotype after all. As a normative or applied ethics consideration, what should the social worker do to help the recipient continue to feel a sense of integration with his new heart? Moreover, should the social worker do anything at all?

### LEARNING EXERCISE 3.2

David works for a for-profit hospital in its psychiatry department. The social work licensing requirements in David's state changed several years ago. They now require all social workers to be licensed. Over the past few years, he and his colleague George have become fast friends. The hospital is interdisciplinary and consists of psychiatrists, psychologists, licensed professional counselors, and others. George and David happen to be the only two social workers in the department. George is an exceedingly conscientious practitioner and excellent at record keeping. His services are made even more valuable because he is bilingual.

David has aspirations of one day having managerial responsibilities and recently became a board-certified social work supervisor in his state. Part of his training involved review of the state board of social work rules, standards, and procedures. During his training, he learned that social workers in his state have an obligation under these rules, standards, and procedures to notify the state board of colleagues who are practicing without a license. The instructor further advised the class to not confront the social worker but rather immediately inform the state board.

David remembered that George had been complaining about not passing his social work exam and decided that he would urge George to try again in order to ensure compliance with the state regulations. Further, David knew that licensure in this practice area was required by Medicare regulations and his was a Medicare approved facility. David attempted to, in a friendly way, encourage his colleague to take his test again. George complained that he couldn't pass the exam, that he went to social work school, earned his master's degree in social work, and does not see the point of licensure. David did not address this issue directly for several months. However, their relationship became more and more strained. Ultimately, David began to be concerned about his liability from failing to report his colleague's nonlicensure.

What, if anything, has David done wrong to this point? What should he do next? From an ethics of care perspective, has George done anything wrong? From a deontological perspective is George's behavior defensible?

### LEARNING EXERCISE 3.3

Merlin and Deanne's 6-year-old son Mickey is a cancer patient at Children's Hospital. Despite aggressive efforts, the pediatric oncologist informed Merlin and Deanne that the cancer continues to spread. The recommendation to the family was that they consider placing Mickey on a research protocol for an experimental drug. There was a minimal chance that Mickey might improve if he were selected to receive the new medication. Merlin and Deanne have little formal education and have always deferred to the physician's recommendation, and agreed immediately. Given their son's limited chances of survival, Merlin and Deanne felt it best to not tell Mickey the details of his treatment and prognosis.

Was the family able to make informed consent in this example? What are some of the problems in explaining treatment options to nonexperts? Does a chance for recovery take precedent over meaningful informed consent? Does informed consent include an attempt to involve the child? What should the oncology social worker do if confronted with such a situation? In answering these questions, identify and implement a social work ethics decision-making model. Describe the steps taken while addressing the dilemma.

### SUGGESTED RESOURCES

The American Journal of Bioethics (<http://www.bioethics.net>)

Euthanasia Information (<http://www.euthanasia.com>)

The Hastings Center (<http://www.thehastingscenter.org>)

Kennedy Institute of Ethics (<http://www.georgetown.edu/research/nrcbl>)



National Association of Social Work Code of Ethics (<http://www.naswdc.org/pubs/code>)

National Human Genome Research Institute (<http://www.genome.gov>)

National Institute of Health's Bioethics Resources (<http://www.nih.gov/sigs/bioethics>)

The President's Council on Bioethics (<http://www.bioethics.gov>)

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## CHAPTER 4

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# Public Health and Social Work

DEBORAH R. SCHILD and MARJORIE R. SABLE

**I**N HIS SEMINAL 1920 piece, “The Untilled Fields of Public Health,” Charles-Edward Amory Winslow, professor of Public Health at the Yale School of Medicine from 1915 to 1945, defined public health as:

the science and the art of preventing disease, prolonging life, and promoting physical health and efficiency through organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organization of medical and nursing services for the early diagnosis and preventive treatment of disease, and the development of the social machinery which will ensure to every individual in the community a standard of living adequate for the maintenance of health. (Institute of Medicine [IOM], 1988, p. 39)

The core functions of public health agencies at all levels of government are *assessment, policy development, and assurance\** (IOM, 1988; Schneider, 2000). Assessment refers to the regular collection, analysis, and sharing of information about health conditions, risks, and resources in a community. Policy development uses assessment data to develop local and state health and social welfare policies and

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\*These and other italicized terms specifically related to public health and PHSW are found in Appendix 4.1 Glossary at the end of the chapter.

to direct resources toward those policies. Assurance focuses on the availability of necessary health services throughout the community. It includes maintaining the ability of both public health agencies and private providers to manage day-to-day operations as well as the capacity to respond to critical situations and emergencies (Rounds & Gallo, n.d.).

Public health is a field of practice with a specific orientation and framework for the various professionals who work within the public health arena. The professionals include both clinical practitioners, such as clinical social workers, nurses, health educators, and physicians, and nonclinical professionals such as epidemiologists, administrators, and policymakers.

Social workers are well prepared to work within public health and with other public health professionals because they share many of the same values, theories, and practice methods. Shared values include a commitment to enhance social and economic justice and a focus on eliminating disparities between and among various populations. Further, social work and public health interventions primarily focus on oppressed, vulnerable, and at-risk groups (Wilkinson, Rounds, & Copeland, 2002). Theoretical approaches to develop interventions are, in social work, the ecological approach of person-in-environment (Germain, 1984; Germain & Gitterman, 1980) and, in public health, social epidemiology (Berkman & Kawachi, 2000). Each is unique, but both rely on an understanding of how social systems relate to health status.

Social workers who work in public health serve as members of transdisciplinary teams, share many of the same skills as their colleagues, and participate in public health interventions. The unique approach that public health social workers bring to public health practice is grounded in social work theory, especially the person-in-environment approach to practice. The practice methods particular to social workers—family centered, community-based, culturally competent, coordinated care—have been integrated into public health practice and adopted by various other providers of public health services (Bishop & Arango, 1997).

This chapter explores public health social work by first examining its history, then exploring its intersection with social work practice, current practices, and future directions.

## CHAPTER OBJECTIVES

- Discuss common approaches in public health and social work practice.
- Define the roles social workers play in various public health interventions.
- Outline the difference between population-based and clinical interventions.
- Review public health interventions for health promotion and disease prevention.
- Discuss Healthy People 2010: The national public health goals and objectives.
- Identify programs targeted at specific at-risk populations.
- Discuss the changing nature of public health social work practice.

## THE HISTORY OF PUBLIC HEALTH SOCIAL WORK

An early public health intervention in the United States was an immunization campaign to prevent smallpox (World Health Organization [WHO], 1998). Public health interventions occurred before the modern era, but the combination of an

increasing sophistication in the medical sciences and the efforts of social reformers helped establish modern public health. The roots of the modern institution of public health in the United States are almost indistinguishable from the roots of social work itself. Social reformers established settlement houses, proposed legislation, and succeeded in establishing programs that had far-reaching impacts on the health status of Americans.

#### SETTLEMENT HOUSES AND SOCIAL REFORM MOVEMENTS

In the late 1890s, residents of settlement houses worked to improve the health of the communities in which they lived. For example, Jane Addams, a cofounder of Hull House in Chicago, ran for and was elected to be the public sanitarian in her ward. She worked to establish rubbish removal, clean water, and sewage management. At Hull House and at the Henry Street Settlement in New York, founded by Lillian Wald (1887–1940), residents taught hygiene and other health-promoting behaviors to the community (Gordon, 1994). These social reform movements, which provided one of the foundations for the social work profession, served to inspire the areas within public health known as community health and public health nursing.

Social reform efforts to improve maternal and child health, begun during the late 1880s and continuing into the progressive era of the first decades of the 1900s, were foundational to public health. Social reformers in Boston and those working with the Kentucky Frontier Nursing Service worked to improve the health of pregnant women. Their work expanded prenatal care to include attention to social conditions. These reformers, along with midwives, visited the homes of pregnant women and focused on assessing the physical and social environments to ensure that soon-to-be mothers and their babies would have safe and clean homes (J. Thompson, Walsh, & Merkatz, 1990). Beginning in 1883 with the establishment of the first milk station in New York City, social reformers focused their attention on infants' and children's health and lives. In 1908, Dr. Josephine Baker established the first Bureau of Child Hygiene in New York City. By 1923, Child Hygiene Bureaus were located in all of the states (Gordon, 1994).

#### THE CHILDREN'S BUREAU

In 1904, Florence Kelley and Lillian Wald founded the National Child Labor Committee (NCLC) to monitor the effects of child labor on development and health (Oettinger, 1962). The work of the NCLC led to the first White House Conference on Children in 1909 and to Congress establishing, in 1912, the federal Children's Bureau (currently the Children's Bureau within the Agency for Children and Families housed within the U.S. Department of Health and Human Services). Julia Lathrop, a Hull House resident, was appointed to be the first chief of the Children's Bureau whose first activities were to conduct studies of infant mortality and its relationship to income. Because of these studies, the pamphlet "Infant Care" was published in 1914. It became the most widely distributed informative pamphlet ever produced by federal offices. Over a period of 50 years, more than 45 million copies were printed and sent to mothers across the nation.

From its inception, the Children's Bureau had close ties to social work. Its first five chiefs were social workers: Julia Lathrop, Grace Abbott, Katherine Lenroot,

Martha May Eliot (who was also a pediatrician), and Katherine Oettinger. Lathrop and Abbott had been Hull House residents (Gordon, 1994; V. Hutchins, 1985). The Children's Bureau conducted many studies of interest to social work. The topics of these studies included child labor, working mothers, childhood nutrition, services for crippled children, and juvenile delinquency (Margolis, Cole, & Kotch, 1997).

The Children's Bureau's campaign to investigate and reduce infant mortality provided the impetus for Congressmen Morris Sheppard of Texas and Horace Towner of Iowa to draft the Maternity and Infancy Protection Act. During the 1919 debates over the act, the Second White House Conference on Children was held, during which the Children's Bureau made recommendations for minimum standards of maternal and child health care (Margolis et al., 1997). The Sheppard-Towner Act has a place in history as the first federal social welfare law and the first federal welfare act for mothers and children; it became law in 1921 and authorized grants to the states for the promotion of maternal and child health. The Sheppard-Towner Act was controversial because it was seen as an intrusion on the family, held to be a private entity that should not be regulated by government. Further, some thought that the Sheppard-Towner Act presaged socialized medicine and considered it tantamount to communism. The funding for the Sheppard-Towner Act ended in 1929 and was not reauthorized (Margolis et al., 1997).

#### TITLE V—THE MATERNAL AND CHILD HEALTH BUREAU AND THE MATERNAL CHILD HEALTH BLOCK GRANT

The Sheppard-Towner Act was the precursor to Title V of the Social Security Act of 1935, which established the role of the federal government in providing and regulating maternal and child health services (Gordon, 1994; Margolis et al., 1997). In 1935, when Congress originally wrote the Title V legislation, it had four parts. Part 1 covered Maternal and Child Health (MCH) services, Part 2 established Crippled Children's Services, Part 3 provided money to the states for Child Welfare Services, and Part 4 funded states to improve and strengthen Vocational Rehabilitation Services. Each part in the Title V legislation provided funding to the states to carry out services to meet needs identified by statewide community assessments. Thus, the federal government did not directly provide or pay for the services provided under Title V.

Title V has been amended many times since 1935. In 1981, shortly after the beginning of the Reagan administration, seven categorical programs were consolidated into a new program, the Maternal and Child Health Services Block Grant. The Division of Maternal and Child Health (now the Maternal and Child Health Bureau [MCHB]) administers the block grants to the states. Like the Children's Bureau, MCHB has close ties to social work. The establishment of the position of Chief Social Work Officer formalized the ties. The first Chief Social Worker was Edith M. Baker (1936–1955), who was followed by Virginia Insley (1955–1980), and Juanita Evans (1980–2000). Since the retirement of Evans, the position of Chief Social Worker has not been filled. Insley and Evans promoted the role of social work in public health and specifically within MCH (V. Hutchins, 1985).

The MCH Block Grant underwent changes in 1989 when the Omnibus Budget Reconciliation Act (OBRA) mandated that states allocate 30% of their MCH block grant funds to children's preventive primary care services, 30% to Children with



Special Health Care Needs (the former Crippled Children's Services) programs, and no more than 10% to administration. States were required to use any remaining Block Grant funds on Special Projects of Regional and National Significance (SPRANS), and this requirement continues today (Margolis et al., 1997).

One example of SPRANS supported projects is Public Health Social Work Institutes. These educational programs for public health social workers have been held for 50 years and provide updates on research, theory, and interventions. They also offer a venue for public health social workers from various regions of the country to meet and share ideas. Although the number of Institutes has declined over the years, this SPRANS project continues to provide much-needed continuing education and other resources to public health social workers.

OBRA 1989 included additional initiatives related to MCH and social work. For example, the act expanded maternal and infant home visiting programs, enhanced rural projects for mothers and children, and funded several other expansions of services (Margolis et al., 1997). OBRA 1989 required that states coordinate their Title V programs with their Medicaid programs. One of the most important amendments to Title V found in OBRA 1989 required Medicaid to cover all pregnant women and children up to age 6 in families with incomes below 133% of the federal poverty level (FPL; Epstein & Newhouse, 1998). States are able to receive federal Medicaid funds to cover prenatal care for women in families with incomes up to 185% of the FPL. Prior to that change, Medicaid could cover women only if they met the AFDC income eligibility level, which differed from state to state. In states with the lowest family incomes, the limit on family income for AFDC eligibility was sometimes set well below the poverty level.

Many of the initiatives that focused on improving infant health and reducing infant mortality have succeeded to varying degrees. Nevertheless, the problems of poor birth outcomes for mothers and infants, compromised infant and child health, and infant mortality remain. The work done by the early social workers in public health laid the foundation for public health social work practice today. The legacy of social workers in public health, especially in MCH, is remembered each year at the annual meeting of the American Public Health Association (APHA). The APHA Maternal and Child Health Section established the Martha May Eliot award and confers the award to honor contributions made by public health professionals to maternal and child health. The APHA Social Work Section honors the efforts of the Public Health Social Worker of the Year with the Insley-Evans Award.

## THE INTERSECTION OF SOCIAL WORK AND PUBLIC HEALTH

As discussed in the introduction to this chapter, public health provides a specific orientation and framework for the various professionals who practice within the public health arena. Public health social workers fill many different positions. These include: case managers; health educators; program planners and evaluators; grant writers; administrators and program directors at the federal, regional, state, and local levels; and executive directors of nonprofit agencies.

Beginning in 1996, a group of public health social workers convened to develop a useful definition of public health social work. They debated whether public health social workers are defined by training, job, or a combination of both. What, they asked, are the common attributes of the person and the job? The debate led



**Box 4.1**  
**Brief Definition of Public Health Social Work**

A Public Health Social Worker is a graduate prepared social worker whose primary practice fulfills core public health functions within a public or private agency. While it includes all of the 10 essential public health functions, Public Health Social Work practice focuses on interventions to strengthen communities, families, and individuals in order to promote health, well-being, and functioning and minimize disability and institutionalization.

*Source:* From Standards Development Committee, *Beyond 2010 Public Health Social Work Initiative*, 2005, *Public Health Social Work Standards and Competencies*, Ohio Department of Health, Columbus, OH.

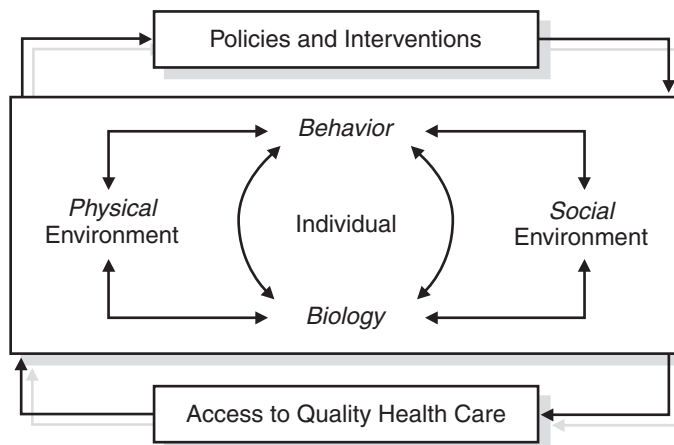
to a brief and a longer definition and a philosophy for public health social work. A brief definition is shown in Box 4.1 but the entire group of definitions, philosophy, and model practice standards and core competencies is found in the Appendix.

Social work practice in public health differs from clinical social work practice in two distinct ways: first, public health practice emphasizes health promotion, protection from environmental harms, and disease prevention; and second, public health practice targets populations rather than individuals and groups (Watkins, 1985). Social work practice skills, such as community assessment, and social work values, such as the promotion of social justice, fit within public health practice.

#### EPIDEMIOLOGY AND THE DETERMINANTS OF HEALTH

The foundation of public health research is epidemiology, the study of the distribution and determinants of disease in populations. Public health uses evidence-based interventions—those that are developed and verified through research.

A focus of epidemiological studies has been to examine the determinants of health and well-being. Figure 4.1 illustrates the complex interactions of biology,



**Figure 4.1** Determinants of Health

social and physical environments, and behavior on health (Healthy People 2010: Determinants of Health, n.d.). Further, larger factors, including public policies and interventions and access to high-quality health care, are important elements in the determination of health.

Lung cancer is a useful example to demonstrate the interactions of health determinants. Biologically, lung cancer is caused by a manifestation of malignant cells. Some individuals may have a genetic predisposition to developing cancer, but other, nonbiologic causes of lung cancer exist. The most important additional determinant of lung cancer is the behavior of an individual. Cigarette smoking is the leading cause of lung cancer and is associated with 87% of cases (National Cancer Institute [NCI], n.d). Secondhand smoke, or passive smoking, is an example of a physical environmental cause of lung cancer. Bars where smoking is accepted and where people often socialize are another physical environment that leads to lung cancer. Although not as powerful a factor in the development of lung cancer as smoking, exposures to airborne toxins such as ash, dust, and asbestos represent another cause.

Lung cancer rates, like those of many diseases, vary by race and socioeconomic status. In the United States, lung cancer rates in the African American community are higher for both males and females compared to the White American community (Ries et al., 2003). Additionally, lung cancer incidence rates for non-Hispanic White, African American, and other people in high poverty areas were, respectively, 45%, 46%, and 23% higher (NCI, 2003). From 1975 to 1999, men living in high poverty areas experienced at least 18% higher mortality than men living in low poverty areas (NCI, 2003).

Numerous social factors promote smoking. One example is the placement of bright and colorful cigarette advertisements at children's eye level in stores, thus enticing the next generation to become smokers. The use of cartoons in advertising, such as Joe Camel, is another marketing method directed at children (Haviland & Sember, 2004; Schooler, Feighery, & Flora, 1996). When smoking is acceptable in one's peer group, the social environment promotes that activity.

The two overarching determinants of health are the macrolevel issues of policies and interventions and access to quality health care. Public health policies address health promotion and disease prevention. Some prevention policies to discourage tobacco use include smoke-free buildings and federal, state, and local laws that prohibit tobacco use where people work, especially in airplanes and restaurants. In addition to reducing smoking behavior, these types of restrictions are also designed to protect employees from constant exposure to secondhand smoke.

Access to care is especially important because the later that cancer is diagnosed, the worse its prognosis. Access to diagnosis and treatment is limited not only by lack of health insurance, but also by other social and environmental factors. System and institutional barriers limit access to health care, especially for lower income families. System barriers include inadequate capacity to serve the populations, and institutional barriers include problems in the organization and delivery of care. Some system factors for lower income people are the limited numbers of health-care providers serving inner cities and rural areas and limited safety-net clinics for those who lack insurance. Clinic hours held only during the workday are an institutional barrier. Another institutional barrier is the lack of accommodation to communication needs of non-English speakers. Research on

disparities in access to health care based on race, ethnicity, and language for those who are insured has shown that Spanish speakers are less likely to get health care than their English-speaking peers. These findings are consistent for physician visits, mental health services, mammograms, and influenza vaccinations (Fiscella, Franks, Doescher, & Saver, 2002). Many facilities have few interpreters and providers sometimes rely on family members, often children, to translate.

## COMMON VALUES

Health disparities exist between and among populations defined by race or ethnicity, gender and gender identification, social class, education, and employment or insurance status. In general, minority groups, the poor, the less well educated, rural-residing, the unemployed, and the uninsured have poorer health status than their counterparts (Berkman & Kawachi, 2000).

## ELIMINATION OF HEALTH DISPARITIES

Despite general improvement in 17 major health status indicators during the 1990s, not all minority groups equally benefited, and in fact, the rates for American Indian or Alaska Natives did not improve for six of the health status indicators. Furthermore, there was increased disparity between minority and White American populations in the 1990s for the following health status indicators: live birth rates for women age 15 to 17 years (3.5% increase); tuberculosis case rates (6.2% increase); suicide death rates (19.9% increase); motor vehicle crash death rates (39.0% increase); and work-related injury death rates (1993 to 1998; 250.8% increase; Keppel, Percy, & Wagener, 2002). Among these 17 health status indicators, the highest disparities existed for tuberculosis case rates, followed by primary and secondary syphilis case rates, homicide deaths, live births among women age 15 to 17 years, and percentage of children under age 18 in poverty (Keppel et al., 2002).

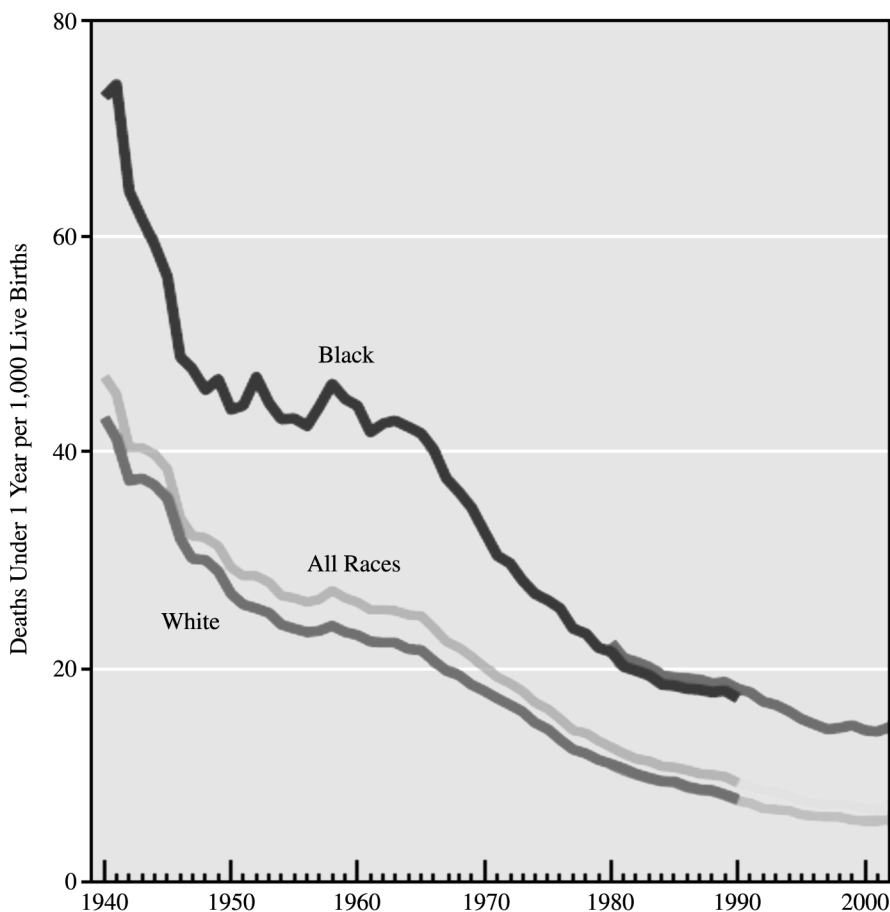
Data from the 2000 National Survey of Early Childhood Health, a nationwide household survey, revealed that Hispanic and African American children were significantly less likely than White American children to be in excellent or very good health (Flores, Olson, & Tomany-Korman, 2005). The National Health and Nutrition Examination Surveys (NHANES) for 1999 to 2002 indicated that racial and ethnic disparities persisted in the awareness of, treatment for, and control of hypertension (Centers for Disease Control and Prevention [CDC], 2005). In one study conducted in Michigan, Medicaid-covered women who were diagnosed with cervical cancer at age 65 or younger were more likely to die from the disease than women not insured by Medicaid (Bradley, Given, & Roberts, 2004). In rural Appalachia, the incidence of cancer of the lungs or bronchus, colon, rectum, and cervix was significantly elevated compared to rates in nonrural regions of the country (Lengerich et al., 2005).

Racially based health disparities are particularly apparent when examining three important maternal and child health status indicators: maternal mortality; infant mortality; and low birth weight. Maternal mortality is defined as death due to complications during pregnancy, childbirth, or the postpartum period. Despite the dramatic decrease over the past century of maternal mortality in the United States, there remains a threefold difference between White American

women (5.1 maternal deaths per 100,000 live births) and African American women (17.1 maternal deaths per 100,000 live births; U.S. Department of Health and Human Services [DHHS], 2002).

Infant mortality, death prior to a child's first birthday, is one of the leading indicators used worldwide to measure a country's health. The U.S. infant mortality rate (number of infant deaths per 1,000 live births) declined rapidly during the latter half of the twentieth century, but it ranks only 26th among industrialized countries (DHHS, 2002). Furthermore, in the United States, the infant mortality rate for African American infants is 2.4 times the rate for White American infants. Figure 4.2 shows both the dramatic decline in infant mortality since 1940 and the persistent gap in infant mortality rates between the White American and African American populations (Kochanek, Murphy, Anderson, & Scott, 2004).

Low birth weight (<2500 grams, or about 5.5 pounds) is the leading cause of infant mortality, and thus is another leading health indicator used throughout the



**Figure 4.2** Disparities in Infant Mortality over Time. *Notes:* Infant deaths are classified by race of decedent. For 1940 to 1990, live births are classified by race of parents and, for 1980 to 2002, by race of mother. See technical notes.

world. Since the mid-1980s, the percentage of low birth weight in the United States has changed little and remains at about 7% for the population as whole. As with maternal mortality and infant mortality, the ratio of low birth weight between White American and African American infants shows significant disparities; about twice as many African American infants are born small compared to White American infants (Kochanek, Murphy, Anderson, & Scott, 2004).

At the request of Congress in 1999, the IOM convened a panel of experts to examine the extent to which racial and ethnic minority health disparities are attributable to disparities in health-care services. Their report, "Unequal Treatment," found a consistent body of research demonstrating minority disparities in health care. Minorities were less likely than White American patients to receive appropriate care for heart disease, such as cardiac medications and bypass surgery, but more likely to receive less desirable medical procedures, such as lower limb amputations for diabetes (Smedley, Stith, & Nelson, 2003).

#### PROMOTION OF SOCIAL AND ECONOMIC JUSTICE

Some current policies and inaccessibility to quality health services lead to social and economic injustice. Both social and economic injustices are determinants of the disparities in health status. Thus, social work and public health both aim to promote changes that will lead to a more just society. Referring to determinants of health (see Figure 4.1), we can say that physical and social conditions that exist in poor neighborhoods contribute to health outcomes of the people who live there (McGinnis, Williams-Russo, & Knickman, 2002). In the early part of the twentieth century, infectious diseases were the leading cause of death. Crowded and unsanitary conditions in tenements (physical environment) contributed to the spread of contagions (biology). Further, healthy behaviors such as hand washing and washing dishes, linens, and other commonly used items were impeded by the crowded conditions and lack of modern facilities. People lived in tenements as a result of social forces that isolated immigrants and the poor from those who were better off. Building codes and policies were needed to ensure rental properties were clean and safe environments, thus removing the barriers to the improved health of tenement residents.

By the end of the twentieth century, chronic conditions had replaced infectious diseases as the leading causes of death. Health behaviors including poor nutrition, sedentary lifestyle, smoking, and substance use contribute to the many chronic illnesses that afflict our society. Some of those illnesses are heart disease, stroke, cancer, and diabetes, which may result from conditions such as obesity.

Social and physical environments that exist in poor neighborhoods, such as inner-city ghettos, contribute to adverse health outcomes. For example, the lack of job opportunities creates a situation in which a neighborhood may tolerate sales of illegal drugs in order to bring in sufficient income to support families. Drug sales in a community lead to addiction and its sequelae, such as illegal activities that lead to violent behavior, morbidity, and mortality. Numerous social factors, including the ubiquitous different stressors such as prejudice and poverty, can also lead to poor health status. Krieger (2003) has been conducting research on racism and health status for many years. She characterizes racism as one of the key factors in establishing health status and identifies five pathways through which racism can harm health. These include economic and social deprivation;

exposure to toxins; socially inflicted trauma; targeted marketing of products harmful to health such as alcohol, tobacco, and illicit drugs; and inadequate or degrading medical care. In various studies, Krieger and her colleagues have shown the effects of perceived racism on differences in low birth weight and infant mortality rates between African American and White American women (Mustillo et al., 2004) and how racism plays into police violence (Cooper, Moore, Gruskin, & Krieger, 2004). Other groups, such as minority religions, and those with different gender expression and identification (LGBT), also are oppressed and particularly vulnerable to system and institutional barriers to primary and secondary care.

Another example of socially created health conditions is obesity. Over the past 40 years, the rate of overweight and obesity (measured using Body Mass Index [BMI], calculated as the ratio of kilograms/meter<sup>2</sup>) in American adults has steadily climbed. In 1962, 44.8% of the adult population was overweight (BMI equal to or greater than 25), and in 2002, that number had risen to 65.2%. During the same time frame, obesity (BMI equal to or greater than 30) rose from 13.3% to 31.1% of the population. Note that the rates for overweight include those who are obese (National Center for Health Statistics, 2004).

Larger restaurant portions, fast food, and lack of exercise are some causes for the increased size of Americans. Public health social workers can contribute to the development of public policies by helping to determine the social and economic forces that encourage overweight and obesity in poor populations. Healthy and nutritious foods are often not affordable or available in local grocery stores in poor neighborhoods (Kieffer, Willis, Arellano, & Guzman, 2002; Kieffer et al., 2001). These same neighborhoods are not perceived as safe, which discourages outdoor activity such as walking or bicycling.

Policies that increase access to quality services are often in the form of redistribution of financial benefits. When targeted well, they can affect better health outcomes. It is known, for example, that participation in prenatal care improves pregnancy outcomes (IOM, 1985). Access to quality prenatal care is limited for poor women, many of whom are minorities (Brown, 1988). In 2002, 6.2% of African American mothers received late or no prenatal care compared with 2.2% of White American mothers (DHHS, 2003). This difference mirrors the disparities between African American and White American infants for low birth weight and infant mortality.

Public health social workers have successfully advocated changes in public policy to improve the health status indicators in the population, particularly for the disadvantaged, such as the Medicaid expansions under OBRA 1989. This and the expanded State Children's Health Insurance Program (SCHIP), established as an optional program for states in 1997, are examples of policies that promote social and economic justice. As of 2003, all states had implemented SCHIP (Gehshan, 2003).

Changing the distribution of financial resources and promoting socially just actions would reduce the disparities in health status of vulnerable populations (McGinnis et al., 2002). The social work profession holds a strong position on the need to achieve economic justice. The Delegate Assembly of the National Association of Social Workers (NASW) meets every 3 years to develop and publish the public and professional policy statements for the Association. A prominent policy position that has been included and updated by NASW is for the development of



public policies that promote economic justice. It continues to advocate on the issues of poverty and access to health care for all (NASW, 2003). To achieve a socially and economically just society will require changes in American social values, but is a worthy goal of both public health and social work.

## COMMON METHODOLOGIES FOR PRACTICE

Sound social work and public health interventions and policy are evidence-based. To arrive at evidence-based practices, both social work and public health rely on strong research and evaluation of programs and policies. One common approach used by social work and public health is the community assessment. Public health also uses social epidemiology for program planning and evaluation. Epidemiological methods used in public health could also be used by social workers in developing interventions at all levels of practice.

Mussolino (2005) analyzed the National Health and Nutrition Examination Survey (NHANES I) to provide evidence of a prospective association between depression and hip fracture. Interventions that target depression in the elderly theoretically may impact the contribution that hip fracture makes to morbidity and mortality. This is an example of how public health social work intervention might improve a public health outcome. Another example is based on data collected from the National Hospital Ambulatory Medical Care Survey (NHAMCS), which established the home as the predominant location of injury for U.S. children. The researchers recommend interventions targeting the home environment to reduce the morbidity and mortality from unintentional injury in U.S. children (Phelan, Khoury, Kalkwarf, & Lanphear, 2005).

### COMMUNITY ASSESSMENT

Community assessment is a method of identifying the strengths and weaknesses in a defined community. Members of the community who are involved in designing and carrying out the assessments and analyzing the information gathered may initiate assessments. Other assessments are initiated by public authorities in response to legal mandate and may or may not involve community members. In either case, the assessments help to define problems and gaps in services so that the community and professionals can advocate for improvements to existing programs and for new policies and programs.

Comprehensive community assessments use various methods to obtain data for analysis. These methods include community surveys, interviews with community leaders, and town hall meetings. Data collection may be from vital records on births and deaths, hospital discharge information, and other data from public health and social service agencies.

Social workers are, through their training, well prepared to conduct community assessments. Public health social workers contribute to public health assessments and, in doing so, provide insights regarding the social context of health and disease. Public health social workers collaborate with other public health professionals to apply social understanding to interventions that are developed in response to community assessment (Wilkinson et al., 2002). For example, they participate in Child Death Review Teams to provide the person-in-environment



perspective. Community assessment is also crucial to the development of culturally competent social marketing strategies. A study that explored factors linking at-risk African Americans with health-promotion programs found that, contrary to common perception, the use of the African American church and the use of a high-profile person to deliver a message may actually be counterproductive to efforts to motivate people to use health prevention programs (Icard, Bourjolly, & Siddiqui, 2003). This is an example of how research should guide practice, what we term evidence-based practice.

#### SOCIAL EPIDEMIOLOGY

Social epidemiology, the study of the impact of social factors on the distribution of health and illness in a population, examines the role of social variables on other known and accepted biological and behavioral factors that shape the health status of a community (Berkman & Kawachi, 2000). Social epidemiology is a research method that uses mostly quantitative data to identify social determinants of health and health outcomes. For example, Lynch and Kaplan (2000) have conducted numerous studies to better understand the impact of socioeconomic position on health. Using the findings from theirs and others' studies, they have developed a theoretical model to explain these effects. This model uses a life-course perspective and takes into account a broad range of conditions and statuses, and it discusses the variation in measures of socioeconomic position. This variation demonstrates the challenges of conducting social epidemiologic studies. As an example, Krieger and her colleagues have studied the effects of racism on health (Krieger, 1999; Krieger, Chen, Waterman, Rehkopf, & Subramanian, 2003; Krieger, Sidney, & Coakley, 1999). To do so, they had to develop a measure of perceived racism, which, though used by others, is still not universally accepted because the experience of racial discrimination can be thought of as subjective, and thus the measure might not work the same way in all settings.

Some social epidemiologists use qualitatively as well as quantitatively obtained data. An example is the Fetal and Infant Mortality Review (FIMR) sponsored and monitored by MCHB (E. Hutchins, Grason, & Handler, 2004; Koontz, Buckley, & Ruderman, 2004). FIMRs are conducted at the community level after a fetal or infant death that cannot be attributed to a medical cause, for example, Sudden Infant Death Syndrome (SIDS). The purpose of a FIMR is to gather medical and social information that can be used to enhance the health and well-being of women, infants, and families. That information can then be used to improve the community resources and service delivery systems to reduce additional fetal and infant deaths. FIMRs are conducted by examining medical care data, autopsies, and assessments, often completed by social workers, of the social environment of the pregnant woman and the infant. Attention is given to housing, number of adults and children in the household, and other family resources. The data are reviewed by transdisciplinary technical advisory committees, which, in addition to physicians and nurses, may include clinical social workers and community volunteers. Public health social workers contribute to these reviews by interpreting the social contexts in which deaths occur.

Both community assessment and social epidemiology are tools that clearly identify the social and physical environmental factors in the determination of health status in a community. With the information gleaned from using these

methods, public health social workers and other public health professionals can work together toward the goal of improving the quality of life of the public.

### LEVELS OF PRACTICE AND COMPONENTS OF PREVENTION

At the micro or direct practice level, public health social workers implement public health interventions using clinical social work skills or provide social work services as part of a larger public health program. At the mezzo, or indirect practice level, public health social workers develop, implement, and administer public health programs. At the macro level, public health social workers contribute their knowledge of psychosocial and cultural issues to the development of public health interventions. They are also involved in surveillance and evaluation of programs that serve low-income and vulnerable populations. Public health social workers are engaged in the policy-making arena in conjunction with other public health professionals.

Much of public health practice takes place at the macro level. Social work and public health administrators at the macro level of practice use community-based assessments to develop interventions. Nonclinical social work interventions to change the social environment, such as job programs and health-care reform, may be used by public health practitioners. Public health practitioners, including public health social workers, conduct theoretical and intervention research in order to advance a shared commitment to evidence-based practice.

### COMPONENTS OF PREVENTION

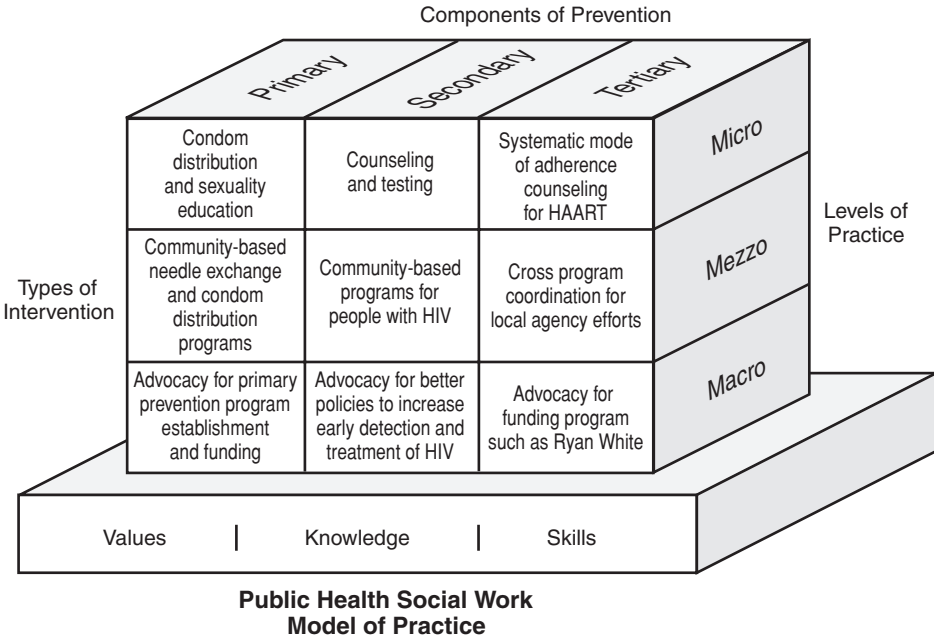
Disease prevention is divided into three levels: primary, secondary, and tertiary (Schneider, 2000). Primary prevention is intended to protect us from injury and disease. Examples include the Back-to-Sleep national campaign for the prevention of SIDS, immunizations against childhood and other diseases, and automobile restraints and airbags. Another primary prevention is the imposition of large taxes on tobacco to limit its use by increasing the cost of cigarettes and other tobacco products.

Secondary prevention is the early diagnosis and treatment of disease and seeks to reverse or retard a disease process from progressing. Examples are Pap smears, mammograms, and prostate specific antigen tests to identify malignant or pre-malignant states and intervene to affect a cure or slow the progression of the illness.

Tertiary prevention includes those actions taken to minimize the effects of a disease and prevent further disability. Periodic eye exams to detect and treat diabetic retinopathy are a type of tertiary prevention because they prevent disability deriving from diabetes, although they do not treat the primary disease.

### TYPES OF PUBLIC HEALTH SOCIAL WORK INTERVENTIONS

The intersection of the three levels of social work practice with the three levels of prevention is displayed in Figure 4.3. The public health crisis of HIV is used to illustrate public health social work interventions within the familiar framework of micro, mezzo, and macro levels of practice and components of prevention.



**Figure 4.3** Components of Prevention and Levels of Practice

**PRIMARY PREVENTION OF HIV AT THE MICRO, MEZZO, AND MACRO LEVELS**

The roles of public health social workers in the primary prevention of HIV at the micro level include condom distribution in clinics, counseling women living with HIV about their health and family planning, and participating in needle exchange programs. At the mezzo level, public health social workers administer community-based programs for safe needle exchange and condom distribution. Needle exchange has been a controversial primary prevention intervention for HIV, and public health social workers who advocate for federal, state, and local policy to permit this intervention are working at the macro level.

**SECONDARY PREVENTION OF HIV AT THE MICRO, MEZZO, AND MACRO LEVELS**

Outreach and early intervention services are particularly important to meet the needs of people living with HIV who are not in care. Many public health social workers work in hospitals, local health departments, and community-based programs that provide counseling and testing for HIV. The Positive Start Program in Missouri provides an interface between the community HIV/AIDS agency and the Department of Corrections. It targets inmates living with HIV who are scheduled to be released (personal communication: Mindy Mulky, executive director, Regional AIDS Interfaith Network, February 10, 2005). This mezzo program creates a connection to the client by providing referrals for case management after release and educates them about prevention when they rejoin society. Public health social workers who fight discriminatory policies targeting people with HIV, such as in employment and housing, are working at the macro level.

### TERTIARY PREVENTION OF HIV AT THE MICRO, MEZZO, AND MACRO LEVELS

Examples of tertiary prevention at the micro level include direct service case-management for medical services, securing resources to enhance health outcomes (supportive services such as housing and food vouchers), and making referrals and providing payment assistance for visits to infectious disease specialists or HIV-focused physicians. Mezzo level public health social workers administer programs that help people living with HIV obtain and maintain stable and high-quality housing, for example. Public health social workers operating in the research and policy arenas to advance improved programs for people living with HIV are working at the macro level for tertiary prevention.

### PUBLIC HEALTH SOCIAL WORK PRACTICE TODAY

Public health social work practice today is a growing field. There are social workers working in public health at all levels of practice and with all components of prevention. The practice settings for public health social workers reflect the partnership between public health and social work.

#### PRACTICE SETTINGS

Public health social workers do not practice in isolation. Their practice, often on transdisciplinary teams, takes place in host settings that are usually public, but may also be private. Public settings include federal public health agencies as well as state and local health departments. At all three levels of government, public health social workers work in various policy-making and program positions. In addition, public health social work practice is primarily at the population level. For example, public health social workers work side-by-side with public health environmental specialists to ensure that safe housing is available to a community of elders. They work with public health nurses, physicians, and epidemiologists to develop, implement, and evaluate programs that serve all ages in the population. They coordinate home visiting programs targeting pregnant women at high risk for poor birth outcomes.

Federal level public health social workers work in national and regional offices. They create and administer regulations for policy implementation. They manage and provide oversight for grants such as the MCH Block Grant, SPRANS, and other federal grants. Some public health social workers provide training and others conduct and use research to inform evidence-based interventions. Federal public health social workers act as liaisons to state programs funded by Block Grants.

Public health social workers are found in a variety of state administered, federally funded programs, such as the Title V Children with Special Health Care Needs Program. They work as the intermediaries between state and local health departments and other public health agencies in managing federal pass-through dollars. Public health social workers provide management oversight for the programs and training managers to comply with federal mandates. Public health social workers at the federal and state levels also provide expert testimony and advocate for public health programs when Congress and state legislatures develop policy and budgets that will affect the public's health.

Local health departments are the workhorses within the public health system, and programs generally associated with these agencies are the maternal and child health programs (family planning, prenatal care, well-child care, immunizations); disease surveillance and treatment programs (tuberculosis control, sexually transmitted infections, West Nile virus); and environmental protection programs (restaurant inspection, vermin control, air quality, milk safety, veterinary-borne disease). In addition, vital statistics (birth and death certificates) are often housed within local health departments.

At the local level, in public health departments as well as in private nonprofit agencies, public health social workers develop and implement programs and provide direct service. Some examples of direct practice are case management for specific populations, home visiting, immigrant health services, HIV/AIDS counseling and testing, outreach to elderly for blood pressure screening and other health services, and family planning and other reproductive health care. Public health social workers also work in community and migrant primary care centers.

Private settings in which public health social workers are employed are usually located in not-for-profit agencies, such as Planned Parenthood (see Box 4.2), domestic violence shelters, AIDS organizations, and established agencies like the YWCA. Public health social work practice in private settings does not usually differ from the practice of those in the public sector. Private agencies are often created to provide services that are limited or prohibited by government regulations, such as counseling clients about abortion. Some programs that operate in the private sector are supported by public funds and must comply with government regulations that apply to the services they provide. Whereas the practice settings remain standard, the areas of concern for public health social workers shift as social and economic conditions change and as diseases emerge.

Beginning in 1980 and continuing through each subsequent decade, the DHHS has developed successive sets of national health promotion and disease prevention objectives, the most recent of which is Healthy People 2010. Described as the prevention agenda for the nation, it provides “national health objectives designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats” (Healthy People 2010 Home Page, n.d., para. 1).

The 2010 initiative has two national goals: The first is to help Americans to increase the years of healthy life and improve the quality of life; and the second is to eliminate the current disparities in health among and between various populations (Healthy People 2010, What Are Its Goals?, n.d.). To achieve these goals, 28

#### **Box 4.2**

#### **Planned Parenthood and the Federal Title X Public Health Service Act**

Many of the local Planned Parenthood affiliates provide family planning services funded through the Title X Public Health Service Act, which provide funds for contraceptive services for the poor. As recipients of these funds, the affiliates must comply with federal regulations that restrict any portion of Title X support being used in support of abortion services. This includes abortion counseling, promotional material, referral for abortion services, and medical or surgical abortions.

focus areas and 467 objectives designed to improve the health of Americans have been developed.

The goals and objectives of Healthy People 2010 are guidelines for policy and prevention strategies. Many, if not most, of the focus areas and their objectives are arenas in which public health social workers practice and provide unique expertise to the development and implementation of public health prevention policies and programs.

An example of one of these objectives is the focus area of Maternal, Infant, and Child Health under Prenatal Substance Exposure. Objective 16-17 is: "Increase abstinence from alcohol, cigarettes, and illicit drugs among pregnant women" (Healthy People 2010, chap. 16, n.d.). The report gives the baseline data from 1996 to 1997 and gives target rates for 2010 in the areas of alcohol use, binge drinking, cigarette smoking, and illicit drug use. Social workers are well acquainted with interventions to reduce alcohol, tobacco, and other substance use and use that expertise to contribute to development of interventions to meet the objective. One example of a public health social work intervention is group work with individuals recovering from chemical dependency (Washington & Moxley, 2003).

Although it is widely accepted that social factors are major determinants of health, the current Healthy People 2010 initiative has only a few social objectives. Missing from our nation's public health objectives are social objectives to reduce the number of children in poverty, to reduce the number of children who go to bed hungry, and to decrease the number of people who are unemployed, all of which are recognized social determinants of ill health. As the primary providers of psychosocial interventions, public health social workers should take the lead in advocating for inclusion of social objectives in the next version of Healthy People.

#### AREAS OF FOCUS

As described, Healthy People 2010 includes 28 focus areas to increase years of life and eliminate health disparities. Table 4.1 lists these areas of focus. Whereas public health social workers function within all areas of focus, several provide excellent illustrations of the tools and interventions employed by public health social workers.

#### MATERNAL, INFANT, AND CHILD HEALTH

Prenatal care is an evidence-based practice to improve pregnancy outcomes, although the mechanisms behind these improvements are not fully understood. In addition to identifying medical care problems early so that they can be addressed, social workers in prenatal care settings assess the psychosocial needs of pregnant women. Research has found that women with unintended pregnancies are less likely to enroll in prenatal care early in their pregnancies than women whose pregnancies were planned (Sable & Wilkinson, 1998). Other research on enhanced prenatal care, which in addition to standard medical care provides health and nutrition education and psychosocial services, has shown that contact with psychosocial providers reduces the risk of preterm birth or low birth weight by about half (D. R. Wilkinson, 1995; D. S. Wilkinson, Korenbrot, & Greene, 1998). The findings from these studies support the importance of public health social work interventions in reducing adverse pregnancy outcomes.



**Table 4.1**  
Healthy People 2010: Focus Areas at a Glance

- 
1. Access to quality health services
  2. Arthritis, osteoporosis, and chronic back conditions
  3. Cancer
  4. Chronic kidney disease
  5. Diabetes
  6. Disability and secondary conditions
  7. Educational and community-based programs
  8. Environmental health
  9. Family planning
  10. Food safety
  11. Health communication
  12. Heart disease and stroke
  13. HIV
  14. Immunizations and infectious diseases
  15. Injury and violence prevention
  16. Maternal, infant, and child health
  17. Medical product safety
  18. Mental health and mental disorders
  19. Nutrition and overweight
  20. Occupational safety and health
  21. Oral health
  22. Physical activity and fitness
  23. Public health infrastructure
  24. Respiratory diseases
  25. Sexually transmitted diseases
  26. Substance abuse
  27. Tobacco use
  28. Vision and screening
- 

*Source: Healthy People 2010.* (n.d.), retrieved from <http://www.cdc.gov/nchs/about/otheract/hpdata2010/2010fa28.htm>.

Public health social workers are also active in infant mortality reduction, another major public health problem area. Public health social workers are involved in program development and implementation to reduce infant mortality. An example is the federal Healthy Start initiative, which began in 1990. Public health social workers are often central to the work of these community-based consortia (M. Thompson, Minkler, Bell, Rose, & Butler, 2003) and participate in this transdisciplinary initiative to conduct community assessments, develop and implement interventions, and evaluate their effectiveness. At its inception, there were 15 Healthy Start pilot projects. Since then, Healthy Start programs have expanded across the nation, and there are currently 96 federally funded Healthy Start projects and 5 main types of Healthy Start grants: Perinatal Health, Border Health, Interconceptional Care, Perinatal Depression, and Family Violence (National Healthy Start Association, n.d.). Healthy Start attempts to impact the social and behavioral determinants of infant mortality; as such, it provides an excellent example of the intersection of public health and social work. M. Thompson et al. (2003) identified facilitators of well-functioning consortia and include flexibility



**Box 4.3****Puertas a La Salud (PALS) Program (Doorways to Health)**

A local health department has secured Title V funding from the state health department to develop a home visiting program for pregnant Hispanic immigrants in a community that has seen a 100% increase in its Hispanic population. Two bilingual social workers were hired, each carrying a caseload of 15 to 20 families, to provide home-based services to these women during their pregnancy and until the child's second birthday. The public health social workers (PHSWs) assess the health, environmental, and social services needs of the clients, make referrals to community agencies to meet these needs, provide interagency coordination of services, and provide social support to the families. They assist in securing prenatal care and WIC services, and assistance with Medicaid enrollment. Immigrants can get temporary Medicaid to cover their prenatal care, enroll in Emergency Medicaid to pay for the delivery, and enroll their infants in the State Children's Health Insurance Program (SCHIP) but the women need help in understanding and navigating the system. Referrals to other services such as the local food bank, Salvation Army, Section 8 housing are provided. The PHSWs also work with lawyers to assist with immigration issues.

PHSWs provide health education to the clients according to their needs. This includes information on maintaining a healthy pregnancy, infant growth and development, infant feeding, parenting skills (including child safety, immunizations, and preventive health care), and contraception. The PHSW works to promote breastfeeding, including support for fathers, effective contraceptive use, sexually transmitted disease prevention, and substance abuse prevention. They work to promote healthy family relationships, and sometimes work with the fathers, especially in cases where domestic violence is present. The PHSWs see the whole family as the client, and work with other family members if they are present.

The PHSWs educate their clients for effective utilization of the U.S. health-care system, teaching them, for example, to avoid going unnecessarily to the emergency room for common, nonemergency ailments. They also discuss folk beliefs that some of the women bring with them from their country of origin. The PHSWs work with the women to support the integration of modern health behaviors with the folk beliefs that are still alive among the people. Some of these folk beliefs include the notion that eating ice cream will cause a pregnant woman to miscarry, or that "heavy" food cannot be eaten for 40 days postpartum.

These are but some of the ways in which PHSWs work collaboratively in public health to improve the health and social well-being of clients.

in locally appropriate structure design, broad institutional support, diverse incentives for participation, adequate resources on multiple levels, and identification with the program and its mission.

All states mandate that newborns undergo screening for certain specific genetic diseases. For some genetic diseases, such as hypothyroidism, early identification provides the opportunity for medical intervention to prevent morbidity. In 2004, The DHHS awarded \$12.6 million in grants to help state and local health agencies improve newborn screening systems, reduce racial and ethnic disparities in infant mortality and low birth weight, and other programs through education and genetic counseling to parents and through screening services and

follow-up care for newborns with heritable disorders (Health Resources and Services Administration [HRSA], 2004).

The first disorder for which screening was mandated was phenylketonuria (PKU), which is an inborn metabolism error that is inherited on an autosomal recessive basis. The incidence is about 1:12,000 in mixed populations in the United States. If not managed correctly by a diet that restricts intake of phenylalanine (an essential amino acid), severe mental retardation will ensue; the restrictive diet must be maintained for life. Social workers were involved in the development of the laws to mandate this screening, and now all states require PKU testing as a secondary prevention measure to eliminate this preventable form of mental retardation. Public health social workers may be involved in the development and administration of support groups for families and young people living with PKU. The University of Minnesota has one such type of program (*A Place of Our Own*, n.d.).

Childhood lead poisoning is also a major preventable environmental health problem with long-term consequences such as lowered intelligence and learning problems (CDC, n.d.). Evidence of elevated lead levels triggers an investigation to determine the source of lead in the child's environment. Public health social workers are involved in working in lead abatement programs, including working with landlords and public housing authorities and communities to remove the lead from the environment. Social workers have also been involved in identifying factors to improve retention rates in longitudinal studies and treatment programs for lead poisoning (Adubato, Alper, Heenehan, Rodriguez-Mayor, & Elsafty, 2003). They found that the presence of a bilingual social worker to provide home visits, missed appointment follow-ups, referrals to ancillary services, and assistance with factors such as housing and transportation to the clinics increased the retention rates in the program from 51% to 88%.

Public health social workers in Children with Special Health Care Needs (CSHCN) programs work with children and their families who have been diagnosed with congenital physical or developmental disabilities. The Division of Services for Special Health Care Needs (within DHHS) has been responsible for administering programs to assure the health of children with special health-care needs. Traditionally, these services focused on rehabilitating "crippled children" [sic] through a professional expert model (McPherson, 1997). Public health social workers participated in transdisciplinary teams to provide psychosocial and referral services to these children and families. A shift in focus to more family-centered and community-based systems of care resulted from the Surgeon General's 1987 "Call to Action" and set forth a "National Agenda for Children with Special Health Care Needs" (Maternal and Child Health Bureau, 1997).

This new focus provided a shift in the social work role as well, from participation in a hospital-based medical model to a systems approach that was both family centered and community based (Bishop & Arango, 1997). Public health social workers still provide psychosocial assessment, support, and resource referral to families, but often in the home-based or community setting where they provide case management and service coordination. Additionally, public health social workers form partnerships with families to work in the advocacy and policy arena, and they work in the many family-centered, community-based, culturally competent, coordinated programs that have emerged to promote inclusion, community living, and improvements in services for children and families. Pub-

lic health social workers are essential to facilitating better linkages among health, mental health, education and social services, partnerships between the private and public sectors, and development of community-based services (Farel, 1997).

Elements of family-centered care noted at the 1996 meeting of the National Commission on Leadership in Interprofessional Education (Shelton & Stepanek, 1994) include:

- Recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families
- Encouraging and facilitating family-to-family support and networking
- Promoting a relationship in which family members and professionals work together to ensure the best services for the child and the family
- Creating an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored
- Bringing to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special health-care needs and their families

Boxes 4.4 and 4.5 describe the lessons learned to translate these approaches into effective social work practice with communities and families (Taylor, 1997).

#### HIV INFECTION

The emergence of HIV/AIDS in the 1980s precipitated a major public health crisis. In addition to the medical issues, the fact that it arose in the gay community subjected this already oppressed group to further prejudice and discrimination (Human Rights Campaign, n.d.). The usual social support networks of family and others that arise when a person becomes critically ill were often not available to people living with HIV/AIDS because of family rejection and the loss of close friends to the disease. During the 1980s, AIDS was a frightening and isolating disease. Advances in medical treatment, however, are credited for HIV/AIDS being considered a chronic, manageable illness (see Chapter 18 on chronic illness).

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, established in 1990, is federal legislation providing funding to ensure access to health care and support for people living with HIV/AIDS. Congress reauthorized and amended the act in 1996 and again in 2000. Public health social workers participate in the implementation of all parts of the Act, including outreach, case management, primary care services, and administration at the state level (Barr, Lee, & Benjamin, 2003).

An emerging issue for HIV/AIDS is the screening of pregnant women. Vertical transmission of HIV can be almost fully prevented if a pregnant woman with HIV receives drugs during labor (Wade et al., 1998). New York State has a law that mandates physicians to offer HIV tests to all pregnant women and requires HIV tests for all newborns (Cameron, 2002). Similar legislation has been suggested in other states. To ensure that newborns who are HIV-positive are provided with rapid treatment, the parents, medical providers, and the state child welfare office

**Box 4.4****Lessons Learned: Practice with Communities**

1. Ask families how they define their community and work with their definitions.
2. Work in partnerships with community members on all activities.
3. Ask communities what they want and plan services around the priorities that community members identify.
4. Learn about the community from the community: the way power is structured, the challenges to cohesive action, and the unique roles of culture, class, and ethnicity.
5. Build partnerships among community members and health, social service, and education systems:
  - a. Develop a common purpose/vision.
  - b. Build consensus by focusing on what families need rather than on agency functions.
  - c. Identify areas of conflict and work to resolve them.
  - d. Establish relationships through face-to-face interactions and nurture them through regular personal contact.
  - e. Establish a culture in which difference is valued and all voices are heard.
  - f. Establish a culture in which the benefits of collaboration for families, professionals, and agencies are regularly acknowledged and appreciated.
6. Plan systems that combine agencies' strengths to respond holistically to families' self-identified needs.
7. Create systems that reflect the cultural diversity of the community.
8. Simplify access to health, education, and social work resources.
9. Support community members in coming together to advocate for themselves.
10. Develop a process that consistently identifies, strengthens, and empowers community leaders.
11. Identify and nurture community strengths.
12. Address needs continually with community members as partners.

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*Source:* From "Responses and Recommendations for Practice" (pp. 93–94), by M. S. Taylor, in *Partnerships at Work: Lessons Learned from Programs and Practices of Families, Professionals, and Communities*, K. K. Bishop, M. S. Taylor, and P. Arango (Eds.), 1997, Burlington: University of Vermont, Department of Social Work. Reprinted with permission.

(if the child is placed in the custody of the state) are all informed about the test results. This means that a woman who declined an HIV test during her pregnancy will receive information about her own status at the same time that she is told of her infant's status (Cameron, 2002). Public health social workers working with pregnant women will have to assist them with their decisions regarding HIV testing and help those who learn of their own status through their baby's test. This entails many ethical issues, such as those outlined in Chapter 3 on ethics.

#### FAMILY PLANNING

Despite widespread availability of a variety of contraceptive methods, unintended pregnancy remains a major public health problem. Fifty percent of pregnancies and 28% of births are unintended (Henshaw, 1998). Women whose pregnancies are unintended are more likely to engage in unhealthy behaviors, such as smoking and use of alcohol and illicit drugs (Brown & Eisenberg, 1995).

**Box 4.5****Lessons Learned: Practice with Families**

1. Believe in families; they want what is best for their children and their communities.
2. Focus on families' strengths.
3. Understand the importance of cultural competence and make its development and enhancement an ongoing priority.
4. If children and families are not being helped, change the helping system.
5. Listen to families and understand their changing needs.
6. Create individualized plans to meet the individual needs of families.
7. Work from a flexible definition of family and include the whole family in programs and services.
8. Transcend professional roles to demonstrate commitment and caring to families.
9. If there are other professionals involved with a family, work with them; if a family wants a team, help them to create one.
10. Create a welcoming environment for families.
11. Create a respectful environment for families and staff.
12. Support community activities and encourage participation of agency staff.
13. Work with youth, families, and the community to assess, implement, and evaluate programs.
14. Bring services to the community in ways that honor families' requests.
15. Value and promote continuity in staffing, which allows the development of accumulated wisdom and builds community trusts in programs.
16. Make commitment to children and their families the foundation of all programs/activities.

*Source:* From "Responses and Recommendations for Practice" (pp. 93–94), by M. S. Taylor, in *Partnerships at Work: Lessons Learned from Programs and Practices of Families, Professionals, and Communities*, K. K. Bishop, M. S. Taylor, and P. Arango (Eds.), 1997, Burlington: University of Vermont, Department of Social Work. Reprinted with permission.

Furthermore, they are less likely to seek early and continuous prenatal care (Sable & Wilkinson, 1998). Public health social workers work in family planning and reproductive health settings to educate women and men about contraceptive methods and provide counseling to women facing unwanted pregnancy.

The United States has the highest rate of teen pregnancy among industrialized nations. Among teens, approximately 82% of pregnancies are unintended, half of which result in abortion (Brown & Eisenberg, 1995). In addition to focusing on contraception, another primary prevention approach takes into account social and environmental factors as noted by Children's Defense Fund founder Marian Wright Edelman in her summary of the organization's adolescent pregnancy prevention program:

Sex education and family planning are only two pieces of the puzzle of adolescent pregnancy. Youth and adult jobs, job training, education, and support services (like child care), which make them possible, are also critical pieces of the complex puzzle. Reversing the pervasive cultural messages, such as "anything goes" and "sex is bliss without consequences," that are often conveyed by television, movies, popular music and advertising is another important piece. We must make it "uncool" to

**Box 4.6****The Adolescent Parenting Program**

The Adolescent Parenting Program (APP), funded and directed by the State Division of Public Health is a statewide program for first-time pregnant or parenting teens. Programs are located in about one-third of the state's counties and are administered under the auspices of a variety of agencies. The programs work with participants to achieve the following six goals: (1) Prevention of a second pregnancy during program participation; (2) completion of high school or a GED; (3) appropriate utilization of health-care services; (4) strengthening parenting knowledge and skills; (5) employment preparation; and (6) prevention of child abuse and neglect. Each program has a full-time coordinator who is a PHSW. The coordinator, in addition to providing services to an average of 12 to 20 pregnant or parenting teens per month, plans and manages the program. These programs are funded through a mix of state appropriations, and Medicaid and Temporary Assistance to Needy Families (TANF) monies.

Direct service responsibilities of the coordinator include recruiting and screening pregnant teens, individual case plan development, case management, facilitating peer support groups, individual counseling, and health education. To strengthen family support networks for teen mothers, coordinators involve family members when appropriate.

Macrolevel practice includes program development and evaluation such as establishing and maintaining collaborative interagency linkages with other agencies and community groups, and supervising volunteers who serve as mentors. An in-house management team and/or a community advisory committee provide supervision and consultation to the coordinator.

In 2000, the state general assembly funded an evaluation of the APP. The state level program officer for the APP formed an evaluation steering committee comprised of state regional PHSW consultants, and local program coordinators to work with a team of evaluators from a university school of social work. This partnership resulted in a web-based data information system that program coordinators use to enter client data and the types and amount of service provision. This enables them to generate timely monthly reports for the state-level program office as well as for local program quality improvement purposes. Annual program reports are used to support funding requests for the programs at the local as well as the state level. State-level program and policymakers use cross-site data from all the local programs to evaluate the effectiveness of the APP at achieving its goals.

have a baby too young, and must couple that message with constructive opportunities for adolescents' futures so that they will see a reason to delay sexual activity and parenting. (Edelman, 1985, p. 7)

More recently, the National Campaign to Prevent Teen Pregnancy (NCPTP) provides an example of an organization that addresses social and environmental factors in its effort to reduce the teen pregnancy rate in the United States by one-third between 1996 and 2005 (NCPTP, 2002). Public health social workers who work in organizations such as NCPTP provide their expertise and knowledge of psychosocial issues in the development of programs.

Adolescent Family Life Programs are secondary prevention initiatives funded by MCHB and administered by the states. These educational programs are primarily directed at teenagers, both girls and boys who are parents, to prevent a



second early pregnancy. The programs address how to parent a first child, reasons and methods for delaying a second pregnancy, and the psychosocial impacts of parenting at a young age. Adolescent Family Life Programs are run by state health departments and are typically managed by public health social workers.

#### NUTRITION AND OVERWEIGHT

State health departments, primarily through local health departments, administer the Women, Infant, and Children (WIC) Supplemental Nutrition Program (funded through the U.S. Department of Agriculture). Public health social workers working with low-income populations interface with WIC by making referrals.

Roby and Woodson (2004) developed a breast-feeding education intervention among Latino women and found that teaching a lactation class in Spanish significantly increased their willingness to breast-feed and empowered them to believe that they could overcome obstacles to breast-feeding.

#### INJURY AND VIOLENCE PREVENTION

Public health social workers play an important role in the prevention of both intentional and unintentional injuries. Intentional injuries include child abuse, interpersonal violence including domestic violence, homicide, and suicide. Clinical social workers traditionally provide services to individuals and families to reduce or eliminate child abuse, a secondary prevention practice. Public health social workers participate in primary prevention of child abuse through policy and program implementation that target community change to alter the social conditions that are determinants of child abuse. Similar public health social work roles exist in the area of domestic and interpersonal violence. For example, screening for intimate partner violence within primary care settings is an intervention in which public health social workers may participate to identify those at risk (Ross, Walther, & Epstein, 2004). The Abuse Assessment Screen (McFarlane, Parker, Soeken, & Bullock, 1992; Soeken, McFarlane, Parker, & Lominack, 2003) has become an established tool for screening for domestic violence. Rather than ask a woman, "Are you a victim of domestic violence?" it is recommended that specific behavioral questions be asked, such as, "In the last year, were you hit, slapped, kicked, or otherwise physically hurt by someone?"

Unintentional injuries to children can be caused by neglect and the caretaker's lack of appropriate education. Other risk factors are the same as those related to intentional injury. Evidence-based primary prevention interventions to reduce unintentional injuries include car seats, smoke detectors, turning down the temperature on hot water heaters, fences around pools and play yards, and helmets and other protective gear for active sports (Deal, Gomby, Zippiroli, & Behrman, 2000). Public health social workers work in injury prevention programs and are involved in public health campaigns such as the Safe Kids Campaign and work to educate parents and other caretakers about safety practices to reduce unintentional injuries. In addition, public health social workers are involved in homicide and suicide prevention in several ways. They advocate for legislation to ensure strict monitoring of the sales of firearms and laws that take firearms out of the reach of children and adolescents. Social workers work to alleviate the social conditions related to both intentional and unintentional injuries. Those conditions are poverty, alcoholism, substance abuse, and early parenting.



Motor vehicle crashes are a major source of unintentional injury and death to adolescents and adults. Motor vehicle crashes account for almost half of unintentional deaths and alcohol is involved in 40% of motor vehicle fatalities (Healthy People 2010, *Leading Health Indicators: Injury and Violence*, 2001). Public health campaigns to reduce motor vehicle fatalities include designated driver programs and community and school-based education. Public health social workers are involved in planning such campaigns and community-based interventions in response to community needs assessments.

#### MENTAL HEALTH AND MENTAL DISORDERS

Public health social workers are actively involved in furthering the Healthy People 2010 goals in the mental health arena. For example, Positive Impact is a community-based program in Atlanta, Georgia, that provides mental health services for people and families affected by HIV (Smith & Bride, 2004). Public health social workers working in the area of addictions take the “harm reduction” approach to minimize the risk of deleterious consequences of a behavior. Reid (2002) describes this public health model with relation to injection drug use, citing needle exchange programs as a means to reduce the spread of HIV transmission. Davey (2004) describes a multiple-family group intervention for homeless families.

Addictions are a major public health concern that impact different populations disproportionately. Substance abuse affects women differently than men, both physically and psychologically. Women have higher rates of poor nutrition, high blood pressure, and sexually transmitted infections. Further, women who abuse substances are often incarcerated or homeless (Grason, Hutchins, & Silver, 1999).

Pregnant and parenting women, in particular, have limited access to addiction treatment. Public health social workers recognizing this have worked with private and public agencies to address this need. The Comprehensive Substance Treatment and Rehabilitation Program (CSTAR) in Missouri is representative of these types of responses. Single women, pregnant women, and women with children may enter specialized women’s CSTAR treatment programs. These Medicaid-funded programs provide a complete continuum of treatment services and housing supports tailored to the unique needs of women and children (Jordon, 1997).

Public health social workers are involved in suicide prevention in several ways. They work to change social conditions that are conducive to the sense of helplessness that precedes suicide. Social determinants of suicide include unemployment, substance use including alcohol and illicit drugs, physical abuse, and mental illness such as Major Depressive Disorder. Some of these determinants and predictors are described by Richman (1999) and Price, Dake, and Kucharewsk (2001).

#### ORAL HEALTH

Oral health is important throughout the life span. Good dentition is essential for good nutrition and good health (National Maternal and Child Oral Health Resource Center, 2003). Access to oral health is severely limited for low-income populations because Medicaid covers acute care only, and does not cover preventive care. Further, Medicare does not cover any dental care. Primary prevention interventions include dental sealants for children and water fluoridation for communities. Rural families who rely on wells may not have a fluoridated water supply,

and dental sealants may be inaccessible to those who lack insurance. Public health social workers can increase access to oral health through organizing community education forums to bring communities together to address this problem and to address the oral health needs in low-income populations. They can also advocate for policy changes to increase access to oral health through Medicaid and Medicare.

## PREPARING TO BE A PUBLIC HEALTH SOCIAL WORKER

There are various ways to prepare to be a public health social worker. Most public health social workers do not have formal public health education or public health degrees, but employers look for sound social work knowledge as it relates to public health practice in applicants for these positions. Typically, public health social workers are trained on the job and learn through continuing education and participation in regional and national meetings of public health social workers. The Public Health Social Work Institutes and the annual meetings of APHA and ASTPHSW are examples of learning and networking opportunities for public health social workers.

Increasingly, social work students who plan on practicing in public health enroll in one of the existing dual or joint MSW/MPH programs. These programs are growing in size and number. Courses completed in one degree fulfill requirements in the second, allowing students to meet all requirements with a reduced credit load. Each university and each of the schools of social work and public health have unique programs and admissions processes.

For social work master's students who are considering public health practice but are not at a school where a dual degree program is offered, there are many other ways to prepare. If there is a public health school, department, or program at the student's university or college, he can take courses in that program as electives. If there is no public health program, there may be one at a nearby institution. Faculty members with public health training can supervise independent study. Students can work with field placement offices to find a practicum experience in a public health agency. Students are welcomed at public health social work meetings and events, often at reduced rates.

Certain areas of knowledge and resources are especially valuable. At the federal level, the primary agency related to public health social work practice is the DHHS. Key agencies in DHHS are the Health Resources Services Administration (HRSA), the National Institutes of Health (NIH), the CDC, the Administration of Children Youth and Families (ACYF), and the Substance Abuse and Mental Health Services Administration (SAMHSA). MCHB and the Office of the Surgeon General are located within HRSA. Each of these agencies publishes documents and reports with essential information about public health. They also sponsor research to develop new knowledge and test interventions related to the public's health. Two other important federal programs within the Department of Agriculture are WIC and the Food Stamp Program.

The federal, state, and local public health programs all relate to one another, usually in regard to the flow of funds. How federal regulations affect state health departments and how state and local health departments interact is critical knowledge for public health social workers.

As professionals, public health social workers are expected to keep current with changes in the field. Important resources for public health social workers are, as mentioned previously, APHA and ASTPHSW. Further, there are numerous texts, federal publications (such as *Healthy People 2010* and the *Morbidity and Mortality Weekly Reports*), and journals that will help inform public health social workers. Some of the important journals are *American Journal of Public Health*, *Health and Social Work*, *Social Work in Health Care*, *Journal of Maternal and Child Health*, *Public Health Reports*, and *Health Affairs*.

## THE FUTURE OF PUBLIC HEALTH SOCIAL WORK

### BEYOND 2010: THE FUTURE OF PUBLIC HEALTH SOCIAL WORK CONFERENCE

The practice methods and theoretical foundation of public health social work are not expected to change significantly in the coming years. Instead, new areas of concern or new understandings about current problems will change the interventions undertaken by public health social workers. In 1996, leaders in public health social work met in North Carolina to consider future aspects of the profession. At the Conference, participants concluded that public health social work would become more prominent because the changes in health issues would focus more on community-based needs, long-term concerns, and work on policies to address new public health issues.

Four action groups were created to address public health social work future concerns (*Beyond 2010*, 2002). The first, Community Building in Public Health and Social Work, completed a project to have community groups and community-based social workers collaborate in mobilizing parents to educate children about sexual health and HIV prevention. The second action group, the Public Health Social Work Workforce Distribution Study, has surveyed state health departments to begin to determine how many social workers are in the agencies and to identify how they are classified.

As discussed earlier, the third group, the Standards group, developed a formal definition and set of practice standards for public health social work (see Appendixes 4.2 and 4.3 for the definition and the indicators that are the basis of the standards). The materials have been widely disseminated and adopted by both state and local health departments, the Social Work Section of APHA, and ASTPHSW. The final group focused on professional education of public health social workers (*Beyond 2010*). The group's major product was an article on including public health content in social work education (Wilkinson et al., 2002). Members of this group worked closely with the Standards group in developing the definition and standards. These groups joined to develop core competencies for public health social workers.

### GLOBAL ISSUES OF TERRORISM, OPPRESSION, AND SOCIAL JUSTICE

Terrorism, war, and disease will shape the focus of much public health social work practice during the coming years. The attacks on the World Trade Center and the Pentagon on September 11, 2001, stimulated awareness among Americans of both the reality of domestic terrorism and of the plights of oppressed people in other parts of the world. The domestic terrorism threat is increasingly an area of

**Box 4.7**  
**Disaster Preparedness and Response Teams**

PHSWs at the Marion County Public Health Department (Indianapolis, Indiana) are key members of the Community Disaster Preparedness and Response Team. These teams are usually composed of PHSWs, PH Nurses, physicians, clergy, and volunteers from local service organizations and public agencies. PHSWs have a crucial role in planning and responding to community emergency situations by providing expertise in crisis planning and management, concrete and psychosocial services, and by serving as liaisons among various community services organizations.

Some specific activities of PHSWs in a community emergency are:

- Critical incident stress debriefing for groups and organizations responding to the emergency.
- Crisis intervention counseling.
- Outreach services to those unable to leave home.
- Mass care (shelter and feeding) to evacuees during a major disaster.
- Temporary relief for individuals and families to begin planning for disaster recovery. Help to locate and reunify families, and assist in obtaining essentials such as food, shelter, and clothing. Special assistance for persons with disabilities and with mental and physical health concerns (DeWolfe, 2000).

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*Source:* Adapted from *Field Manual for Mental Health and Human Service Workers in Major Disasters*, second edition, DHHS Publication No. ADM 90-538, by D. J. DeWolfe, 2000, Washington, DC: Department of Health and Human Services, Substance Abuse and Mental Health Administration, Center for Mental Health Services.

practice for public health social workers who are active members of disaster preparedness and response teams (see Box 4.7).

#### OPPRESSION

Internationally, particularly in West Asia, the Middle East, and countries ruled by Islamic law, Americans have learned that the health of women and children has been highly compromised by war, isolation as part of religious rules, and political policies of western governments. Growing numbers of public health social workers will be members of international teams to improve the health of refugees and residents in foreign nations. A particular focus of their work will be in the maternal and child health arena to improve women's overall and reproductive health and prevent and protect communities from the effects of poverty and the aftermath of war and terrorism.

In the United States, HIV/AIDS is now being treated as a chronic disease. The ability of America and other industrialized nations to achieve this state is due to the wealth that supports the provision of anti-retroviral drugs to people living with HIV/AIDS. In developing countries, the expensive drugs are not only beyond the reach of the HIV/AIDS populations but also of governments with very limited monetary resources.

The epidemic of HIV/AIDS in sub-Saharan Africa, which affects up to 25% of the population in some countries, results in social and economic consequences

that can be addressed by public health social workers. In response to the President's Emergency Plan for AIDS Relief (PEPFAR) proposed in 2003, Congress enacted the U.S. Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act of 2003, PL 108-25 (U.S. Department of State, 2004). This 5-year, \$15 billion initiative offers four objectives to meet the program's goal: (1) prevention of HIV transmission; (2) provision of quality, comprehensive, evidence-based HIV disease management; (3) improvement in the quality of life of infected individuals and their families; and (4) provision of quality, comprehensive, and compassionate care for AIDS orphans and other vulnerable children (Announcement of the President's Emergency Plan, 2003; President's Emergency Plan For AIDS Relief, n.d.). Interventions to meet the four objectives of PEPFAR are within the scope of public health social work practice. United States social workers can be participants on international transdisciplinary teams to address them.

### SOCIAL JUSTICE

*Access to Health Care* Until universal access to health care is achieved in the United States, public health social workers will remain active in efforts to bring comprehensive, quality, and affordable health care to all. Social work must help to define comprehensive care to include primary and secondary prevention as well as psychosocial health assessments and interventions. Further, public health social workers will advocate for public policies that contribute to the improvement of the nation's health, for example, through antipoverty programs, jobs programs, environmental health programs, and education (NASW, 2003).

Under our current health-care delivery system, the poor and the elderly will continue to rely on the publicly financed programs, such as Medicaid, SCHIP, and Medicare. Public health social workers will be involved in the evaluation of these programs in order to propose and advocate for changes that reflect the social work values of social and economic justice. Expansion of these programs may be the strategy used to increase access to health care for all.

Incremental changes to these programs will include more of the nonelderly and uninsured adult populations over time. For example, Medicare covers those individuals age 65 and older. SCHIP and Medicaid cover children ages 0 to 21. Other than pregnant women and certain low-income and disabled groups, persons between the ages of 21 and 65 have no access to publicly funded health insurance. An incremental change would be to raise the income eligibility limits and concurrently raise the age of SCHIP and Medicaid coverage in 5-year increments until all American residents are included. Medicaid covers low-income pregnant women during pregnancy and for 60 days following the birth of their infants. Expansion of Medicaid eligibility to cover reproductive health care for an extended period of time (e.g., 2 years) would be a primary prevention strategy to decrease the rate of unintended pregnancy in this population. Public health social workers were involved in the Medicaid reforms of the 1980s and 1990s and will continue to be on the forefront of further policy reforms.

*Mental Health Services* The first Surgeon General's Report on Mental Health was issued in 1999 (U.S. DHHS, 1999). This report is important, as was emphasized in Chapter 8 of this *Handbook*, because it acknowledges the association between mental and physical health. It describes the toll of mental illness on the popula-

tion and states that mental health programs in the United States are founded on a public health population-based model. Further, the report highlights the issue of disparities in treatment based on culture, race, gender, and financial access. Finally, the Surgeon General's Report identifies stigma associated with mental illness as a major obstacle.

In suggesting courses of action to the public health and medical communities, one that is presented in the Surgeon General's Report is to facilitate entry into the mental health system. In recognition of the links between mind and body, the report identifies primary care providers as one route of entry to mental health services.

Clinical social workers constitute the largest profession in the delivery of mental health care. Public health social workers have the potential to develop and contribute to population-level interventions to address the concerns cited in the Surgeon General's Report, such as alleviation of stigma, barriers to care, and disparities in diagnosis and treatment.

#### RESEARCH

Evidence-based interventions and sound public policy result from well-planned and executed research. As more public health social workers become involved in research, such as that described in this chapter, the importance of including social, behavioral, and environmental factors as determinants of health will become more apparent. Assessing these psychosocial determinants will lead to more comprehensive interventions to address public health problems.

#### THE IMPACT OF PUBLIC HEALTH SOCIAL WORK

This chapter addressed only a sample of the issues, practice settings, and interventions encountered by public health social workers. Other issues that public health social workers address include services for immigrants and refugees, health care for men and women not related to reproduction, and inner city and rural concerns such as safety, crowding, and social and physical isolation, all of which impact the ability of these populations to achieve the maximum potential health status.

While medical social workers work with patients and their families to adapt to sudden and severe illness or trauma, public health social workers operate at the population level promoting primary prevention interventions to address the causes of these health problems. Public health social workers contribute their expertise, grounded in the person-in-environment orientation, to incorporate responses to behavioral, social, and physical environment determinants of health in public health interventions.

The problems will change over time, but well-prepared public health social workers will be ready to take on these new challenges. The new generation of public health social workers will carry on the traditions of the founders of social work who created settlement houses and worked to improve environmental conditions, develop economic reforms, and protect children, all of which contributed to the improvement of the public's health. Their work laid the foundation of federal programs for children and families and gave direction for the future of our profession.



## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 4.1

The purpose of this exercise is to apply your understanding of the determinants of health to a public health problem and discuss the role of public health social work in addressing the problem.

Your class will be divided into small groups and each assigned one of 28 focus areas from Healthy People 2010 (see Table 4.1) at one class session. In the interval between classes, your homework assignment is to gather data about the area and prepare a fact sheet for your classmates. In the next class session, each group will meet to identify determinants of the health problem in the various domains as identified in Figure 4.1 and how they interact.

After identifying the determinants, your group will explore the roles of public health social workers in promoting health and preventing the public health problem and then present your understanding to the class. The presentation must identify issues of diversity and disparities in the distribution, treatment, and prognosis of the illness at the core of the problem. In addition, you should be prepared to present on issues of social and economic justice associated with the health concern.

### LEARNING EXERCISE 4.2

The purpose of this exercise is to understand the intersections among the components of prevention and the levels of public health social worker practice.

Choose one of the 28 focus areas presented in Table 4.1, or a public health problem of your choice and fill in each of the nine boxes in Figure 4.3 with public health social worker activities representing primary, secondary, and tertiary prevention at each of the micro, mezzo, and macro levels of practice.

You may want to consult with a local public health social worker as you complete this assignment.

### LEARNING EXERCISE 4.3

The purpose of this exercise is to explore primary, secondary, and tertiary levels of prevention that can be applied to an intervention for a public health problem.

In this activity, you will be assigned to play a role on a committee that has gathered to address a public health problem in your community. The professionals on the committee, in addition to a PHSW, the other professionals may include a physician, an epidemiologist, a public health nurse, and/or a public official such as a prosecuting attorney, a city council member, or a law enforcement officer. The committee will meet and use data that were provided to you by your instructor to collaborate in the design of interventions at the three levels of prevention, and then to decide which intervention will best serve the community.

Possible topics:

- Perinatal substance abuse
- Teen pregnancy



- Sudden increase in the number of syphilis cases
- Motor vehicle accidents involving adolescents and alcohol
- Rise in suicide rate
- Rise in childhood obesity
- Asthma in a minority population
- Domestic violence
- Dental caries

#### APPENDIX 4.1: GLOSSARY

**Assessment** Collection, analysis, and sharing of data about health conditions, risks, and resources in a community.

**Assurance** Monitoring the availability of health services in a community.

**Epidemiology** The study of distribution and determinants of disease in populations.

**Evidence-Based Practice** Interventions that are based on theory that is supported by empirical research.

**Fetal and Infant Mortality Review (FIMR)** A review conducted to gather medical and social information after a fetal or infant death.

**Healthy People 2010** The public health goals and objectives for the United States as set by the U.S. DHHS.

**Infant Mortality (IM)** Death prior to an infant's first birthday; one of the leading indicators used worldwide to measure a country's health.

**Low Birth Weight (LBW)** A weight of <2500 grams or about 5.5 pounds at birth; LBW is a cause of infant mortality and thus is one of the leading indicators used worldwide to measure a country's health.

**Policy Development** Use of assessment data to develop local and state health and social welfare policies and to direct resources toward those policies.

**Population-Based Intervention** Focus is on health promotion/disease prevention in populations, rather than on the treatment of individuals.

**Prevention, Primary** Promote health, prevention of disease or trauma before it occurs.

**Prevention, Secondary** Early diagnosis and treatment of disease.

**Prevention, Tertiary** Action taken to minimize the effects of a disease and prevent further disability.

**Social Epidemiology** The study of the impact of social factors on the distribution of health and illness in a population.

**Title V of the Social Security Act of 1935** Provides for maternal and child health programs that are delivered by states through a block grant mechanism. Title V programs are administered by the Maternal and Child Health Bureau of the Health Services and Resources Administration [HRSA] of DHHS.

#### APPENDIX 4.2: DEFINITIONS

##### PUBLIC HEALTH SOCIAL WORKER

A Public health social worker is a graduate prepared social worker whose primary practice fulfills core public health functions within a public or private agency. While it includes all of the 10 essential public health functions, public health social work practice focuses on interventions to strengthen communities,

families, and individuals to promote health, well-being, and functioning, and minimize disability and institutionalization.

#### PUBLIC HEALTH SOCIAL WORK

The major characteristic of public health social work is an epidemiological approach to identifying social problems affecting the health status and social functioning of all population groups, with an emphasis on intervention at the primary prevention level. Public health social workers focus on the promotion of positive health behaviors in the development of lifestyles by individuals, families, and groups; enhancement of the environment; and avoidance of risks. They assess the health needs of the target population and determine the association between social factors and the incident of health problems. They plan and implement intervention strategies based on the five levels of prevention. They emphasize reducing the social stress associated with health problems, and determining the social supports that promote well-being and provide protection against ill health.

The practice of public health social work is usually conducted within the context of a multidisciplinary setting where social workers participate with other health and human service professionals in assuring that all persons in the target population have access to health care and social services. Public health social work is a blending of roles: provider of direct services, researcher, consultant, administrator, program planner, evaluator, and policymaker. Each function is dependent on the other in assuring the health and social needs of the total population.

#### PUBLIC HEALTH SOCIAL WORK PHILOSOPHY

Public health social workers address health from a broad perspective that include physical, social, emotional, and spiritual well-being throughout the continuum of the life cycle. They address health issues by identifying and implementing strategies/interventions that address pivotal times of transition from one phase of individual development to another. Public health social work assures the competency of its practice to address the issues of public health effectively through a core body of knowledge, philosophy, code of ethics, and standards.

Public health social work employs a range of strategies to implement essential public health functions in a measurable fashion as specified next:

1. Public health social work uses the principles of epidemiology to:
  - Assess and monitor social problems affecting the health status and social functioning of at-risk population within the context of family, community, and culture.
  - Identify and assess the factors associated with resiliency, strengths, and assets that promote optimal health.
  - Identify and assess the social factors contributing to health problems, health hazards, and stress associated with ill health.
  - Evaluate the effectiveness, accessibility, and quality of population-based and individual health interventions.

2. Public health social work uses social planning, community organization and development, and social marketing principles to:
  - Inform and educate the public, families, and individuals about public health issues.
  - Mobilize community collaboratives to identify, prioritize, and solve health and related social problems. These collaboratives should be comprised of key stakeholders and be as broad based as possible.
  - Empower individuals, families, and communities through capacity-building activities to become active participants in the identification of public health concerns, the creative resolution of these issues, and the advancement of individual, family, and societal well-being.
  - Promote and enforce legal requirements that protect the health and safety of communities, families, and individuals.
  - Assure public accountability for the well-being of all, and most especially, vulnerable populations.
  - Develop primary prevention strategies that promote the health and well-being of communities, families, and individuals.
  - Develop secondary and tertiary prevention strategies to alleviate health and related social concerns.
3. Public health social work provides leadership and advocacy to assure the:
  - Elimination of health and social disparities wherever they exist, such as, but not limited to, those based on community, race, age, gender, ethnicity, and culture.
  - Promotion of policy development for the provision of quality and comprehensive public health services within a cultural, community, and family context.
4. Public health social work supports and conducts research and evaluation that identifies:
  - The social and behavioral determinants of health status for populations and individuals.
  - The effectiveness of specific programs and interventions.
  - System barriers to accessing quality and comprehensive services.
  - Cultural-based interventions to best meet the needs of all populations and especially vulnerable and underserved populations.
  - “Best-practice” models of health-care programs and delivery systems.

#### APPENDIX 4.3: PUBLIC HEALTH SOCIAL WORK STANDARDS

These model standards of practice for public health social work were developed by the PHSW Standards Development Group, *Beyond 2010: The Future of Public Health Social Work*.

##### PROFESSIONAL STANDARD #1

Public health social work (PHSW) uses social epidemiology principles to assess and monitor social problems affecting the health status and social functioning of at-risk populations within the context of family, community, and culture.

*Public Health Social Work Performance Indicators*

- 1.1 PHSW assesses and monitors social problems affecting the health status and social functioning of at-risk populations within family, community, and culture contexts.
- 1.2 PHSW tracks health status and social functioning of the general population to monitor the progress of the at-risk population over time for:
  - Individuals and families at the direct-practice level.
  - Community programs and policy development.
- 1.3 PHSW assures that assessment and monitoring tools are based on social epidemiology principles.
- 1.4 PHSW assures that assessment and monitoring tools are developed through an interdisciplinary collaborative process with input from intra/interagency, community partners/consumers, and diverse populations.
- 1.5 PHSW assures that assessment and monitoring tools are relevant to the full continuum of physical and social well-being through all stages of the life cycle.
- 1.6 PHSW develops guidelines for sharing health status and social functioning data with community partners to facilitate optimal individual and societal well-being.

PROFESSIONAL STANDARD #2

PHSW uses social epidemiology principles to identify and assess the factors associated with resiliency, strengths, and assets that promote optimal health.

*Public Health Social Work Performance Indicators*

- 2.1 PHSW promotes an assets-based model for assessing physical and emotional health at the individual, family, and community levels.
- 2.2 PHSW seeks to identify factors which promote individual, family, and community resiliency. These factors are culturally based and supported by a broad range of community partners.
- 2.3 PHSW identifies protective factors for individuals, families, and communities.
- 2.4 PHSW develops creative tools to measure strengths and/or assets that promote and protect the health and well-being of individuals, families, and communities.
- 2.5 PHSW identifies and assesses factors that help individuals, families, and communities to change behaviors and environmental risk factors that trigger disease.
- 2.6 PHSW identifies factors that reduce the intensity of crises and enhance adaptation.

PROFESSIONAL STANDARD #3

PHSW uses social epidemiology principles to identify and assess the social factors contributing to health problems, health hazards, and stress associated with ill health.

*Public Health Social Work Performance Indicators*

- 3.1 PHSW develops measures to identify and assess the social factors contributing to health problems, health hazards, and stress.
- 3.2 PHSW identifies and assesses risk factors related to social conditions.
- 3.3 PHSW develops interventions that address the social factors related to mental and physical health, illness, and disability.
- 3.4 PHSW applies explanatory models to assist in identifying social factors that contribute to disease and emotional and social dysfunction.
- 3.5 PHSW identifies the relationships between poor housing, poor working conditions, and poverty, and high rates of infant mortality, tuberculosis and, behavioral and other health problems.
- 3.6 PHSW identifies and measures risk behaviors and lifestyle choices which contribute to poor social functioning and ill health.

PROFESSIONAL STANDARD #4

PHSW uses social epidemiology principles to evaluate the effectiveness, accessibility, and quality of individual, family, and population-based health interventions.

*Public Health Social Work Performance Indicators*

- 4.1 PHSW develops criteria for measuring program interventions and determining their effectiveness.
- 4.2 PHSW establishes outcome measures that analyze the effectiveness, accessibility, and quality of individual and population-based interventions.
- 4.3 PHSW develops tools that measure disruptive changes in physical and coping capacity, environmental resources, and health.
- 4.4 PHSW assures that qualitative and quantitative evaluation tools are developed to determine accessibility, quality, effectiveness, and cultural competency of individual, family, and population-based health interventions.
- 4.5 PHSW develops mechanisms to utilize evaluation results to enhance individual, family, and population-based health interventions, delivery, and quality.
- 4.6 PHSW develops tools that measure emotional and societal morbidity affecting access to and utilization of the public health system of care.

PROFESSIONAL STANDARD #5

PHSW uses social planning, community organization and development, and social marketing principles to inform and educate individuals, families, and communities about public health issues.

*Public Health Social Work Performance Indicators*

- 5.1 PHSW identifies public health issues relevant to individuals, families, and communities by:
  - Surveying individuals, families, and communities to determine baseline knowledge of public health issues.
  - Combining data and research with community priorities.

- 5.2 PHSW develops a range of community-based and creative strategies to deliver healthy lifestyle messages:
- Culturally relevant forums.
  - Media opportunities.
  - Printed materials for distribution in grocery, drugstores, and video stores, restaurants, and so on.
  - Community meetings.
  - Youth speak-outs.
  - Health fairs.
- 5.3 PHSW utilizes the resources of faith communities, and social and cultural groups to disseminate materials and speak on the value of public health by focusing on a public health problem facing that community.
- 5.4 PHSW develops public education messages that promote strategies of protection and resilience to enhance emotional, social, and physical well-being.
- 5.5 PHSW develops communication methods for individuals, families, and communities that make the information relevant and clear to all ages, cultural groups, educational levels, and abilities.
- 5.6 PHSW educates social service organizations about the relationships between health and social functioning from a public health perspective.
- 5.7 PHSW collaborates with a range of health and social service professionals and organizations to develop consistent health messages to inform and educate the public.
- 5.8 PHSW educates individuals, families, and communities about the relationship of social welfare, risk-taking behaviors, and poor health outcomes.
- 5.9 PHSW utilizes developmentally appropriate learning principles when developing public health messages.
- 5.10 PHSW develops strategies for promoting public health messages to specific populations such as those in prison, youth correctional or nursing facilities, homebound, or homeless.

#### PROFESSIONAL STANDARD #6

PHSW uses social planning, community organization and development, and social marketing principles to empower and mobilize individuals, families, and communities through capacity building activities to become active participants in identifying public health concerns, creatively resolving these issues, and advancing individual, family, and societal well-being.

#### *Public Health Social Work Performance Indicators*

- 6.1 PHSW develops a collaborative network of diverse stakeholders including traditional and nontraditional partners to identify, prioritize, and develop solutions for health and social problems. Disenfranchised and vulnerable populations must be active members and leaders of the effort.
- 6.2 PHSW mobilizes community collaboratives to identify, prioritize, and solve health and related social problems.
- 6.3 PHSW develops and validates methodologies for presenting options to diverse groups to assure that proposed strategies respect their values and priorities.

- 6.4 PHSW develops resources (financial and infrastructure) that support activities surrounding community collaborations.
- 6.5 PHSW conducts capacity building activities that provide individuals, families, and communities with the tools to creatively resolve public health issues.
- 6.6 PHSW develops group work and other methodologies that promote the acceptance of culturally relevant and respectful communication techniques to engage communities.
- 6.7 PHSW mentors the leadership ability of individuals, families, and communities to creatively resolve public health concerns.
- 6.8 PHSW helps individuals, families, and communities to identify their assets and liabilities and to develop solutions for their problems that preserve their cultural and family roots.
- 6.9 PHSW establishes communication strategies within the public health system that are responsive to community issues, priorities, and solutions. These strategies identify and remedy barriers that limit active participation of diverse consumers.
- 6.10 PHSW promotes an interdisciplinary planning model which integrates and enhances the medical model and traditional public health planning process to address the needs of vulnerable and diverse populations.

#### PROFESSIONAL STANDARD #7

PHSW uses social planning, community organization and development, and social marketing to promote and enforce legal requirements that protect the health and safety of individuals, families, and communities.

#### *Public Health Social Work Performance Indicators*

- 7.1 PHSW develops and promotes regulations that assure the health and safety of all, especially for vulnerable populations.
- 7.2 PHSW educates communities about legal rights and requirements, and how they impact their health and well-being.
- 7.3 PHSW promotes regulations that assures vulnerable and underserved populations have access to needed health and social services.
- 7.4 PHSW advocates for communities in identifying and abating environmental concerns affecting health.
- 7.5 PHSW provides leadership in enforcing and simplifying rules related to entitlements and services.
- 7.6 PHSW provides pertinent data to stakeholders to impact environmental regulations.

#### PROFESSIONAL STANDARD #8

PHSW uses social planning, community organization and development, and social marketing to assure public accountability for the well-being of all, with emphasis on vulnerable populations.



*Public Health Social Work Performance Indicators*

- 8.1 PHSW creates culturally diverse partnerships that delineate clear and responsible roles in assuring the well-being for all with the emphasis on vulnerable and underserved populations.
- 8.2 PHSW documents and responds to individual, family, and community complaints and concerns about the delivery and practice of health and related social services.
- 8.3 PHSW provides leadership in the dissemination of information about the effectiveness of public health and social interventions to policymakers, funders, and community groups.
- 8.4 PHSW assists communities in the development of a public health agenda that assures accountability for the well-being of all.

PROFESSIONAL STANDARD #9

PHSW uses social planning, community organization and development, and social marketing to develop primary prevention strategies that promote the health and well-being of individuals, families, and communities.

*Public Health Social Work Performance Indicators*

- 9.1 PHSW promotes a wide range of primary prevention strategies, both traditional and nontraditional, which are relevant across the life cycle and to diverse populations.
- 9.2 PHSW includes a broad range of stakeholders in developing primary prevention interventions to promote optimal health (e.g., spiritual, emotional, psychological, bio-physical, and social).
- 9.3 PHSW develops common and consistent messages utilizing interdisciplinary teams and collaborative groups to promote healthy and culturally relevant lifestyles.
- 9.4 PHSW assures that primary prevention strategies address root causes of the essential elements of health and well-being from a cultural perspective.

PROFESSIONAL STANDARD #10

PHSW uses social planning, community organization and development, and social marketing to develop secondary and tertiary prevention strategies to alleviate health and related social and economic concerns.

*Public Health Social Work Performance Indicators*

- 10.1 PHSW utilizes traditional, nontraditional, and culturally relevant methods to develop secondary and tertiary prevention intervention techniques.
- 10.2 PHSW engages a broad range of stakeholders, including family members, in developing secondary and tertiary prevention interventions to promote optimal health and the remediation of poor health outcomes (e.g., spiritual, emotional, psychological bio-physical, and social).

- 10.3 PHSW develops common, consistent, and culturally competent screening and assessment methods for early identification of behaviors and risk factors which contribute to poor health outcomes.
- 10.4 PHSW assures that secondary prevention strategies address root causes of poor health outcomes beyond the presenting signs and symptoms.
- 10.5 PHSW promotes a range of secondary and tertiary prevention strategies, which are relevant to diverse populations throughout the life cycle.
- 10.6 PHSW develops culturally relevant strategies to enhance quality of life of individuals and families living with a chronic or terminal disease.
- 10.7 PHSW assures that tertiary preventions are individualized through the use of family centered, community based, integrated, and coordinated care.

PROFESSIONAL STANDARD #11

PHSW provides leadership and advocacy to assure the elimination of health and social disparities wherever they exist, such as, but not limited to, those based on community, race, age, gender, ethnicity, culture, or disability.

*Public Health Social Work Performance Indicators*

- 11.1 PHSW provides leadership in presenting research and data in a manner which documents health and social disparities clearly and understandably.
- 11.2 PHSW advocates for a broad range of strategies with diverse stakeholders to eliminate health and social disparity at the local, state, and national levels.
- 11.3 PHSW works with vulnerable communities to promote coordinated and integrated interventions for the reduction and elimination of health and social disparities.
- 11.4 PHSW provides leadership to inform policymakers of the economic, environmental, and social factors impacting health and social disparities.
- 11.5 PHSW develops, in conjunction with other social and public health disciplines, methods to document health and social disparities.
- 11.6 PHSW advocates for legislation and policies that promote eliminating health and social disparities.
- 11.7 PHSW advocates for eliminating categorical funding streams in order to reduce barriers to service provision, and to better address the magnitude of health and social disparities wherever they exist.

PROFESSIONAL STANDARD #12

PHSW provides leadership and advocacy to assure and promote policy development for providing quality and comprehensive public health services within a cultural, community, and family context.

*Public Health Social Work Performance Indicators*

- 12.1 PHSW develops and promotes public health and social policy that assures the health and safety of all, especially for vulnerable populations.
- 12.2 PHSW develops public health and social policy which assures that vulnerable and underserved populations have access to needed health and social services.

- 12.3 PHSW provides leadership in developing and simplifying rules related to entitlements and services.
- 12.4 PHSW collaborates with social service organizations, educational institutions, and related health professional organizations to support policy development and legislative action that promotes the optimal health of a community.
- 12.5 PHSW develops and maintains mechanisms that promote open dialogue between policymakers and the community.
- 12.6 PHSW develops public health and social policy to assure provision of quality services, which are responsive to individual, family, community, and cultural needs.
- 12.7 PHSW develops public health and social policies which promote integrating and coordinating services across health and social service programs.

PROFESSIONAL STANDARD #13

PHSW supports and conducts data collection, research, and evaluation.

*Public Health Social Work Performance Indicators*

- 13.1 PHSW develops and utilizes culturally appropriate data collection systems to identify social and behavioral determinants of health status for individuals and populations.
- 13.2 PHSW contributes to the development and utilization of culturally appropriate qualitative and quantitative evaluation methods to assess the effectiveness of specific programs and interventions with emphasis on the needs of vulnerable populations.
- 13.3 PHSW contributes to the development and utilization of methodologies to document system barriers which affect the quality and comprehensiveness of services.
- 13.4 PHSW conducts or participates in interdisciplinary public health research which promotes the replication and institutionalization of best practice models.
- 13.5 PHSW conducts surveys that measure client satisfaction for on-going quality improvement.
- 13.6 PHSW develops measures of emotional and societal factors which affect health status and access to public health.
- 13.7 PHSW develops results-oriented methodologies for the continuous improvement of the public health service system.

PROFESSIONAL STANDARD #14

PHSW assures the competency of its practice to address the issues of public health effectively through a core body of social work knowledge, philosophy, code of ethics, and standards.

*Public Health Social Work Performance Indicators*

- 14.1 PHSW incorporates standards of care from a range of social work and health organizations.
- 14.2 PHSW adheres to the National Association of Social Workers Code of Ethics and the American Public Health Association Creed.

- 14.3 PHSW practices its profession in accordance with state licensure and/or regulations.
- 14.4 PHSW collaborates with schools of social work and public health to incorporate the core body of knowledge and principles of public health social work.
- 14.5 PHSW advocates for including public health social work in publicly and privately funded training programs, such as those through Health Resource Services Administration, CDC, and the Robert Wood Johnson Foundation.
- 14.6 PHSW develops professional competencies that enhance the skill base of public health social work.
- 14.7 PHSW conducts periodic workforce analyses and studies about public health social work changing roles.
- 14.8 PHSW conducts periodic surveys to identify ongoing continuing education needs.
- 14.9 PHSW advocate for the hiring of appropriate personnel with the expertise to address the economic, environmental, and social factors which impact health status.
- 14.10 PHSW develops guidelines and protocols, and provides consultation for training in public health social work methodologies in public health agencies.
- 14.11 PHSW interprets the roles and concepts of public health social work practice to other health and social service disciplines.
- 14.12 PHSW promotes the social work philosophy of public health being broad based which encompasses but not limited to the physical, social, emotional, and spiritual well-being of individuals, families, and communities throughout the continuum of the life cycle.

#### APPENDIX 4.4: PUBLIC HEALTH SOCIAL WORKERS' CORE COMPETENCIES

##### THEORETICAL BASE

Public health social work will demonstrate knowledge and understanding of:

- The principles of social epidemiology
- The principles and theories of population-based health promotion and empowerment
- The normal patterns of individual and family growth and development from an intergenerational and life span perspective
- The impact of economic, environmental and social issues for at-risk populations
- The impact of protective or risk factors, for example, gender, racism, ageism, classism, sexual orientation, sexual identity, disability, or religious basis on the health and well-being of individuals, families, and communities
- The theories and principles of community organization, planned change, and development
- The characteristics of health systems, including the dimensions of, use of, and access to health care

- Knowledge of macrolevel methods on the promotion and enforcement of regulations (policies and legislation) formulated to protect the health and safety of at-risk populations in social work practice

Public health social work should demonstrate the following skills:

- Apply macrolevel methods, for example, social planning, community organization/development, and social marketing, employed in public health social work practice.
- Apply knowledge of demographic, health, familial, sociocultural, and environmental and community factors to design public health programs and services.
- Critically analyze inequities in health status based on race/ethnicity, socioeconomic position, and gender.
- Recognize different strengths, needs, values, and practices of diverse cultural, racial, ethnic, and socioeconomic groups and determine how these factors affect health status, health behaviors, and program design.
- Apply primary and secondary strategies to address the health, social, and economic issues of individuals, families, and communities.
- Apply development, practice, and epidemiologic theories to substantiate interventions and program development designed to promote health behavioral change.

#### METHODOLOGICAL AND ANALYTICAL SKILLS

Public health social workers will demonstrate knowledge and understanding of:

- Research design, sampling, basic descriptive and inferential statistics, and validity/reliability assessment of measures
- Epidemiological/socioepidemiological concepts and descriptive epidemiology/socioepidemiological
- The use of data to illuminate ethical, political, scientific, economic, social, and overall public health issues
- Principles and key features of community needs assessment, program design, implementation, and evaluations

Public health social workers should demonstrate the following skills:

- Prepare and interpret data from vital statistics, censuses, surveys, service utilization, and other relevant reports on social and health status, especially for vulnerable populations
- The ability to detect meaningful inferences from data and to translate data into information for community assessment (gaps, barriers, and strengths analysis), program planning, implementation, and evaluation
- Formulate hypotheses or research questions and, in collaboration with internal or external resources, develop and implement an analytical strategy to influence health and social planned change

#### LEADERSHIP AND COMMUNICATION SKILLS

Public health social workers will demonstrate knowledge and understanding of:

- Theories and practices of organizational culture and change
- Theories of leadership and communication practices for diverse internal and external groups
- The application of inter-organizational theories including grantsmanship, contractual agreements and linkages and the use of principles of systems development, management, and analysis
- Appropriate use of networking, inter/multidisciplinary team building, and group work processes
- The theories of social change, advocacy, negotiation, and conflict resolution
- The techniques of social work community organization and coalition building to address the issues of social and health disparities
- Techniques for soliciting and maintaining consumer and other constituency involvement at all levels of an organization
- Strategic planning, organizational development, performance and outcome measures, and program evaluation activities

Public health social workers should demonstrate the following skills:

- The ability to vision and motivate staff to actualize the mission, goals, and objectives of their organization (public health)
- The ability to commit to individuals, families, and communities, and the diverse cultural values they hold
- The ability to operationalize best-practice prevention and intervention strategies to eliminate social inequity and health disparities
- The capacity to build on the strengths and assets of individuals, families, and communities to develop innovative and creative solutions to social and health issues
- Apply knowledge of management and organizational theories and practices to the development, planning, budgeting, staffing, administration, and evaluation of public health programs, including the implementation of strategies promoting integrated service systems, especially for vulnerable populations
- Develop mechanism to monitor and evaluate programs and service networks for their effectiveness and quality, including the use of performance and outcome measures
- Develop, implement, monitor, and evaluate grant-funded programs
- Effective written and oral communication skills, including accurate and effective preparation and presentation of reports to stakeholders, for example, agency boards, administrative organization, policymakers, consumers, and/or the media using demographic, statistical, programmatic, and scientific information
- The ability to communicate effectively with diverse and multicultural organizations, community/consumer boards, and coalitions
- Develop strategies to assure integrated service systems for populations at risk for health and social issues

#### POLICY AND ADVOCACY SKILLS

Public health social workers will demonstrate knowledge and understanding of:

- Federal and state mandates that guide the funding and implementation of health and social services programs
- Knowledge and synthesis of contemporary and alternative health and social policies
- Knowledge of the legislative, administrative, and judicial processes at the national and local levels
- The historical development and scientific basis of public health and social policies and practices for federal, state, and local agencies

Public health social workers should demonstrate the following skills:

- Apply critical thinking to every stage of policy development and practice
- Identify essential gaps in the delivery system of health and social services
- Identify public health laws, regulations, and policies related to specific programs
- Collect and summarize data relevant to a particular policy/problem; articulate the health, fiscal, administrative, legal, social, and political implications of each social policy option
- Coalition building and agenda settings to address the gaps in the system of social and health care
- State the feasibility and expected outcomes of and barriers to achieving each policy option and decide on the appropriate course of action
- Write a clear and concise policy statement, position paper, and/or testimony appropriate for a specific audience
- Develop a plan to implement a policy, including goals, outcomes, and process objectives, implementation steps, and evaluation plan
- Translate policy into organizational plans, structure, and programs

#### VALUES AND ETHICS

Public health social workers will demonstrate knowledge and understanding of:

- The philosophy, values, and social justice concepts associated with public health and social work practices
- Knowledge of the National Association of Social Work's Code of Ethics and the American Public Health Association Creed
- The philosophical concepts and rationals underlying the delivery of family centered, comprehensive, integrated, community-based, and culturally competent public health and social services and programs, including the recognition of family and community assets
- The principles and issues involved in the ethical and sensitive conduct of practice and research especially with vulnerable populations, and in the organization and delivery of public health services within communities and governmental agencies; including the ethical and confidential collection of data and its management, analysis, and dissemination
- Knowledge of state licensure and/or regulations

Public health social workers should demonstrate the following skills:

- Application and integration of professional values and principles of ethics within community and organizational practice settings



- Ethical conduct in program management, research, and data collection and storage
- Promotion of cultural competence concepts within public health settings
- Build partnerships with public health and social services communities and constituencies to foster community empowerment, reciprocal learning, and involvement in design, implementation, and research aspects of public health and social systems
- Identify and apply social work standards and principles in the resolution of ethical dilemmas

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## CHAPTER 5

# Health Policy and Social Work

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**S**Ocial workers serve in numerous roles that require expertise in health policy issues. As practitioners in various settings, social workers assist clients in obtaining and navigating federal and state health programs with complex eligibility rules and application procedures, directly provide publicly supported health services, and disseminate information to individuals and groups about numerous aspects of health care. As advocates for poor, disadvantaged, and disenfranchised individuals and families, social workers act to influence health policies and legislation that enhance the welfare of at-risk and vulnerable populations and improve existing health-care delivery systems. As policymakers working in local, state, or federal agencies, social workers formulate health policies and administer health programs.

This chapter provides an overall framework for understanding health policy that is essential to successful direct practice, advocacy, and policymaking. The framework includes exposure to the key overall concerns of health policy—access, costs, quality, and accountability—as well as an introduction to the key organizational, finance, and payment structures in health care. We then provide an introduction to the structure and key issues in Medicare and Medicaid, the two main public programs for social work. Due to space considerations, we focus only on federal health policy actions. For readers who are interested in state health policy issues, we suggest some resources that are listed at the end of this chapter. With this background, we review the history of health reform and the key alternatives going forward. Finally, the chapter raises a set of policy issues and provides a number of key resources for ongoing involvement for social workers interested in understanding and influencing health policy.

### CHAPTER OBJECTIVES

- Introduce the organization, financing, and payment structures of the health-care system.
- Describe the key components of Medicare and Medicaid.



- Describe the major recent developments in federal health-care policy.
- Discuss recent and historical efforts to reform the health system.
- Identify key emerging health policy issues.

### A FRAMEWORK FOR UNDERSTANDING HEALTH POLICY

Although the U.S. health-care system represents one of the largest economies in the world in its own right, health policy exists in a context of relative scarcity of resources. This is evident in much of the public debate: despite spending \$1.5 trillion on health services, a truism in public discourse is that we are not “spending enough” on mental health, research, Medicaid nursing home reimbursement, or other worthy causes. Because medical knowledge and technology are constantly producing fantastic new possibilities for intervention and treatment, the overarching challenge of health policy is to allocate resources toward care that is effective and cost worthy.

In this environment of tremendous spending and resource scarcity, clinicians, managers, and policymakers face four general problems of health policy: access, cost containment, quality, and accountability.

Access refers to the “actual use of personal health services and everything that facilitates or impedes their use” (Andersen & Davidson, 2001, p. 3). Measures of access provide signals of the fairness or social justice of health systems, provide indicators of its efficiency or effectiveness, and provide important sign posts for policy attention.

Costs of health care represent the opportunities foregone in the national economy as a result of devoting resources to health care. Resources allocated to health services mean that they are not available for their best alternative use, whether that consists of wages and salary, investments in things such as education or plant and equipment, or for other forms of consumption. The problem of cost containment is endemic in health care. The preoccupation of employers who share in the costs of insurance, governments who finance public programs, and individuals who bear significant out-of-pocket costs for medical expenses such as prescription drug coverage.

Quality of health care can refer to structural, process, or outcome dimensions of health-care delivery. Structural dimensions of health-care quality include the facilities, technology, workforce, and other observable “inputs” into care. In the early history of accreditation of health-care organizations, for example, surveyors focused on life safety and hygienic aspects of providers as the most salient measures of quality. As health-care organizations became more sophisticated and standardized, quality improvement focused on processes of care and more recently on outcomes (Lawlor & Raube, 1995).

Accountability of health care refers to the assurance that health care is clinically effective, prudently delivered, and is serving the best interests of patients and payers. Examples of accountability measures in health policy include recent efforts to provide a patients’ bill of rights, the administrative efforts to reduce fraud and abuse, and the legal efforts to reform medical malpractice litigation.

Virtually all policy endeavors can be understood as responding to access, cost, quality, or accountability concerns in health care. Efforts to change insurance coverage are largely motivated by access concerns; efforts to increase the cost sharing (such as co-payments and deductibles) are driven by cost containment

concerns; efforts to reduce medical errors in hospitals are a form of quality initiative; and legislation to reform medical malpractice is a form of accountability change in the health system.

## HEALTH SERVICES ORGANIZATION

The American approach to health-care delivery is an especially complicated mixture of public, nonprofit, and for-profit entities. To conceptualize all of the moving parts, it is helpful to separate out the organizations, finance and payment, and regulatory components of the system. In its organization, the health-care system is a complicated web of government, nonprofit, and for-profit organizations that interact in a mix of public and private relationships.

Government is responsible for a significant portion of health-care finance (appropriating and distributing money, primarily through taxes, that goes into the system); regulating access, cost, and quality; as well as actually *producing* health services in hospitals, clinics, prisons, and other settings.

The nonprofit sector in health care is extremely varied and includes organizations such as BlueCross BlueShield; academic centers who carry out the training of physicians, nurses, social workers, and other personnel; foundations who fund research and health services; and nonprofit hospitals and clinics; and tasks such as research and provision of care.

The for-profit (otherwise known as the proprietary or investor-owned) sector has varying emphasis in the system, depending on the industry or sector. The pharmaceutical industry is almost entirely for-profit, the nursing home industry is roughly 66 percent for-profit, and the hospital industry is only 14% for-profit.

To understand health-care politics and policy, it is important to recognize that, taken together, these sectors add up to a large industry: from pharmaceutical manufacturers, to suppliers of medical devices and durable goods, to architects, to ambulances, to consultants, and social workers. All of these actors are both politically and economically invested in health policy. Social workers need to appreciate that in addition to access and quality of clinical care that is the usual priority of professionals working in the system, health care is a political economy in its own right with all of the power and vested interests that aggregate up to a \$1.5 trillion industry. This power has been most visibly on display when reform is proposed, especially when interests such as the pharmaceutical industry, the insurance industry, or hospitals see their control and markets being threatened.

## FINANCE AND PAYMENT

Social workers, whether in clinical, policy, management, or advocacy roles, need to understand the relationship of finance, payment systems, providers, and actual provision of health services.

Table 5.1 illustrates the basic elements of this framework for understanding the flow of dollars through the health system. Financing arrangements gather up dollars, whether through taxes in the public sector or premiums for insurance in the private sector. These dollars are then paid out in various payment systems that carry their own incentives for cost savings, preventative care, or other policy goals. For example, Diagnosis Related Groups (DRGs) are the payment methodology that

**Table 5.1**  
Examples of Finance, Payment, Provider, and Service Relationships

Finance	Payment Systems	Providers	Service
Payroll tax	DRGs	Hospitals	All inpatient expenses
Employer/employee premiums	Capitation	Managed care organization	All covered health services, including prescription drugs
Federal and state (Medicaid) tax revenues	Fee for service	Physicians	Office visits
Out-of-pocket expenditures	Fee for service	Dentist	Procedure

Medicare uses to reimburse hospitals for inpatient care. In payment systems, the dollars typically flow to particular *provider types*, whether they be ambulances, physicians, hospitals, HMOs, or any of the hundreds of other provider types. Finally, payments that go to particular providers are calibrated for each individual *service*. For example, physicians are often paid on the basis of a fee schedule that sets the specific amount to be paid based on cost, risk, or other criteria for payment.

*Finance* Health services are financed via a complicated patchwork of out-of-pocket expenditures, employer and employee payments to insurers and other private intermediaries, and tax revenues that flow to public programs and public providers such as the Veterans Administration or county public hospitals.

Tax revenues flow into the health-care system through a number of routes. The most important sources of public funds for health service are payroll tax contributions and general revenue receipts for Medicare. Payroll tax contributions are deposited in a Part A Trust Fund for Hospital Insurance. General revenue contributions are combined with premiums (75% general revenues, 25% Part B premiums) to finance physicians' services, home health, and other nonhospital expenses in Medicare. A combination of federal and state tax revenues finance Medicaid. The exact contribution of federal and state sources varies from state to state depending on a formula, but averages about 50/50.

The federal government finances a variety of other health services and programs through appropriations in the federal budget: for example, Veterans services, payments to Federally Qualified Health Centers (under the Health Resources and Services Administration), HIV and AIDS services (under the Centers for Disease Control and Prevention), and Indian Health Services (under the Bureau of Indian Affairs). States fund a variety of health programs and providers as well as provide a significant amount of direct health services through state hospitals, state schools, and departments of correction. Cities and counties are responsible for funding a variety of health services ranging from school health to public hospitals and clinics.

A considerable amount of health care is provided without obvious sources of payment, either as charity care (provided as in-kind services or by writing off bad debt). The most interesting form of unfunded health care is free care provided by individual providers, such as physicians who provide care in their offices without

payment or organizations such as free clinics. This care, officially known as uncompensated or charity care, is a significant though often unaccounted for component of the health system. Particularly for some providers, such as inner-city teaching hospitals, charity care can be a significant proportion of overall care, and must be supported by subsidies or other care, fund-raising, or other sources.

Monies that are paid by employers and employees to health insurance plans, usually in the form of premiums for health coverage, account for about 36% of all health-care revenues. Indeed, 60% of Americans receive health insurance through their employers (DeNavas-Walt, Proctor, & Mills, 2004). Employees are charged amounts that may reflect characteristics of their group—either their demographics or their cost and experience in using health services—the generosity of coverage, and the degree to which their employer wishes to distribute the burden differently among higher or lower compensated employees. Thus, the premiums that individuals pay for health insurance coverage vary widely across firms, occupations, and geography. Small firms with an expensive record of health-care costs and little ability or desire to subsidize coverage can face prohibitively high costs of coverage for workers.

Out-of-pocket expenditures are usually given to providers in the form of co-payments or deductibles. Co-payments require individuals to share in the costs of a service, such as a physician visit or a prescription drug order, in order to make the user sensitive to the price or cost of that service. Deductibles also create a kind of price-sensitivity to the use of health services and typically apply to the first dollars of service use, such as the first day or days of a hospitalization. A large body of economic research, most notably the RAND Health Insurance Experiments, documents the reductions in the costs and use of care when patients are charged even small co-payments or deductibles (Newhouse & the Insurance Experiment Group, 1993).

These kinds of financial disincentives to use health services can discourage needed or appropriate care. The rise of “consumer-directed health care” has been accompanied by an increase in the use of co-payments, deductibles, limits, and other features of health insurance coverage that are designed to reduce costs and force patients to be prudent users of services. At the extreme, new plan types known as Medical Savings Accounts (MSAs) combine high deductibles, catastrophic coverage, and favorable tax treatment to encourage consumers to make very calculated choices about their use of medical resources. Because consumers get to keep and roll over any savings that may accrue when they do not spend out-of-pocket dollars for health services, policymakers believe they will be much more careful and prudent about decisions to use resources. Critics of the MSAs worry that relatively healthy enrollees will select into these plans, leaving other insurance pools with sicker and more costly enrollees and, ultimately, much higher premiums.

*Payment* In general, payment systems can be designed as prospective or retrospective, cost-based or risk-based. A prospective payment system establishes the amount to be paid in advance, leaving the provider to assume the financial risk if a patient costs more than the predetermined amount. A cost-based system attempts to reimburse providers for the actual resource use in an episode of care. The disadvantage of these systems is that they fail to provide incentives for providers to be efficient; in an early era, cost-based systems such as in Medicare

came to be known as “blank check Medicare.” Risk-based systems push the costs (or risks) of health services back to providers, and this gives powerful incentives to be efficient.

The most famous prospective payment system, and the one most consequential for social workers, was the Medicare Prospective Payment System (PPS), originally introduced in 1983. The unit of payment for the Medicare PPS was the diagnosis-related group, defined by the ICD-9 codes applied to the patient’s condition or diagnosis at discharge. Hospitals were paid a fixed, prospectively determined amount based on the resource intensity of a particular diagnosis. This fixed prospective payment is a powerful example of a risk-based system. For example, a hip fracture would be classified into a particular DRG category, “DRG 210 hip and femur procedure except major joint, without comorbidities or complications.” The hospital would be paid a fixed amount based on the DRG weight for that case, which has a mean length of stay of 4.5 days.

In general, if the hospital treated the patient quickly and at low cost, it could retain the margin it earned on this episode of care; if the patient had a long and costly hospital stay, the hospital could lose considerable money on that particular patient. The theory of this payment system is that, with large numbers of patients, the winners and losers would net out, resulting in a small operating margin for the hospital. The incentives in this system were for hospitals to treat patients quickly and efficiently.

For social workers, the introduction of PPS resulted in a tremendous emphasis on discharge planning because quick and effective discharge was the key to reduced lengths of stay, especially reductions in what hospital managers termed “administratively necessary days,” the time it took to find an appropriate subacute setting, such as a skilled nursing facility to provide the next episode of care for the patient. Because of the economic importance of discharge planning, hospital social workers were diverted into this activity up to the point where it became the dominant task and even a professional identity for hospital social workers. In many hospitals, hospital social workers became discharge planners.

Prospective payment systems can take many forms. Typically, managed care organizations pay providers for taking care of persons for a year-long term (thus the expression, per person per year), for bundles or packages of services (such as for a package of cardiac care services: preoperative, surgical, postoperative), or for treating certain diagnoses.

Retrospective payment systems, as the term suggests, pays for services after they have been delivered either on the basis of costs or on the basis of a fee schedule. The principal difference with prospective systems is that the risk for more or less costly cases is shifted away from the provider. Up until the mid-1980s, the widespread use of retrospective cost-based payment systems, sometimes referred to as “blank check medicine,” was implicated in rapidly increasing health-care costs. Providers had no incentives to limit costs; rather, the more costly services they provided, the more they were paid.

Managed care organizations typically rely on versions of risk-based payment systems that force the insurer or provider to assume some degree of financial risk or responsibility for the costs of covering enrollees. HMOs were based on a model of prepaid health care, known as *capitation*, in which plans were paid a single payment per person per year (known as a capitation payment) irrespective of the illnesses or cost experience of that individual en-

rollee. The theory of these payments was that through the laws of large numbers, variations in the costs of illness experience of enrollees would smooth out, and if the capitation payment was close to the average costs of covering this population, the managed care provider would have a strong incentive to control costs. Critics of these models charged that HMOs engaged in selection behavior, picking off the healthiest enrollees for their plans, or engaged in treatment practices that restricted needed services or disadvantaged vulnerable patients.

As experience with and criticism of particular payment systems build, inevitably there are movements to refine and improve payment systems. Examples of refinement would include the adoption of so-called partial capitation models (that attempt to blend fairness with the incentive effects of capitation), the extension of outlier payments in DRGs (to take account of extremely costly cases), or the application of sophisticated payment models to new provider types (such as the adoption of prospective payment in long-term specialty hospitals). As these payment systems become more fine-tuned, the overall complexity of the system escalates.

#### KEY FEDERAL HEALTH PROGRAMS: MEDICARE AND MEDICAID

Social workers in the field of health care undoubtedly will encounter Medicare and Medicaid, two federal health insurance programs enacted into law in 1965. Together, Medicare and Medicaid cover one in four Americans or more than 80 million beneficiaries. Medicare, Medicaid, and State Children's Health Insurance Program (SCHIP) account for one-third of national health spending (Centers for Medicare and Medicaid Services, 2005).

In an era of increasingly complex and changing rules in federal health programs, knowledge about federal health policies and expertise in eligibility have become requisite skills for social workers to effectively connect clients with available resources and advocate for improvements in the programs. Social workers are poised to help clients overcome persistent barriers to coverage that result from lack of knowledge or misinformation about public health programs.

#### MEDICARE

Medicare is a federal health insurance program that covers more than 41 million persons, of whom 35 million are persons age 65 and older and 6 million are persons under age 65 with disabilities (Henry J. Kaiser Family Foundation, 2004). Medicare's history is rich and consequential—eligibility, payment systems, public support, and the model of acute care delivery that guides most of Medicare's coverage are the products of overt political choices over its history (Lawlor, 2003). Medicare has four parts: A, B, C, and D.

Part A covers inpatient hospital, skilled nursing facility, hospice, and some home health-care services. People who are eligible to receive Social Security payments receive Part A automatically when they reach age 65. It is financed primarily by a mandatory payroll tax paid by employees and employers. Beneficiaries admitted to a hospital pay a \$912 deductible in 2005 for the first 60 days; thereafter, beneficiaries pay additional amounts per day for an inpatient stay.



Part B covers services offered by physicians and other providers (including clinical social workers); outpatient hospital services; some home health care; laboratory tests, x-rays, and other radiology services; physical and occupational therapy and speech pathology services; and medical equipment and supplies for home use. Part B is voluntary, although 93% of persons eligible for Part A elect Part B coverage (Centers for Medicare and Medicaid Services 2004h). Part B is financed by beneficiary premiums, which are set by law at 25% of the cost of Part B benefits, and general revenues (75%) from the U.S. Treasury. In 2005, the monthly premium was \$78.20 (U.S. Department of Health and Human Services, 2004). Beneficiaries also are required to meet an annual Part B deductible (\$110 in 2005) and pay 20% coinsurance for most Part B services.

Added as part of the Balanced Budget Act of 1997, Part C (originally called Medicare+Choice and renamed Medicare Advantage) provides beneficiaries the option to enroll in managed care plans. Only five million beneficiaries (12.6%) were enrolled in Medicare Advantage health plans in 2004, despite 3 decades of effort and expectations that the Medicare enrollment in managed care would increase (Centers for Medicare and Medicaid Services, 2004e; Lawlor, 2003).

Added under the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Part D provides a prescription drug benefit, beginning in 2006. Part D will be financed jointly by a beneficiary premium (25.5%) and general revenues (74.5%) from the U.S. Treasury (Henry J. Kaiser Family Foundation, 2004).

Although most Medicare beneficiaries are elderly, Medicare does not pay for the cost of long-term care. Medicaid, discussed next, is the major public program that pays for long-term care in a nursing home.

## MEDICAID

Medicaid is a means-tested health insurance entitlement program financed jointly by the federal government and the states. Medicaid covers more than 50 million persons, of whom 38 million are low-income persons and 12 million are elderly and disabled persons.

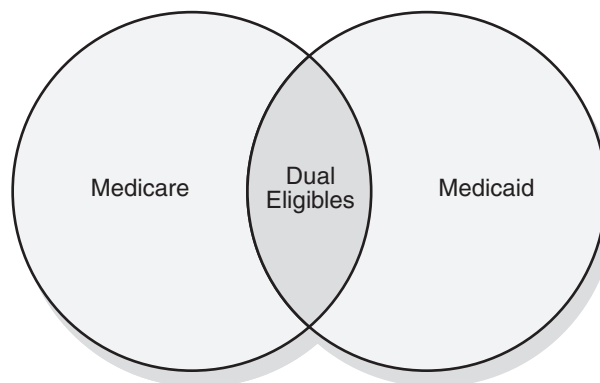
Within broad federal guidelines, states establish their own eligibility criteria, determine the scope of covered services, establish payment rates, and administer the program. Consequently, the Medicaid program varies widely across states. Federal Medicaid law requires that states cover individuals who fall within certain categories, including persons who meet the requirements of the Aid to Families with Dependent Children (AFDC). Although the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) replaced the open-ended entitlement to cash assistance, AFDC, with time-limited Temporary Assistance for Needy Families (TANF), states are not required to provide Medicaid coverage to TANF recipients. Only persons who would have been eligible for AFDC under the AFDC requirements in effect on July 16, 1996, are guaranteed Medicaid coverage; pregnant women and children under age 6 with family income at or below 133% of the federal poverty level; children under age 19 who are born on or after September 30, 1983, and have family income at or below the federal poverty level; Supplemental Security Income (SSI) recipients in most states; recipients of adoption or foster care assistance under Title IV; and certain low-income Medicare beneficiaries. States have the option to extend coverage to groups beyond federal minimum standards.



Federal Medicaid law also requires that states provide certain basic services, including inpatient and outpatient hospital services, physician, midwife, and nurse practitioner services; family planning services and supplies, prenatal care, vaccines for children, early and periodic screening, diagnosis and treatment (EPSDT) for children under age 21, laboratory and x-ray services, rural health clinic services, federally qualified health center services, home health care, and nursing home care. States have the option to expand the scope of services to provide certain optional services, such as prescription drugs, transportation services, optometrist services and eyeglasses, prosthetic devices, home and community-based care, and rehabilitation and physical therapy services.

Medicaid expenditures are spent disproportionately on elderly and disabled persons. While the elderly and disabled comprised 25% of the beneficiaries in 2002, they consumed 70% of Medicaid spending. Moreover, more than 40% of all Medicaid spending is attributable to persons who receive both Medicare and Medicaid; they are known as “dual eligibles” (see Figure 5.1; Kaiser Commission on Medicaid and the Uninsured, 2004). Dual eligibles may receive full Medicaid benefits plus assistance with Medicare cost sharing or may receive only assistance with paying Medicare premium and co-payments. Dual eligibles are arguably among the most vulnerable Medicare beneficiaries because they are poorer and sicker and more likely to be members of a minority group than other Medicare beneficiaries. They experience higher rates of chronic disease, are more likely to suffer from mental disorders and Alzheimer’s disease, are more likely to receive assistance with activities of daily living or instrumental activities of daily living and are more likely to be unable to walk without assistance than other Medicare beneficiaries (Kasper, Elias, & Lyons, 2004). Because of their multiple, complex needs, dual eligibles require services and supports that often fall outside Medicare’s scope of services.

Medicare beneficiaries who are dually eligible for Medicaid often do not know about Medicaid or do not think they are eligible for it. It is estimated that between 41.5% and 47.9% of Medicare beneficiaries who are eligible for payment of cost-sharing expenses under the so-called “Medicare buy-in” program are not receiving assistance (Families USA Foundation, 1998). Social workers who advise clients about available programs can play a crucial role in remedying this problem



**Figure 5.1** Medicare/Medicaid

(Ozminkowski, Aizer, & Smith, 1997). Medicare beneficiaries with incomes at or below the federal poverty level are eligible to receive assistance with cost sharing (i.e., Medicare premiums, deductibles, and co-payments). Furthermore, Medicare beneficiaries with incomes between 100% and 120% of the federal poverty level are eligible to receive assistance with their Medicare Part B premiums only. Medicare beneficiaries with incomes between 120% and 135% of the federal poverty level are eligible to apply for full payment of their Medicare Part B premium and beneficiaries with incomes between 135% and 175% of the federal poverty level are eligible to apply for partial payment of their Medicare Part B premium through a block grant program; unlike low-income Medicare beneficiaries with incomes at or below 120% of the federal poverty level, the Block Grant has limited funds and serves beneficiaries on a first-come, first-served basis. All four programs impose asset limits (excluding home and one car and some other items) of \$4,000 for individuals and \$6,000 for couples (Centers for Medicare and Medicaid Services 2004c). By informing clients about the Medicare buy-in options, social workers can help their eligible Medicare clients save thousands of dollars per year.

Social workers also routinely work with populations who are ineligible for public programs. Notably, because Medicaid relies on categorical eligibility, nearly half of the poor do not qualify for Medicaid. Ineligible populations include nondisabled adults without children and poor parents in states with eligibility below the federal poverty level. Neither Medicare nor Medicaid pays for health services received by undocumented immigrants, except Medicaid covers labor and delivery. Moreover, legal immigrants' access to Medicaid was restricted as a result of changes adopted in the PRWORA. Before PRWORA, Medicaid eligibility was the same for citizens and noncitizens. PRWORA imposed a 5-year ban on Medicaid eligibility for new legal immigrants entering the United States after August 1996. Furthermore, PRWORA required the counting of an immigrant's sponsors' income in determining an immigrant's eligibility for Medicaid, effectively excluding many immigrants from Medicaid (Kaiser Commission on Medicaid and the Uninsured, 2003). Numerous studies (Capps et al., 2002; Fix & Zimmerman, 1998; Maloy, Darnell, Kenney, & Cyprien, 2000) have cited fear of deportation and confusion about eligibility as barriers to enrollment of eligible immigrants into Medicaid. Social workers can assess their noncitizen clients' eligibility for Medicaid and encourage those who are eligible to enroll in the program.

The major developments in Medicare and Medicaid of the past decade include the decoupling of Medicaid and welfare under the PRWORA, the shift from fee-for-service to managed care as the dominant method of financing and delivering care to Medicaid beneficiaries, the enactment of the State Children's Health Insurance Program, and the promise of prescription drug coverage under Medicare in 2006 with passage of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003. Social workers need to understand these new laws and their likely impact on clients. A time line of other key federal actions is provided at the end of the chapter.

#### DECOUPLING OF MEDICAID AND CASH ASSISTANCE

The PRWORA severed the linkage between Medicaid eligibility and receipt of cash assistance. Before PRWORA, recipients of AFDC automatically received

Medicaid coverage. With the repeal of AFDC and its replacement by TANF, persons who receive cash assistance under TANF are not guaranteed Medicaid coverage. To preserve Medicaid eligibility for persons who lose eligibility for cash assistance, Congress retained an entitlement to Medicaid for persons meeting AFDC-related standards in effect on July 16, 1996, under Section 1931 of the law (Rosenbaum & Darnell, 1997a); the section in which the new eligibility category was established—low-income families with children—is sometimes called “Section 1931 eligibles.” As a consequence of the decoupling of Medicaid and cash assistance, persons may continue receiving Medicaid for as long as they remain eligible. Medicaid coverage may, however, be difficult to maintain because persons who qualify for one program may not qualify for another, states must make two separate eligibility determinations, and persons may be unaware of their eligibility (Ellwood & Ku, 1998; Ku & Coughlin 1997; Rosenbaum & Darnell 1997a).

In the years immediately following the enactment of PRWORA, Medicaid enrollment among low-income individuals and families declined (Families USA Foundation, 1999; U.S. General Accounting Office, 1998, 1999; Guyer, 2000; Guyer, Broaddus, & Cochran, 1999; Stapleton & Englert, 1999). More recent studies suggest that problems still persist, as persons who are eligible for Medicaid coverage are not receiving needed benefits (e.g., Darnell & Merrill, 2002; Darnell & Nagatoshi, 2002) and some states are making it more difficult for parents to enroll in Medicaid and/or are lowering the eligibility thresholds (Ross & Cox, 2003). To guard against losses in Medicaid as a result of participation in TANF, social workers can educate their clients about their options to continue Medicaid coverage, such as 12 months of transitional Medicaid assistance, when clients transition from welfare to work. Outreach by social workers is required now more than ever because states have curtailed their outreach and education campaigns as a result of state budget deficits. Social workers also can advocate that states develop or maintain simplified application procedures for low-income families with children and expand or maintain eligibility thresholds for working parents.

#### PROLIFERATION OF MEDICAID MANAGED CARE

Arguably, President Clinton’s decision to make active use of the demonstration waiver authority granted under Section 1115 of the Social Security Act to permit states to undertake extensive changes in their Medicaid programs prompted the proliferation of managed care for Medicaid beneficiaries on a large scale. While states previously had the option to offer Medicaid beneficiaries the choice to enroll in prepaid health plans, or mandate enrollment in managed care under a different waiver authority, Section 1915(b), Section 1115s waiver authority was much broader (Rosenbaum & Darnell, 1997b). Section 1115 permitted states to restructure the delivery system and financing structure of Medicaid, making it much easier to operate managed care plans (Kaiser Commission on the Future of Medicaid, 1997). As of August 2003, 19 states have mandated enrollment in managed care plans under Section 1115 waiver programs (Centers for Medicare and Medicaid Services, 2003). The Balanced Budget Act of 1997 permitted states to implement mandatory Medicaid managed care for most groups of Medicaid beneficiaries without applying for a waiver

(Schneider, 1997). As of June 2003, more than 25 million Medicaid beneficiaries (nearly 60%) were enrolled in managed care plans (Centers for Medicare and Medicaid Services, 2004d).

As Medicaid managed care enrollment continues to grow, the number of managed care plans leaving state Medicaid markets also is growing. One study (Felt-Lisk et al., 2001) reported an annual exit rate of 15% to 17%. This percentage translates to a burden of having to select a new plan or potential discontinuity of care for 1.2 million Medicaid beneficiaries (Felt-Lisk, Dodge, & McHugh, 2001).

With the majority of Medicaid beneficiaries enrolled in managed care plans, it is important to understand how beneficiaries enroll in these plans. One study of Medicaid managed care plans in 9 states (Maloy, Silver, Darnell, & Rosenbaum, 1998) found that, on average, more than one-third of beneficiaries failed to voluntarily select a plan and were "autoenrolled" into a plan. Moreover, in two states, the percentage of enrollees making their own selection was less than half. A more recent study in Florida (Yemane & Hill, 2002) confirms that autoenrollment continues to be an issue, with autoenrollment responsible for more than 50% of all Medicaid enrollment in managed care. High rates of autoenrollment suggest that beneficiaries lack (or fail to comprehend) the information to make an informed choice. Indeed, Maloy et al. (1997) found that lack of information about which providers were in the available plans and receipt of large packets of information in the mail were barriers to making a voluntary choice.

While ensuring beneficiary choice of plans is neither a primary concern of managed care plans nor state Medicaid agencies, it is central to the social work value of self-determination. By educating their clients about the available health programs through face-to-face interactions or partnering with community-based organizations that beneficiaries know and trust, social workers can assist their clients in enrolling in new managed care plans in the event of initial selection or plan exit. Although the issue of autoenrollment is raised here in the context of Medicaid managed care, its application is widespread. For example, the new law establishing the Medicare pharmacy benefit (described in more detail later) contains a provision requiring that persons who are dually enrolled in Medicare and Medicaid are autoenrolled in a benchmark prescription drug plan if they do not voluntarily enroll in another drug plan. Several different scenarios are foreseeable. It is possible that the formulary for the benchmark plan may not be as comprehensive as the drug coverage the beneficiaries had through Medicaid, thus potentially disrupting their continuity of care (Medicare Consumers Working Group, 2004). Further, it is possible that the premium subsidy is lower than the cost of the benchmark plan, thus compelling beneficiaries to choose between paying added premiums or foregoing drug coverage (Medicare Consumers Working Group, 2004). Finally, it is possible that beneficiaries may opt out of the Medicare plan under the mistaken view that they may continue to receive drug coverage under Medicaid, thus leaving these beneficiaries without any coverage or the state paying the full cost of drug coverage (Rutgers Center for State Health Policy, 2004). These hypothetical cases demonstrate the need for social workers to be informed about the available prescription drug choices in their area so that they can adequately educate their clients, especially those clients with mental illness and cognitive impairments and other special needs

who likely depend on prescriptive drugs and/or have difficulty understanding the range of available choices.

#### STATE CHILDREN'S HEALTH INSURANCE PROGRAM

As part of the Balanced Budget Act of 1997, Congress enacted the State Children's Health Insurance Program (SCHIP), a federal program that allows states to extend health insurance coverage to children with incomes up to 200% (or higher) of the federal poverty level. (States that already had extended coverage to children to levels at, near, or above 200% of poverty when the new law was enacted could further extend coverage up to 50 percentage points above whatever limits were in place in March 1997.) States that elect to participate in the program are entitled to higher federal contributions for every state dollar spent on child health programs. In designing their child health programs, states have the option to extend Medicaid coverage, create a separate program, or fashion some combination of the two. Unlike Medicaid, SCHIP is not an open-ended entitlement but a "capped" entitlement; states, not children, are entitled to assistance (Rosenbaum, Johnson, Sonosky, Markus, & DeGraw, 1998). Moreover, the law caps federal financial contributions to states at an annual aggregate level. Nearly \$40 billion in federal funds was made available to states between 1998 and 2007 with an average allocation of \$4 billion per year (Dubay, Hill, & Kenney, 2002).

As of October 2004, all states (and DC) participate in the SCHIP program. Of these, 12 states (including DC) expanded their existing Medicaid programs, 18 states created new state child health programs, and 21 states adopted some combination (Centers for Medicare and Medicaid Services, 2004g). States that choose to implement a separate child health program have the flexibility to adopt more limited benefit packages than the state's Medicaid program, impose cost sharing at significantly higher levels than in Medicaid, and cap enrollment. A recent study (Ross & Cox, 2004) found that 7 states froze enrollment in their SCHIP programs and 16 states raised premiums or imposed premiums on lower income families.

Two notable aims of the law were to encourage states to publicize the availability of new child health programs and to simplify application procedures. Consequently, most states have undertaken broad outreach campaigns and have streamlined enrollment in numerous ways, such as creating short application forms and/or joint application forms for SCHIP and Medicaid, allowing applicants to submit applications by mail, eliminating asset tests, and reducing required documentation in determining eligibility. There is mounting evidence, however, that budget deficits are prompting states to scale back their outreach activities and rescind their simplification strategies. Many states curtailed their outreach efforts, eight states adopted reporting and verification requirements, and one state reestablished an asset test for certain low-income children (Ross & Cox, 2004). These actions make it more difficult for families to become eligible for coverage or deter eligible families from applying.

As states roll back their outreach efforts and simplification strategies, social workers can help fill the void by educating clients about their coverage options and the requirements to maintain coverage. Indeed, social workers employed in

hospitals, ambulatory clinics, schools, and social service agencies have been conducting application assistance and outreach since SCHIP's enactment. During a period of retrenchment, social workers can apply their community organizing skills to build coalitions among numerous organizations and residents to advocate for child health policies to be more responsive to the needs of individuals, families, and the community (Patterson & Cox, 2001).

#### MEDICARE PRESCRIPTION DRUG COVERAGE

One of the major missing pieces of Medicare coverage for the aged and disabled, extending back to the enactment of Medicare in 1964, was the lack of prescription drug coverage. The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (MMA) provided a complex package of prescription drug and other reforms of the Medicare program, to be implemented in stages over a 6-year period. Prescription drug coverage constitutes a new Part D of Medicare. The first phase of drug coverage for Medicare took the form of discount drug cards made available by plans and pharmacies to beneficiaries. Depending on the card, beneficiaries were provided reductions in the costs of prescription drugs covered under the plan. Analysts attributed the relatively low participation in the discount card program to the complexity of the choices and confusion among beneficiaries about the potential benefits of participating.

Beginning in 2006, Medicare beneficiaries can elect to participate in Part D prescription drug coverage by paying a premium. Once on the plan, beneficiaries must pay the first \$250 of drug expenses (the deductible) before any coverage is provided. After the deductible, Medicare will pay 75% of the next \$2,000 of expenses (up to a total of \$2,250 in total prescription drug expenses). Over the next \$1,000 interval in drug expenses, the so-called "donut hole," Medicare Part D provides no additional coverage. The donut hole represents a gap in coverage where beneficiaries get no additional payments if they have prescription drug costs between \$2,250 and \$5,100. Finally, Part D covers 95% of any prescription drug expenses over \$5,100.

Organizationally, new prescription drug coverage will be provided either by free-standing private Prescription Drug Plans, or as part of the overall coverage provided by managed care Medicare Advantage Plans. These plans require the private vendors to take on some amount of financial risk in offering prescription drug coverage. All plans are required to provide basic drug coverage, meaning a standard plan with a defined formulary, or its actuarial equivalent. In the event that two or more private plans do not emerge in an area, special "fall back" plans (with limited financial risk) will be created to assure that all beneficiaries have access to a prescription drug plan in each region.

Several aspects of the new prescription drug plan were controversial. First, the complexity and gaps in financial coverage for older persons meant that the implications of the bill were hard for beneficiaries to understand, and some individuals would not necessarily be better off as a result of the new plan. Second, the entire negotiation with pharmaceutical companies over prices and terms for prescription drugs was left in the hands of the private plans—the government was specifically prohibited from engaging in negotiations. Many analysts believed these provisions prevented the Medicare program from extracting volume dis-



counts or attractive pricing from pharmaceutical suppliers. Third, the complex interaction of the MMA financing and coverage provisions with existing state pharmacy assistance programs and Medicaid, left states concerned that they would be left with a net increase in fiscal responsibility for Medicare beneficiaries' drug coverage.

Beyond the prescription drug provisions, the MMA authorized demonstration projects that would test new competitive Medicare Advantage plans against traditional Medicare in selected markets, beginning in 2010. The law also created a number of changes in payment levels and systems for Medicare managed care, hospitals, and physicians. Among the new coverage provisions, MMA provided for reimbursement of initial physical examinations, diabetes screening, and cardiovascular screening, all with an eye toward enhancing the preventative orientation of Medicare services.

### HEALTH-CARE REFORM

It is often cited that the United States remains the only industrialized Western nation without a national health insurance program. The percentage of the population without health insurance, indeed the lack of universal insurance coverage, has been the most visible and controversial shortcoming of the U.S. health-care system. Lack of insurance coverage creates numerous problems both for patients and providers. For patients, it is well established that no or inadequate insurance coverage leads to late diagnosis and treatment, poor health status and outcomes, and inappropriate use of health services, such as the use of emergency rooms for outpatient care. The failures of national health reform have spurred incremental reforms to expand coverage to specific groups, such as poor children. Enactment of the State Children's Health Insurance Program (described previously) illustrates this trend.

In 2003, 44.7 million residents lacked health insurance coverage, 18% of the nonelderly population. In part because of the success of Medicaid and SCHIP coverage efforts described earlier, 35.5 million of these uninsured residents were adults, primarily living in working poor households with incomes below 200% of the poverty line. Young adults age 19 to 34, working part-time or in small firms, in particular occupations or industries (such as food services or the arts), exhibit very high rates without insurance.

Over the past century, there have been numerous attempts to pass a national health insurance program to guarantee that all Americans are insured for basic health care. Each attempt has failed. As a result of successive failures to provide universal health insurance coverage, our health system resembles a patchwork of insurance coverage. A brief historical review of such failed efforts is instructive because it points to the differences in approaches and raises issues that are likely to be revisited again. The debate also inherently raises a moral question about a right to a basic and adequate standard of health care. Framed as a moral issue, the health-care reform debate is congruent with a core social work tenet: regard for the inherent worth and value of all human beings.

Health-care reform proposals implicitly acknowledge problems in the access, delivery, and financing of our health-care system. Consistent across various periods in history, the impetus for national health reform efforts grew out of concerns



about inequities in access to health care, inadequacies in our model of health care that focuses on treatment rather than prevention, and escalating health-care costs.

Support for national health insurance dates back nearly a century. President Theodore Roosevelt in his unsuccessful reelection bid against Woodrow Wilson in 1912 endorsed health insurance for all Americans (Davis, 2001; Kronenfeld & NetLibrary, Inc., 2002; Starr, 1982). The first national health insurance reform model bill was proposed in 1915 by the American Association for Labor Legislation (AALL), a group of social progressives. The AALL's model bill provided medical coverage to lower-paid workers and their dependents. It was financed by a tax on wages paid by employees, employers, and the states. Its eventual defeat is attributed to opposition from special interests (physicians, labor, and business) and America's entry into World War I (Starr, 1982).

The movement for universal health insurance stalled. Notably, President Franklin Roosevelt omitted national health insurance in his proposed Social Security bill because of concern that opposition would jeopardize the entire proposal (Kronenfeld & NetLibrary, Inc., 2002).

Momentum for universal health insurance coverage did not emerge again until the 1940s. Introduced in 1943 in the U.S. Congress by Senators Robert Wagner and James Murray and Representative John Dingell, the Wagner-Murray-Dingell bill was the first congressionally sponsored bill to provide mandatory national health insurance. The bill sought to provide physician and hospital care to employees and retirees under the Social Security system. It included an employer mandate system of finance in which employers and employees contributed to a national trust fund that reimbursed providers (Bodenheimer & Grumbach, 2002; Starr, 1982). Amid opposition from organized medicine, Congress never voted on the bill (American Historical Association n.d.). In 1945, President Truman endorsed a similar bill, becoming the first president to send a national health insurance bill to Congress. Physicians and other health-care interests opposed the health-care bill and federal agencies opposed the plan or bestowed only lukewarm support (Starr, 1982). Ultimately, only one component of the bill, the Hospital Survey and Construction Act (known as the Hill-Burton Act), was signed into law.

Despite the defeat of the Wagner-Murray-Dingell bill, it set the stage some 20 years later for the enactment of Medicare in 1965 (discussed in detail earlier). In an era when fewer than 15% of the elderly population had health insurance, Congress adopted the Wagner-Murray-Dingell approach but restricted it to persons age 65 and older. As with the original Wagner-Murray-Dingell bill, insurance is compulsory and is financed (in part) by a payroll tax. A companion program, Medicaid (also described earlier), and enacted in 1965, adopted a very different model with coverage provided only to certain groups of low-income persons and financed by general federal and state taxes (Bodenheimer & Grumbach, 2002).

In 1970, Senator Edward Kennedy and Representative Martha Griffiths introduced a universal health insurance plan that went further than either the AALL legislation or the Wagner-Murray-Dingell bill. A single-payer plan, the Kennedy-Griffiths proposal provided a national health insurance system administered by the federal government. It was financed by employment taxes (payroll and self-employment) and by general tax revenues. Like its predecessors, the bill could not overcome opposition from organized interests (Bodenheimer & Grumbach, 2002).

As an alternative to the Kennedy-Griffiths bill, President Nixon proposed a national health insurance plan that was administered privately (not by the gov-

ernment) and imposed an employer mandate for employers with 25 or more employees (Bodenheimer & Grumbach, 2002; Davis, 2001) and public plans that would replace and improve Medicare and Medicaid (Davis, 2001). With its focus on the private sector, the Nixon proposal marked a clear departure from earlier proposals that relied on government financing (Bodenheimer & Grumbach, 2002). Its defeat is attributed to lack of public will (Bodenheimer & Grumbach, 2002) and political scandal (Plissner, 2001).

President Carter supported a comprehensive program of national health insurance during his successful bid for the presidency, but skyrocketing inflation rates detracted attention from national health reform (Kronenfeld & NetLibrary, Inc., 2002).

A congressionally mandated commission, the Bipartisan Commission on Comprehensive Health Care (called the "Pepper Commission" after its first Chairman, Congressman Claude Pepper, who served until his death) in 1990 recommended a "pay-or-play" approach to employer coverage. Interest in comprehensive health reform legislation accelerated following the Commission's recommendations (Mueller, 1993). Senator Mitchell later adopted the pay-or-play model in bipartisan legislation (Davis, 2001). The legislation required employers to either provide a health plan for their employees or pay into a state insurance fund. A comparison of these major types of health-care reform approaches is found in Table 5.2.

President Bill Clinton pushed strongly for comprehensive health-care reform in what culminated as the Health Security Act legislation introduced in Congress in 1993. The legislation assured universal coverage through an "individual mandate," which required citizens and legal residents to purchase standardized comprehensive insurance coverage through a regional alliance, a state-established intermediary that contracted with health insurance plans. The legislation created an "employer mandate"; universal coverage was financed principally by

**Table 5.2**  
A Comparison of Major Types of Health-Care Reform Approaches

Type of Reform	Mandatory/Voluntary	Brief Description
Single payer	Mandatory	A single government-run insurance organization collects health-care fees and reimburses providers.
Employer mandate	Mandatory	Employers are required to contribute to the cost of health care coverage for their employees and dependents.
Vouchers/tax credits	Voluntary	Individuals purchase health insurance with the assistance of government subsidies.
Medical savings accounts	Voluntary	Individuals save money in tax-exempt accounts that they can use to pay medical expenses.
Individual mandate	Mandatory	Employees are required to purchase insurance.

mandatory contributions from employers (roughly 80%). Emphasizing individual responsibility, the legislation also required contributions from employees (roughly 20%). (Persons who were not in the workforce were entitled to income-related subsidies to purchase coverage through the alliance.) Federal subsidies supplemented contributions made by many firms and individuals. The Medicare program remained in place and was expanded to include prescription drug coverage. Medicaid coverage was supplanted by the alliance plans, except nonacute care for cash assistance recipients who enrolled in health plans through the alliance but retained Medicaid coverage (Fuchs & Merlis, 1993). Its defeat in 1994 is attributable to numerous factors. Commentators ascribe failure to the political process, and, in particular, to misguided leadership (Johnson & Broder, 1996), political naivety (Brown, 1996), failure of public deliberation (Hecl, 1995), a narrow base of presidential political support (Hecl, 1995), insufficient attention to timing (Hamburg & Ballin, 1995; Johnson & Broder, 1996), failure to sell the plan to the public (Blendon, Brodie, & Benson, 1995), opposition from special interests that had a stake in the status quo (Judis, 1995; Oberlander, 2003), and the structure of U.S. political institutions (Oberlander 2003). Its defeat also is attributed to the size and complexity of the legislation itself (Johnson & Broder, 1996; Starr, 1995) and to anti-statist values (Jimenez, 1997; Johnson & Broder, 1996; Oberlander, 2003; Skocpol, 1995).

The failed health reform proposals share commonalities. Each was opposed by representatives of organized interests. The focus on national health reforms often was derailed by unforeseen events. Misinformation was pervasive. But apart from the political realities that contributed to each bill's failure, ideological differences assured their defeat. Social workers can potentially have the most impact in future debates over universal coverage by helping shape the discussion on (and build a consensus for) a right to health care. Topics for social workers to consider are informed by Chapman (1994) who advocated a human rights approach for health-care reform. In assessing the Clinton health-care reform plan, Chapman (1994) proposed 10 criteria. We adopt these criteria as guides for crafting (or evaluating) sound health reform plans:

1. Is there a guarantee to a basic and adequate standard of care to all citizens and residents?
2. Is equality of all persons assured?
3. Is health care treated as a social good?
4. Are the needs of disadvantaged and vulnerable populations a priority?
5. Are individuals or groups empowered to assert their claims?
6. Is health care affordable and publicly financed?
7. Is there public participation and accountability?
8. Does government assume primary responsibility for access to health care?
9. Is there recourse for persons with grievances or complaints?
10. Is there a balance between individual needs and the collective good of society?

Each question poses a host of issues that are beyond the scope of this chapter. For now, these broad questions serve to suggest areas where social workers can impart their specialized knowledge to expand the range of issues considered as part of any health-care reform agenda. Indeed, social workers' belief in the intrinsic

sic worth of all human beings; close proximity to low-income, at-risk, and vulnerable populations; orientation to empower individuals and groups; and understanding of the interrelationships between lifestyle, diet, and environment on health outcomes; poise them to challenge the conventional conceptions of what it means to reform health care and move the debate beyond issues of cost containment, fairness, and health security.

## POLICY ISSUES FOR SOCIAL WORK

In addition to the big programmatic issues that surround Medicare, Medicaid, and national health reform, social work has particular interests in the alleviation of health disparities, the viability of the so-called health safety net, as well as the revitalization and replenishment of social work professional roles in health care.

### HEALTH DISPARITIES

Wide disparities in access, costs, quality, and outcomes exist across groups in their health-care use, quality, and outcomes. The most visible examples have been differences in infant mortality, low birth weight, and adverse birth outcomes by race. African Americans experience infant mortality rates double those of White Americans. This differential has been stubbornly consistent, even as infant mortality rates have dropped precipitously over the past 4 decades. Prostate cancer rates are 60% higher for African American men, as compared to White American men. African Americans experience significantly higher rates (and higher death rates) from cardiovascular disease and stroke, diabetes, and HIV/AIDS, as well as other major categories of disease and mortality. Other ethnic and racial groups also exhibit high rates of morbidity and mortality that are apparently not well addressed by the public health or health delivery system. For example, obesity and diabetes present at high rates in the American Indian/Alaskan Native population, the Mexican American population, and the Pacific Islander/Asian American population.

Racial and ethnic disparities have long been known to health services researchers and policymakers, but have more recently become a matter of significant policy concern. A major impetus for national policy attention to racial and ethnic disparities was the Institute of Medicine (IOM) report on *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (Smedley, Stith, Nelson, & U.S. Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, 2002). The IOM report documented significant differences in use and quality of health services—test, sophistication of treatment, and so on—even when insurance and income were controlled. The report was controversial because it identified discrimination in medical practice as a significant factor over and above the traditional access factors and operation of the delivery system. More specifically, the report focused on stereotyping and prejudice by clinical providers, whether conscious or unconscious.

The federal government, as well as numerous health foundations, has identified racial and ethnic disparities as a major initiative for funding, clinical and services attention, and research. Congress now requires an annual report, prepared by the Agency for Healthcare Research and Quality (AHRQ) on issues in addressing disparities across a variety of vulnerable groups: the low-income population, racial and

ethnic minorities, women, children, the elderly, and individuals with special or chronic health-care needs. The issues are complex and involve interactions between underlying social circumstances, health behaviors, and health services delivery.

#### THE HEALTH-CARE SAFETY NET

In a system where one out of every six persons lacks health insurance coverage, the delivery of care by public and nonprofit organizations that provide care for free or on the basis of ability to pay is a critical issue (Smedley et al., 2002). These so-called safety net providers include public hospitals and clinics, federally qualified health centers (FQHCs), specialty providers (such as reproductive health centers), and free clinics that rely principally on volunteer contributions. Significant amounts of care are also provided by hospitals, physicians, and clinics in the form of free or subsidized care. Particular services, such as emergency room care or burn care is disproportionately provided to uninsured patients because of the association with poverty, shortcomings of the primary or public health systems, or regulatory requirements.

During a period when health insurance coverage is eroding, the viability of safety net providers is an increasing concern. These providers rely heavily on grants from federal, state, and local sources; Medicaid and FQHC reimbursements; and private philanthropy. All three sources are under stress in most states, and none has been keeping up with real costs of delivering health services. In the short run, financing issues for these providers are paramount, especially in an era of reductions in Medicaid coverage and payment. In the longer run, many urban centers will need to address planning, governance, and coordination of the safety net providers if patients without insurance are going to have access to quality and appropriate primary care services.

Rural safety net providers have faced even greater challenges as the combined effects of technology growth, difficulties in recruiting and retaining physicians and allied health personnel, and payment policies have conspired against rural areas efforts to maintain small hospitals and access to primary care (Ormond, Wallin, & Goldenson, 2000). It is difficult to achieve the efficiencies and technologies of care demanded in modern medicine with the relatively small number of patients that, by definition, are present in rural hospitals and clinics. Doctors looking for colleagues, looking to be able to refer to specialists, or looking for access to sophisticated equipment or facilities will naturally practice in more urban settings. The fact that many rural areas have disproportionately high numbers of uninsured and low-income residents means that providers face a kind of triple jeopardy: a poor payer environment, disadvantaged and often high-risk patients, and high unit costs. Both Medicare and Medicaid have promoted policies to support rural providers and physicians, and providers have endeavored to respond with mergers, affiliations, and the use of new technologies such as telemedicine. The plight of the rural safety net, however, continues to be a major area of policy concern.

#### THE SOCIAL WORK PROFESSIONAL ROLE

Virtually absent from the policy discussions of health reform or more narrow considerations of state Medicaid policy or urban health-care delivery is the role

of social work as a profession in the health-care system. Professional roles for social workers have changed dramatically in recent years, in part as a result of policy changes. The implementation of the Medicare Prospective Payment System (PPS), for example, fundamentally changed the responsibilities for medical social workers to an emphasis on discharge planning. The priority for hospitals was to shorten lengths of inpatient stays, and with that a priority an emphasis emerged in finding placements and making arrangements for expedited discharge. Social workers, with their knowledge of community resources, their ability to work with families, and their interdisciplinary orientation became the default solution to this institutional need. Unfortunately, the status of medical social work and the breadth of responsibilities that medical social workers enjoyed in hospitals devolved as social work increasingly became identified simply with “discharge planning.”

With the aging of the population, the growing primacy of chronic conditions such as diabetes and asthma, and the shift to new forms of community health-care delivery, the social work profession has the opportunity to define and advocate for new roles in practice. Several demonstration initiatives, such as the Council for Jewish Elderly in Chicago program, *Partners in Care*, are piloting new roles for social workers in outpatient settings. Other developments, such as the National Cancer Institute’s initiative to introduce “patient navigators” to assist families and vulnerable patients in negotiating clinical, service, and social aspects of cancer treatment represent important areas for role definition (or loss of role definition) for social work in health care. Key to reinvigorating the social work professional role in health services delivery will be advocacy in policy: making sure that criteria, payment, and management designate social work as the professional provider of choice. Other allied health professions, such as occupational therapy, have seen an erosion of professional status and practice authority in health care as reimbursements for its services have been cut.

As advocates and proponents of social justice, social workers also have a role in arguing for sound and compassionate policy responses to disparities and lack of access to health care. At a national level, this includes the quest for universal health-care coverage. At a state level, social workers have been an important voice and source of analysis for Medicaid and SCHIP coverage and reimbursement policy. At a local level, especially in the absence of universal coverage, social workers play an important policy and political role in the maintenance of the so-called health-care safety net: public and nonprofit providers that serve low income, uninsured, or underinsured patients. At each of these levels of advocacy, substantive knowledge of programs and policy is essential. One source of political capital that social workers bring to legislative, administrative, and regulatory decisions is their expertise in the workings of programs such as Medicare and Medicaid, as well as their understanding of the real-life consequences of these programs on vulnerable populations and communities.

## CONCLUSION

Health policy in the United States attempts to address systemic problems of access, costs, quality, and accountability. The dominant issue for health-care reform—extending back at least to the New Deal legislation of the 1930s, is the lack of universal health insurance coverage in the United States, currently estimated



at 45 million persons. Despite the lack of insurance coverage for a significant group of the population, the costs of health care are regarded to be high and rapidly rising. Looked at more carefully, the problem of costs is not simply the level of health-care costs in the United States, but rather a concern about the value or benefit that these services produce. As the government and private payers for health care have attempted to gain control over health-care expenditures, more and more policy attention has been paid to assuring the quality and accountability of the system. Health policy is increasingly preoccupied with outcomes, information, and incentives for quality care.

The key policy levers for affecting the size and scope of health services are financing arrangements (such as taxes and insurance premiums), payment arrangements (such as DRGs or managed care capitation payments), and information sources about quality and efficiency of services.

While access, cost, quality, and accountability concerns are the primary issues for policy analysis and reform, all legislative and regulatory action in the health system takes place in a context of huge political and economic interests. The recent history of reform, especially the Clinton Health Security Act and the Medicare Modernization and Prescription Drug Act, is dominated by large interests such as the insurance and pharmaceutical industries, shaping public perceptions and congressional behavior.

The two large policy arenas for social work in health care are the Medicare and Medicaid programs. In Medicare, the addition of prescription drug coverage and the evolution to more competitive and “consumer-driven” approaches to health plan choice and coverage will be important frontiers for social work advocacy and practice. Medicaid is facing threats to coverage, financing, and its historic package of benefits in many states. In its place, states are considering significant reductions in the categories and numbers of eligible beneficiaries, reductions in financing (and its associated federal match), and potential movement to a Block Grant and defined contribution approaches that limit both financial exposure and financial protection for low-income populations. A key population of concern as these changes roll out will be the “dual eligibles,” low-income aged or disabled beneficiaries who are entitled to both Medicare and Medicaid coverage.

Social workers will need to be savvy about these health policy changes in their own practice, in professional roles that attempt to formulate or implement health policy, and in promoting broader advocacy for health-care reform. Rapidly escalating costs, the aging of the population, and the increasing pressures to control public spending will continue to place health care at the top of the national policy agenda, providing important opportunities for social workers to exercise their important professional, advocacy, and leadership roles.

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## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 5.1 IDENTIFY THE ELIGIBILITY CRITERIA FOR MEDICAID FOR A LOW-INCOME DISABLED PERSON IN YOUR STATE

Is the person eligible for other health insurance coverage-Medicare? Under what circumstances would the individual be dually eligible for Medicare and Medicaid? What other programs would you explore? What prescription drug coverage



is available to this individual? What safety net providers are available to provide health-care coverage? What gaps in service do you anticipate?

LEARNING EXERCISE 5.2 INVESTIGATE A CURRENT (OR RECENT) FEDERAL OR STATE PROPOSAL TO PROVIDE UNIVERSAL HEALTH INSURANCE COVERAGE FOR ALL AMERICANS (OR ALL STATE RESIDENTS, ALL CHILDREN, ALL LOW-INCOME PERSONS)

Questions to consider include: How does the plan propose to achieve universal coverage? Assess the strengths and weaknesses of the approach. What lessons can be learned from previous failed attempts to provide universal health insurance that would help you design a political strategy for the success of this proposal? Is this health insurance proposal responsive to social work values and concerns?

LEARNING EXERCISE 5.3 PROPOSE A NEW PROFESSIONAL ROLE FOR SOCIAL WORKERS IN THE MODERN HEALTH-CARE SYSTEM

Provide a one paragraph job description of this role. How would you advocate the benefits and rationale of this role to senior policy leadership at the Centers for Medicare and Medicaid Services? How would you propose this role be financed and reimbursed? How would this role relate to other professionals—physicians, health-care administrators, nurses, and so on—in the health system?

LEARNING EXERCISE 5.4 IDENTIFY THE SINGLE MOST COMPELLING POLICY PROBLEM FOR SOCIAL WORKERS TO ADDRESS IN HEALTH CARE

Is it disparities in access or outcomes? Is it the cultural competence of providers? Is it the erosion of Medicaid coverage in states? What strategies and approaches would you propose for social work to influence the path of health policy formulation?

### SUGGESTED RESOURCES

More detailed presentations of program data, policy analysis, and eligibility rules can be found in government documents, foundation reports, web resources, and journals. Social workers with ongoing interests in health policy should familiarize themselves with the overall government program structure and resource commitment to health services: The most comprehensive guide to government entitlement programs (especially Medicare and Medicaid), the *Green Book*, is published periodically by the U.S. House Ways and Means Committee and is also available on the web (Committee on Ways and Means, March 2004) at [www.frwebgate.access.gpo.gov](http://www.frwebgate.access.gpo.gov).

Social workers interested in deeper understanding of Medicare and Medicaid should be familiar with the federal program's documents, especially "Medicare and You," available through the Centers for Medicare and Medicaid Services at [www.cms.gov](http://www.cms.gov).

Ongoing policy issues in Medicare and Medicaid, as well as specific topics in minority health, HIV/AIDS, and access for the uninsured, are thoroughly covered by the Kaiser Family Foundation, and its extensive web resources. More information can be found at [www.kff.org](http://www.kff.org).

Key journals with which social workers interested in health policy should be familiar include *Health Affairs*, *Health Care Financing Review*, and *Social Work and Health*.

A comprehensive glossary of health-care terminology has been published as *AcademyHealth Glossary of Terms Commonly Used in Health Care*, 2004 edition, and can be found at [www.academyhealth.org](http://www.academyhealth.org).

#### ADDITIONAL RESOURCES

The Assessing the New Federalism project of the Urban Institute ([www.urban.org/Content/Research/NewFederalism/StateFocus/StateFocus.htm](http://www.urban.org/Content/Research/NewFederalism/StateFocus/StateFocus.htm))

The Health Division of the National Governors' Association ([www.nga.org/center/divisions/1,1188,T\\_CEN\\_HES,00.html](http://www.nga.org/center/divisions/1,1188,T_CEN_HES,00.html))

The Intergovernmental Health Policy Project ([www.gwu.edu/~ihpp](http://www.gwu.edu/~ihpp))

The National Academy for State Health Policy ([www.nashp.org](http://www.nashp.org))

The National Council of State Legislatures ([www.ncsl.org](http://www.ncsl.org))

The Rutgers Center for State Health Policy ([www.cshp.rutgers.edu](http://www.cshp.rutgers.edu))

The state health policy area of the Kaiser Family Foundation ([www.kff.org/statepolicy/index.cfm](http://www.kff.org/statepolicy/index.cfm))

#### APPENDIX: TIME LINE OF KEY FEDERAL HEALTH POLICY ACTIONS SINCE THE NEW DEAL

##### 2000s

- 2003 Medicare Prescription Drug Improvement and Modernization Act of 2003
- 2001 Federal health centers program expanded under presidential initiative
- 2000 Breast and Cervical Cancer Prevention and Treatment Act of 2000 permitted states to provide Medicaid to certain women diagnosed with breast or cervical cancer, regardless of their income or resources

##### 1990s

- 1999 Ticket to Work and Work Incentives Improvement Act of 1999 expanded the availability of Medicare and Medicaid for certain disabled beneficiaries who return to work
- 1997 Balanced Budget Act of 1997 established the State Children's Health Insurance Program (SCHIP) and created the Medicare+Choice program
- 1996 Health Insurance Portability and Accountability Act (HIPAA); Personal Responsibility and Work Opportunity Reconciliation Act of 1996; Mental Health Parity Act of 1996
- 1994 Clinton Health Plan defeated
- 1993 Health Security Act (Clinton Health Reform Plan) introduced in Congress; Family and Medical Leave Act of 1993
- 1990 Americans with Disabilities Act (ADA); Ryan White Comprehensive AIDS Resources Emergency Act

**1980s**

- 1989 Omnibus Budget Reconciliation Act of 1989; Medicare Catastrophic Coverage Act repealed
- 1988 Medicare Catastrophic Coverage Act of 1988 provided coverage for catastrophic illness and prescription drugs
- 1987 Omnibus Budget Reconciliation Act of 1987 expanded Medicaid eligibility for pregnant women and children and established the resource-based relative value scale for reimbursing physicians under Medicare; Stewart B. McKinney Homeless Assistance Act
- 1986 Omnibus Budget Reconciliation Act of 1986; Omnibus Health Act
- 1985 Emergency Deficit Reduction and Balanced Budget Act; Consolidated Omnibus Budget Reconciliation Act
- 1984 Deficit Reduction Act of 1984 (DEFRA) required states to extend Medicaid coverage to children born after September 30, 1983 up to age 5 in families meeting AFDC standards; Child Abuse Amendments established treatment and reporting guidelines for severely disabled newborns
- 1983 Social Security Amendments established the Medicare prospective payment system (PPS), including the Diagnosis Related Groups (DRGs) scale for reimbursing inpatient services for Medicare and Medicaid patients
- 1982 Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA)
- 1981 Omnibus Budget Reconciliation Act of 1981
- 1980 Omnibus Budget Reconciliation Act of 1980

**1970s**

- 1979 Surgeon General report, *Healthy People*, laid foundation for national prevention agenda
- 1977 Departments of Labor and Health, Education, and Welfare Appropriations Act for FY 1977 created the Hyde Amendment, which prohibited federal Medicaid payments for abortions, with certain exceptions
- 1973 Health Maintenance Organization (HMO) Act
- 1972 Social Security Amendments of 1972 established the Supplemental Security Income (SSI) program, created Professional Standards Review Organizations (PSROs), extended Medicaid eligibility to certain disabled persons receiving SSI, and extended Medicare eligibility to persons with end-stage renal disease (ESRD); National School Lunch and Child Nutrition Amendments established the Women, Infants, and Children (WIC) program

**1960s**

- 1967 Social Security Amendments of 1967 enacted the Early and Periodic Screening Diagnosis and Treatment (EPSDT) benefit under Medicaid; Mental Health Amendments of 1967
- 1965 Social Security Amendments of 1965 created Medicare and Medicaid
- 1960 Social Security Amendments of 1960

**1950s**

- 1950 National Science Foundation Act of 1950

**1940s**

- 1946 Hospital Survey and Construction Act (Hill-Burton Act) provided federal grants and loans to build hospitals; National Mental Health Act
- 1944 Public Health Service Act of 1944
- 1943 Emergency Maternal and Infant Care Program provided maternity care and infants for wives and children of service members

**1930s**

- 1935 Social Security Act of 1935 passed including Title V, Maternal and Child Health

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Sources: Adapted from *Contemporary Health Policy*, by B. B. Longest and NetLibrary Inc., 2001, retrieved from <http://www.netLibrary.com/urlapi.asp?action=summary&v=1&bookid=72524>; *Healthcare Reform in America: A Reference Handbook*, by J. J. Kronenfeld and M. R. Kronenfeld, 2004, Santa Barbara, CA: ABC-CLIO; *Appendix 1: Medicaid Legislative History—1965–2000*, by Henry J. Kaiser Family Foundation, n.d., retrieved November 20, 2004, from <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=14255>; *Breast and Cervical Cancer Prevention and Treatment*, by Centers for Medicare and Medicaid Services, 2004a, retrieved October 20, 2004, from <http://www.cms.hhs.gov/bccpt/default.asp>; *CMS History Page Quiz*, by Centers for Medicare and Medicaid Services, 2004b, retrieved November 20, 2004, from <http://www.cms.hhs.gov/about/history/quiz/answers.asp>; *The Mental Health Parity Act*, by Centers for Medicare and Medicaid Services, 2004f, retrieved October 17, 2004, from <http://www.cms.hhs.gov/hipaa/hipaa1/content/mhpa.asp>.

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## CHAPTER 6

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# Community and Health

CHRISTOPHER MASI

**S**TARTING FROM GESTATION and continuing through adulthood, day-to-day social and environmental experiences can have important positive and negative health effects. The pathways of influence are several and include the effects of air, water, and food quality, as well as exposure to physical, social, and psychological stressors. Access to and quality of medical care also affect the onset and course of disease. It has been estimated that shortfalls in medical care account for 10% of early mortality while adverse social circumstances account for 15% and environmental exposure accounts for 5% (McGinnis, Williams-Russo, & Knickman, 2002). Behavioral patterns and genetic predisposition may account for as much as 40% and 30% of early mortality, respectively. Not surprisingly, each of these factors, including genetic predisposition, can be strongly influenced by the resources and characteristics of a community. As counselors, coordinators, and advocates, social workers have unique opportunities to maximize the positive and minimize the negative effects of communities on health.

This chapter reviews the ways in which communities affect health and addresses several questions, including the extent to which neighborhoods differ with respect to ethnic composition and resources which are important to health. This chapter discusses the distinction between contextual and compositional neighborhood features and addresses the relationship between community characteristics and each of the major domains of health determinants. In some cases, the connection between the social/physical environment and health will be obvious. In other cases, the pathways of influence are less straightforward and are explained in greater detail. This chapter uses a life-course model to demonstrate the potential effects of the social and physical environment on each stage of the life cycle. Finally, implications of the neighborhood-health connection for social work practice are discussed.

### CHAPTER OBJECTIVES

- Document key differences in community characteristics.
- Illustrate ethnicity- and income-related health disparities.

- Review the distinction between contextual and compositional community features.
- Demonstrate pathways through which community characteristics influence health.
- Identify community effects on health throughout the life course.
- Outline the implications of the relationship between neighborhood quality and health for social work practice in health-care settings.

### COMPOSITION OF U.S. NEIGHBORHOODS

Neighborhood characteristics in the United States, whether urban or rural, vary widely in terms of ethnic makeup and income. This is due to many factors, including resources, personal preferences, and discrimination. With some exceptions, individuals tend to live near those in similar economic circumstances while individuals of a particular ethnicity or cultural background often prefer to live near other individuals of similar ethnicity or culture. Residency patterns are also influenced by discrimination in realty and lending practices. In the United States, these practices have limited the housing opportunities of many groups and resulted in neighborhood differences that do not reflect the wishes or best interests of all populations.

While it is not always apparent, racial segregation is still practiced in the United States. In 2000, the typical White American person lived in a neighborhood that was 80.2% White American, 6.7% African American, 7.0% Hispanic, and 3.9% Asian. In contrast, the typical African American person lived in a neighborhood that was 51.4% African American, 33% White American, 11.4% Hispanic, and 3.3% Asian. The average Hispanic person lived in a neighborhood that was 45.5% Hispanic, 36.5% White American, 10.8% African American, and 5.9% Asian. The typical Asian person lived in a neighborhood that was 17.9% Asian, 54% White American, 9.2% African American, and 17.4% Hispanic (Mumford Center, 2001).

The five U.S. cities with the highest degree of Black-White American segregation are Detroit, Milwaukee, New York, Chicago, and Newark. Each has an Index of Dissimilarity of 80 or greater; meaning 80% of either group would have to move to different census tracts for the two groups to become equally distributed throughout each city. While segregation has declined over the past 20 years, the slow rate of change suggests it will take another 40 years before the level of Black-White American segregation in the United States declines to the level of Hispanic-White American segregation (Mumford Center, 2001).

Economic and school segregation are also prevalent in the United States. According to the 2000 U.S. census, 3.5 million people live in neighborhoods with poverty concentrations of 40% or greater (Orr et al., 2003). In schools attended by the average African American student, 38.3% of the students are poor, whereas in schools attended by the average Hispanic student, 44% of the students are poor. In contrast, in public schools attended by the average White American student, only 19.6% of the students are poor (Orfield, 2001).

Unfortunately, there is evidence that public school segregation is increasing in the United States. In 1980, 62.9% of African American students attended schools with minority enrollment of over 50%. In 1998, this figure had risen to 70.2% while more than one-third of African American students attended schools with

minority enrollment of 90% to 100%. School segregation has also increased for Hispanic students. Between 1968 and 1998, the proportion of Hispanic students who attended schools with minority enrollments of 90% to 100% increased from 23.1% to 36.6% (Orfield, 2001).

Employment discrimination is another source of neighborhood disparity. In the United States, communities with high proportions of minority residents often have higher unemployment rates and lower average incomes. Among Chicago's 77 community areas, unemployment rates in the most economically depressed areas varied from 25.8% to 33.5% in 2000. In these communities, the proportion of African American residents varied from 85.5% to 97.8%, and median household income was \$17,209. The five Chicago community areas with the lowest unemployment rates (2.8% to 3.4%) had populations that were 79.4% to 93.3% White American, and the median household income was \$56,455 (Kouvelis, Harper, & Thomas, 2003).

While diversity is part of the fabric of the United States, diversity between neighborhoods is often greater than diversity within them. Segregation and unequal distribution of resources, in the form of housing quality, green space for exercise, health-care access, and food quality all have important health ramifications.

#### DOES HEALTH DIFFER BY INCOME AND ETHNICITY?

Income-related health disparities have been noted for several centuries. Reference to the relationship between health and wealth can be found in ancient Chinese and Greek texts (Krieger, 2001; Porter, 1997). In the early twentieth century, Chapin (1924) found that the annual death rate among non-taxpayers was over twice that of taxpayers in Providence, Rhode Island. More recently, health outcome differences by income have been documented in the United States, the United Kingdom, and throughout the world.

According to a recent U.S. survey of 32,374 adults, poor health continues to affect lower income individuals to a greater extent than those with higher incomes (Pleis, Benson, & Schiller, 2003). Among those with household incomes below the federal poverty line, 23.1% reported having hypertension and 3.0% reported having had a stroke. In contrast, only 17.2% and 1.4% of those with incomes greater than or equal to 200% of the poverty threshold reported having hypertension or stroke, respectively. The rates of diabetes and kidney disease were 8.1% and 3.1% among the poor and 4.6% and 1.0% among the not poor, respectively. Obesity among those with incomes of less than \$20,000 was also more prevalent (23.8%) compared to those with incomes of \$75,000 or more (17.2%).

Differences in health behaviors and access to care may contribute to differences in income-related disease prevalence. In the National Health Interview Survey, 28.7% of those with annual incomes less than \$20,000 smoked while 15.2% of those with annual incomes of \$75,000 or more did so (Pleis et al., 2003). Of those with incomes of \$75,000 or more, 91.4% had a usual place of care while 80.4% of those with incomes less than \$20,000 reported a usual place of care.

Both disease prevalence and access to care vary by ethnicity. According to the National Health Interview Survey, the prevalence of obesity (defined as a Body Mass Index greater than or equal to 30) was 29.9% among African Americans, 23.3% among Hispanics, and 20.4% among White Americans. The prevalences of

hypertension and stroke were 19.3% and 2.2% among White Americans, 25.2% and 2.5% among African Americans, and 11.9% and 1.3% among Hispanics, respectively, while the rates of diabetes and kidney disease were 5.6% and 1.5% among White Americans, 8.8% and 2.0% among African Americans, and 6.4% and 1.6% among Hispanics, respectively. Among White American respondents, 86.7% reported a usual place of care. This percentage was lower for African American (84.8%) and Hispanic respondents (70.9%; Pleis et al., 2003).

Given the strong relationship between ethnicity and illness, it is not surprising that ethnicity is related to both life expectancy and mortality. In 2001, the life expectancy at birth was 72.2 years for African American infants and 77.7 years for White American infants. Contributing to this difference in life expectancy are differences in infant death and death due to chronic disease. For deaths of infants under 1 year of age, the rate per 100,000 was lower among White American infants (570.9) compared to African American (1,304.5) and Hispanic infants (572.7) in 2001. For cause-specific mortality, the age-adjusted Black:White American ratio was 1.3 for diseases of the heart, 1.3 for malignant neoplasms, 1.4 for cerebrovascular disease, 2.1 for diabetes mellitus, and 2.9 for hypertensive disease. The overall age-adjusted death rate (per 100,000) was higher among African Americans (1,101) compared to White Americans (836.5) and Hispanics (658.7) in 2001 (Arias, Anderson, Kung, Murphy, & Kochanek, 2003).

When considering the ways in which income and race are related to illness and mortality, some links are more obvious than others. Health behaviors, including diet and access to care, mediate this relationship to some extent. Less well understood is the mechanism by which psychological distress may also mediate income- and ethnicity-related differences in health outcomes. In the National Health Interview Survey, those with household incomes less than \$20,000 reported higher rates of psychological distress compared to those with incomes of \$75,000 or greater in the following areas: feeling sad all or most of the time (6.4% versus 1.7%), feeling hopeless all or most of the time (4.0% versus 0.9%), feeling worthless all or most of the time (3.7% versus 0.7%), or reporting everything is an effort all or most of the time (8.6% versus 2.0%). Ethnic differences also existed in some of these domains. Feeling sad all or most of the time was higher among African American people (4.0%) compared to White American people (3.0%). Reporting everything is an effort all or most of the time was also more common among African Americans (7.1%) compared to White Americans (4.4%; Pleis et al., 2003).

There is some evidence that education may modify the relationship between income/ethnicity and health. Specifically, those with higher education, regardless of income or ethnicity, tend to have lower mortality rates compared to those with less education. In 2001, the age-adjusted mortality rate (per 100,000) among those with fewer than 12 years of education was 576.6. Among those with 13 or more years of education, the rate was 214.6 (Arias et al., 2003). The effect of education on health is not completely understood, but it appears to operate through such important mediators as health behaviors, access to care, place of residence, and ability to cope with stressful situations.

#### HOW ARE NEIGHBORHOOD EFFECTS IDENTIFIED?

Given the diversity of factors that affect health, it is not surprising that particular neighborhood features, including health-care resources, the presence of green

space for exercise, availability of healthy foods, quality of housing, norms and values, and crime have all been associated with health outcomes. But how important are these factors when compared to individual characteristics such as genetic predisposition and health behaviors? In other words, what are the relative health effects of contextual or neighborhood-level factors compared to compositional or individual-level characteristics? Contextual features include neighborhood norms and values, number of parks, quality of schools, and amount of crime in a given neighborhood. Compositional features include individual ethnicity, income, education, and health behaviors. One way to distinguish contextual from compositional effects is by performing multilevel analysis, a statistical approach that categorizes data by level (i.e., individual, classroom, school) and assesses the relative effect of each level on the outcome. If two communities differ in terms of an important health outcome, such as infant mortality, a key question addressed by multilevel analysis would be, "Is the difference in infant mortality due to contextual factors (such as community health-care resources or quality of community drinking water) or does the difference exist because mothers in these two communities are different in important ways (i.e., income, smoking behavior)?" When contextual effects are found, it suggests there is something about a community or neighborhood (i.e., contaminated drinking water) that exerts an effect on the outcome (infant mortality) over and above the effects related to individual characteristics.

In the absence of obvious culprits, such as contaminated drinking water, multilevel analysis cannot always separate individual from community-level effects. For example, multilevel studies have demonstrated significant contextual effects on a variety of health outcomes, but the strength of these effects is often diminished when multiple individual characteristics are considered (Pickett & Pearl, 2001). This suggests that either the contextual effect is weak or the relationship between the contextual feature and the health outcome is mediated by one or more individual characteristics, such as diet or tobacco use. While not negating them, the mediation of neighborhood effects by health behaviors makes contextual effects more difficult to identify.

Another way to distinguish contextual from compositional effects is to perform an experiment in which individuals living in a community are randomly assigned to either remain in the community or move to a new community with different characteristics. If both groups are similar with respect to individual characteristics at the beginning of the study, then post-intervention interviews and analyses permit an assessment of the contextual effects on health. Such studies are difficult to perform due to financial and ethical constraints but experiments of this type occasionally arise.

One example is the Moving to Opportunity (MTO) for Fair Housing Demonstration Program. Conducted by the U.S. Department of Housing and Urban Development, MTO is a randomized social experiment designed to assess the effects of moving out of poor neighborhoods. Families with very low incomes with children under the age of 18 living in public housing or private assisted housing in poor neighborhoods of five cities—Baltimore, Boston, Chicago, Los Angeles, and New York City—were eligible. Between 1994 and 1998, eligible families were randomly assigned to one of three groups: the experimental group, the Section 8 group, or the control group. Individuals in the experimental group were offered housing vouchers that could be used only in low-poverty areas. This group also received assistance finding and leasing units. In addition, to retain their vouchers, families were required to stay in their new neighborhoods for at least 1 year.



Those in the Section 8 group were offered housing vouchers with no restrictions on where the vouchers could be used and no assistance finding or leasing units. Control group members were not offered housing vouchers. They continued to live in public housing or receive project-based housing assistance (Orr et al., 2003).

In 2002, nearly 8,900 participating adults and children were contacted to assess follow-up status in several domains, including physical and mental health, child educational achievement, youth delinquency and risky behavior, and adult and youth employment and earnings. On average, individuals in the experimental group and Section 8 group reported significant increases in their perceptions of safety and substantial decreases in their risk of observing or being a victim of a crime. Compared to the control group, the intervention group also reported less difficulty getting police to respond to their calls and large reductions in the presence of abandoned buildings, public drinking, litter, trash, and graffiti.

Adult health differences noted on follow-up included significant reductions in the prevalence of obesity, in psychological distress, and in depression among the experimental but not the Section 8 group, compared to the control group. Calmness and peacefulness were reportedly significantly increased in the experimental group. Among girls age 12 to 19, researchers noted reductions in psychological distress and generalized anxiety disorder in the experimental group compared to the control group. Among girls age 15 to 19, those in the experimental group were significantly less likely to use marijuana or smoke cigarettes compared to the control group (Orr et al., 2003).

*Moving to Opportunity* is important in that it assessed the relationship between neighborhood characteristics, health, and health behaviors. Because of randomization, those in the intervention group were not different from those in the control group. Therefore, differences noted in health and health behaviors were due to contextual factors, not individual differences. These results provide evidence that neighborhood features, including neighborhood wealth, can affect health independent of individual characteristics. In this case, greater availability of police and decreased exposure to crime and delinquency appear to have had a positive impact on psychological well-being.

## MECHANISMS BY WHICH COMMUNITIES INFLUENCE HEALTH

As mentioned earlier, an individual's social circumstances and physical environment represent two ways communities can affect health. Social circumstances include neighborhood educational level, employment, income disparities, poverty, crime, and social cohesion. A community in which social relationships are easy to make and maintain is likely to be a healthier environment than a community in which residents are afraid to venture from their homes due to concerns about crime. A study from the United Kingdom found that individuals who recently had a heart attack and who had a confidant or intimate partner were about half as likely to die or have a further cardiac event compared to similar patients without a confidant or partner (Dickens et al., 2004).

Number and type of social relationships also depend on neighborhood norms and expectations. Laumann, Ellingson, Mahay, Paik, and Youm (2004) recently documented this in four Chicago communities: one predominantly African American community on the South Side, one Mexican American community on the



West Side, one mixed but predominantly Puerto Rican community on the North-west Side and one primarily White American community on the North Side with a large heterosexual and homosexual population. Each neighborhood had distinct opportunities, or "markets," for social relationships, some more supportive of relational or committed encounters and others more amenable to transactional (relatively uncommitted and often short-term) relationships. In this study, market type was influenced by the neighborhood's economy, as well as the ethnicity and sexual orientation of its residents. For example, family, friends, and church played an important role in forming committed relationships in Hispanic communities. In contrast, the transactional market in the North Side community was important for gay men but not for lesbians, who preferred the relational market.

Physical environment refers to sanitation; quality of housing, food, and water; and exposure to environmental toxins and pathogens. Public health and safety programs often monitor these environmental characteristics. Statistics regarding life expectancy and causes of death indicate that environmental problems pose less of a risk in developed countries compared to third-world countries. For example, the life expectancy of an infant born in 2001 in the United States is 79.8 years for females and 74.4 years for males (Central Intelligence Agency [CIA], 2003). Currently, the leading causes of death in the United States are heart disease (29%), cancer (22.9%), and stroke (6.8%; Arias et al., 2003). The remaining causes, including chronic lung disease, accidents, diabetes, and infections, each account for fewer than 10% of deaths, and only a very small percentage of deaths are directly attributable to environmental conditions.

In contrast, 7 out of the top 10 causes of childhood mortality in developing countries are related to communicable diseases. These include pneumonia, diarrheal diseases, malaria, measles, HIV/AIDS, pertussis, and tetanus (World Health Organization [WHO], 2003). In Haiti, the life expectancy at birth is 50 years for females and 49 years for males. In 2001, it was estimated that 80% of Haitians lived in poverty and the per capita gross domestic product (GDP) was \$1,408. By comparison, the poverty rate in the United States that year was 12.7% while the per capita GDP was \$35,992. In 2001, the annual renewable water supply per capita in Haiti was 1,723 cubic meters while the global average was 27,347 cubic meters (Nationmaster, 2003). Lack of potable water and inadequate sewage disposal are risk factors for infections such as hepatitis A, typhoid, and cholera while poor housing conditions and overcrowding are risk factors for airborne diseases including influenza and tuberculosis. In Haiti, the respiratory disease death rate among children age 0 to 14 years was 98 per 100,000 in 2001, and there were 190 cases of tuberculosis per 100,000. In the United States, there were two cases of tuberculosis per 100,000 in 2001 (Nationmaster, 2003).

It is important to remember that the relationship between national wealth and public health infrastructure is not always positive or linear. Living conditions and environmental quality also reflect national priorities and the relative amount of resources dedicated to public health programs. A comparison of the United States and Cuba is illustrative. Despite having a per capita GDP less than one-tenth that of the United States (\$2,724 versus \$35,992 in 2001), Cuban health statistics compare favorably. In Cuba, female life expectancy at birth is 79 years and male life expectancy at birth is 75 years. At six cases of tuberculosis per 100,000, the Cuban tuberculosis case rate is much closer to that of the United States than Haiti. In fact, low-income communities in the United States with high numbers of immigrants have tuberculosis case rates that exceed the Cuban rate. The tuberculosis

case rate among foreign-born U.S. residents was 32.9 per 100,000 between 1993 and 1998 (Talbot, Moore, McCray, & Binkin, 2000). Despite fewer resources per capita, Cuba has developed a public health system that controls many of the environmentally associated diseases that plague third-world countries and continue to afflict low-income communities in the United States.

Whether or not a person exercises, eats a balanced diet, smokes, or engages in high-risk sexual practices is often a function of a neighborhood's social and physical environment. For example, studies have shown that adults are more likely to exercise in their neighborhood if they perceive it to be safe (Wilbur, Chandler, Dancy, & Lee, 2003) or if they have access to parks, trails, and other areas conducive to physical activity (Huston, Evenson, Bors, & Gizlice, 2003). Other studies have found that healthy foods, such as fruits and vegetables, are less available (Mooney, 1990; Morland, Wing, & Roux, 2002) and more expensive (Sooman, MacIntyre, & Anderson, 1993) in poor neighborhoods compared to wealthy neighborhoods. Obesity has been linked to increased portion sizes and consumption of high-fat foods, such as those served at fast-food restaurants. A recent study of restaurant density found people living in the poorest socioeconomic status category had 2.5 times the exposure to fast-food restaurants compared to those living in the wealthiest category (Reidpath, Burns, Garrard, Mahoney, & Townsend, 2001). In the United States, low-income individuals are exposed to more outdoor tobacco advertising than higher income individuals (Hackbarth, Silvestri, & Cosper, 1995; Stoddard, Johnson, Sussman, Dent, & Boley-Cruz, 1998).

In addition, patterns of social relationships and sexual practices are tied to the economy and culture of the community. Laumann and his colleagues (2004) found that residents of higher income communities tend to meet their partners at school or work and form longer-term relationships more frequently. In contrast, residents of low-income communities are more likely to be in polygamous or short-term, transactional relationships. The links between poverty, prostitution, and sexually transmitted disease are well established and add to the disease burden of low-income communities (Edlund & Korn, 2002; Girard, 2000; Satz, 2003).

Access to medical care often reflects the resources and provider practices within particular communities. Newer tests and procedures may be available in urban areas long before they become standard practice in rural communities. For example, a recent study of U.S. patients with cardiac arrest found survival differed markedly by location of arrest. The survival rate was 9% in rural areas, 14% in suburban areas, and 23% in urban sites. These differences were attributed to several factors related to the communities, including medical response time, transport time, resuscitative skill, and type of medical intervention (Vukmir, 2004). In a comparison of diabetes care in urban versus rural clinics in Alabama, Andrus, Kelley, Murphey, and Herndon (2004) found that rural patients were less likely to be at their goals for glycosylated hemoglobin (a measure of blood glucose control), cholesterol level, and blood pressure. Compared to their counterparts at urban clinics, these patients were also less likely to receive screening and preventive services such as eye examinations, urinary protein screening, aspirin therapy, and vaccinations. In Mexico, the mortality rate from cervical cancer is three times higher in rural areas than it is in urban areas. In the rural state of Chiapas, the cervical cancer mortality relative risk was 10.99 times that of the risk in Mexico City. This difference has been attributed to lack of formal education and in-

sufficient access to medical care (Palacio-Mejia, Rangel-Gomez, Hernandez-Avila, & Lazcano-Ponce, 2003).

Differences in type of care and quality of care also differ markedly across urban settings in the United States. Studies of so-called "small-area variations" in care were pioneered by Dr. Jack Wennberg at Dartmouth in the 1980s. Since that time, the Dartmouth group has documented regional variations in Medicare spending, use of cancer screening tests, physician adherence to national health-care guidelines, and frequency of surgical procedures (McAndrew-Cooper & Wennberg, 1999). For example, regional rates of mammography screening in the United States vary from 12.5% to over 50%, with women in the Northeast, Florida, and Michigan being more likely to receive mammography than women elsewhere. Annual screening for colorectal cancer also varies by geography, from 2.4% among Medicare enrollees in Terre Haute, Indiana, to 22.2% in Takoma Park, Maryland. In general, compliance with national colorectal cancer screening is higher in the East and South compared to the Midwest and West regions of the United States. Medicare enrollees in some areas of the country are also more likely to undergo coronary angiography and carotid endarterectomy than in others. Alarming, a significant proportion of these procedures are performed unnecessarily. The Dartmouth group has shown that use of medical care resources often reflects capacity (i.e., number of physicians, number of hospital beds) more than need for care. The causes of these small-area variations are numerous and likely reflect the effects of prominent physicians who influence local practice through lectures and consultation (Wennberg et al., 1997).

There is growing evidence that societal factors can also influence the onset and course of several gene-associated diseases, including type II diabetes mellitus, cancer, and cardiovascular disease. For example, obesity leads to insulin resistance, which is a significant trigger for type II diabetes mellitus. As the prevalence of obesity has increased in the United States, so too has the prevalence of diabetes. During the period 1988 to 1994, 23.3% of U.S. adults were obese. By 2000, this proportion had increased to 30.9% (Flegal, Carroll, Ogden, & Johnson, 2002). Between 1990 and 2000, the percentage of individuals in a national survey who reported being diagnosed with diabetes increased by 49%, from 4.9% to 7.3% (Mokdad et al., 2001). This study also revealed that diabetes rates vary by state in the United States. In 2000, the rate was 8.8% in Mississippi and 5.4% in Nebraska. The increasing prevalence of obesity appears to have several causes, including the decrease in cost of food as a percentage of income, a shift toward higher calorie diets, and a decrease in physical activity (Philipson & Posner, 2003). State-to-state variation in cost of food, dietary patterns, and physical activity likely contribute to state differences in obesity and diabetes prevalence.

Not only can community resources affect diet and disease onset among adults, these same factors can affect disease onset in subsequent generations. For example, fetuses exposed to hyperglycemia *in utero* appear to be at higher risk of developing diabetes as adults. In a study of Pima Indians, the offspring of women with type II diabetes were more obese and had a higher rate of diabetes (50%) compared to the offspring of women who developed diabetes after the pregnancy (8.6%; Pettitt, Nelson, Saad, Bennett, & Knowler, 1993). These findings suggest that predisposition to disease can be modified *in utero* by maternal diet and blood glucose control. This phenomenon has been labeled "fuel-mediated teratogenesis" (Freinkel, 1980).

The “thrifty gene” hypothesis contends that higher rates of obesity and diabetes among ethnic minorities, including Pima Indians and African American populations in the United States and Aborigines in Australia, arise from a genetic predisposition to energy storage in abdominal fat in these populations. In times of famine or when diets consist of low-fat, low nutrient-dense foods, such a trait confers survival advantage. However, when food is plentiful (as in modern United States and Australia) and diets are high in carbohydrates and fats, efficient energy storage becomes a liability and leads to obesity. Although there is evidence for this theory, it is unclear whether a thrifty gene influences health outcomes among ethnic minorities to the same extent as other important factors, such as the dietary and psychological changes that can occur with discrimination and economic marginalization (McDermott, 1998).

### COMMUNITY EFFECTS AND THE LIFE COURSE

The community effects described can impact individual health at any or all stages of the life course, including gestation, childhood, adolescence, adulthood, and end of life. Interest in community effects on health has spurred interest in health geography and area analysis of epidemiological data. The following are examples of studies that analyze the relationship between neighborhood or community characteristics and health outcomes at each stage of life.

#### GESTATION

Because maternal health is a strong predictor of fetal and infant health, many investigators have examined the relationship between the social experience of pregnant women and the health of their newborns. In a study of 176 U.S. cities with a population of 50,000 or more, LaVeist (1989) found infant mortality among African American infants was positively associated with the city’s index of segregation. The mean infant mortality rate in this study was 19.31 per 1,000 live births among African American infants and 11.09 per 1,000 live births among White American infants. In cities with the lowest level of segregation, mortality among African American infants was almost 5% below the mean for all African American infants, while in cities with the highest index of segregation, the rate was almost 3% above the overall mean. LaVeist suggested that higher African American infant mortality rates in highly segregated cities reflect older housing stock, higher levels of stress and environmental toxins, and reduced levels of city and medical care services in minority communities. According to LaVeist, these effects are ameliorated as the level of ethnic integration increases.

The notion that ambient stressors can adversely affect pregnancy outcomes is supported by several studies. In Santiago, Chile, women living in high-violence neighborhoods in 1985 and 1986 were five times more likely to experience pregnancy complications (including gestational hypertension, fetal growth retardation, and miscarriage) compared to women living in lower violence neighborhoods (Zapata, Rebolledo, Atalah, Newman, & King, 1992). Collins and colleagues (1998) found the odds ratio of very low birth weight (<1,500 grams) was 1.7 to 3.2 for African American mothers in Chicago who rated their neighborhoods unfavorably in terms of police protection, protection of property, personal safety, friendliness,

delivery of municipal services, cleanliness, quietness, and schools compared to controls. Using multilevel statistical techniques, which account for maternal as well as neighborhood characteristics, another study found mean birth weight decreased among African American infants as the neighborhood level of economic disadvantage increased (Buka, Brennan, Rich-Edwards, Raudenbush, & Earls, 2003). Maternal factors considered in this study were parity, prenatal care, education, age, marital status, and smoking history. Neighborhood disadvantage reflected an aggregate measure of the proportion of residents in a neighborhood who lived below the poverty line, were on public assistance, or were unemployed. A similar multilevel analysis found a significant inverse association between birth weight and census tract violent crime among African American, White American, and Hispanic populations (unpublished data).

The links between maternal psychological stress, preterm delivery (<37 weeks of gestation), and low birth weight (<2,500 grams) are not well understood. We know, however, that maternal stress can lead to increased fetal cortisol, a stress hormone that stimulates placental corticotropin-releasing hormone (Chrousos, Torpy, & Gold, 1998; Norwitz, Robinson, & Callis, 1999). Corticotropin-releasing hormone has been labeled a "placental clock" because elevations of this hormone appear to be crucial to the initiation of labor (McLean et al., 1995). Preterm delivery is the primary determinant of low birth weight, and both are risk factors for health problems later in life. Approximately three-fourths of neonatal mortality and almost one-half of long-term neurological impairment in children have been linked to preterm birth (Alexander, 1998). In a series of studies, Barker and colleagues (1998) found evidence that low birth weight is a risk factor for coronary artery disease, stroke, diabetes, and hypertension later in life. These studies and others point to the importance of maternal health, including psychological well-being, to the health of offspring during infancy and later in life.

#### CHILDHOOD

Positive and negative childhood experiences can have both immediate and long-term health effects. These experiences usually reflect the child's care environment as well as her neighborhood characteristics. Effects on health can be direct, involving physiologic pathways, or indirect, involving long-term health behaviors. Using a retrospective cohort design, Rauh, Parker, and Garfinkel (2003) found third-grade reading scores in the New York City public schools were significantly related to both individual and community level predictors. At the individual level, male gender, low birth weight, unmarried mother, and low maternal education predicted lower reading scores. Controlling for individual-level risk, lower reading scores were significantly associated with concentrated community poverty, defined as more than 40% of families in the community living below the federally defined poverty level. It is well established that childhood reading ability predicts subsequent educational attainment and avoidance of high-risk health behaviors later in life.

Childhood exposure to lead dust is strongly associated with housing stock, which itself is related to the date of housing construction and neighborhood resources. Using National Health and Nutrition Examination Survey (NHANES III) data from 1988 to 1994, Bernard and McGeehin (2003) found blood lead levels (BLL) were greater than or equal to 5 micrograms/dL in 42.5% of children living



in housing built before 1946 but only 14.1% of children living in housing built after 1973. In this study, non-Hispanic Black children were 3 times more likely to have BLL greater than or equal to 5 micrograms/dL compared to non-Hispanic White children. Cognitive changes associated with lead toxicity include a decrement in IQ, distractibility, poor organizational skills, and hyperactivity. The effects of lead toxicity among children appear to be irreversible and may contribute to adverse behaviors, including delinquency and teen pregnancy (Bellinger, 2004).

Childhood maltreatment, including neglect, physical abuse, and sexual abuse also appear to be related to community social organization. Coulton, Corbin, Su, and Chow (1995) found the highest risk of maltreatment occurred among children who lived in neighborhoods characterized by poverty, high numbers of children per adult resident, population turnover, and concentration of female-headed households. The psychological and physiological effects of childhood maltreatment can be long lasting. In a study of 49 women age 18 to 45, Heim et al. (2000) found women with a history of childhood abuse demonstrated increased pituitary-adrenal and autonomic responses to stress compared to controls. Stress-related peak levels of adrenocorticotrophic hormone (ACTH) were six times higher among women with a history of childhood abuse and current major depression compared to age-matched controls. Dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis has been associated with several diseases in adults, including chronic fatigue syndrome, fibromyalgia, rheumatoid arthritis, and asthma (Heim, Ehler, & Hellhammer, 2000). Developmental neurobiologists are currently examining pathways through which childhood stress and trauma influence brain development and function later in life (Teicher, Anderson, Polcari, Anderson, & Navalta, 2002).

#### ADOLESCENCE

Several studies have found positive associations between neighborhood socioeconomic status and adolescent educational attainment (including years of schooling completed), probability of completing high school, and likelihood of attending college (Leventhal & Brooks-Gunn, 2000). Depending on the study, neighborhood socioeconomic status represents one or more of the following community characteristics: percentage of college-educated residents, percentage of residents living below poverty, percentage of managerial/professional residents, high school drop-out rate, levels of female family headship, and female employment. Coulton and Pandey (1992) found teen birth and juvenile delinquency rates were higher among adolescents living in Cleveland census tracts where more than 40% of the population lived below the poverty threshold.

An evaluation of a scattered-site public housing program in Yonkers, New York, revealed that youths who remained in low-income neighborhoods were more likely to have used marijuana in the prior year and show signs of problem drinking in the previous month compared to adolescents who moved to middle-income neighborhoods (Briggs, 1997). In the National Survey of Adolescent Males, a high rate of neighborhood unemployment was associated with impregnating someone and fathering a child (Ku, Sonnenstein, & Pleck, 1993).

Mediation of the relationship between neighborhood characteristics and adolescent behaviors likely involves several pathways. In a review of this literature,

Jencks and Mayer (1990) described five conceptual models or pathways of influence, each emphasizing a different neighborhood construct: institutional resources, collective socialization, contagion or epidemic effects, competition, and relative deprivation. In their study of 877 Los Angeles adolescents, Aneshensel and Sucoff (1996) found evidence for some of these effects. In this study, youth in low socioeconomic status neighborhoods perceived greater ambient crime, violence, drug use, and graffiti compared to youth living in neighborhoods with high socioeconomic status. This effect was independent of individual socioeconomic status, and the perception of neighborhood hazard was associated with symptoms of depression, anxiety, oppositional defiant disorder, and conduct disorder. These results suggest that neighborhood characteristics can have important effects on adolescent physical health and social behavior.

#### ADULTHOOD

Several dimensions of the neighborhood environment have been linked to illness and mortality among adults. These dimensions include crime rates, ratio of homeowners to renters, percent of residents receiving public assistance, index of segregation, percentage of unemployment, percentage of households headed by women, income, education, collective efficacy, and housing value. As with studies of children and adolescents, the central question is whether neighborhoods truly influence health outcomes or if differences in health are simply due to differences in the age, race/ethnicity, and health behaviors of the residents. In other words, do contextual effects exist above and beyond the compositional associations with health? As mentioned before, one way to address this question is to perform multilevel analysis, which simultaneously accounts for individual- and neighborhood-level variables.

One of the earliest studies demonstrating a contextual, or area, effect examined mortality over a 9-year period in Alameda County, California (Haan, Kaplan, & Camacho, 1987). From the 1,811 study participants, data were obtained regarding baseline health conditions, socioeconomic factors, health practices, social networks, and psychological factors. The researchers also noted if the participants lived in a designated poverty area. Analysis revealed the age-, sex-, and race-adjusted relative risk of mortality was 1.71 times higher among those living in poverty areas compared to those living in non-poverty areas. The addition of baseline health conditions and other individual characteristics to the analysis lowered the relative risk of mortality slightly, but it remained significantly higher among poverty area residents. The authors speculated that adverse health outcomes in poverty areas were mediated by higher crime rates, poorer housing, lack of transportation, higher levels of environmental contaminants, or a combination of these factors.

In another study, individual- and family-level information from the 1986 national Americans' Changing Lives study was linked to 1980 census information to assess the relative effects of personal and neighborhood characteristics on three health outcomes: number of chronic conditions experienced in the previous year, level of functional limitation, and self-rated health (Robert, 1998). The individual-level indicators were age, race, gender, and education while the family-level indicators were income and level of assets. At the community level, four indicators



were included: percentage of households receiving public assistance, percentage of families with an income of \$30,000 or more, percentage of adult unemployment, and a composite index of the three.

Initial bivariate analysis indicated that education and family income were more highly correlated with all three measures of health compared to the community-level variables. Controlling for individual-level and family-level socioeconomic status, the percentage of households receiving public assistance had an independent association with self-rated health. In addition, percentage of families earning \$30,000 or more, percentage of adult unemployment, and a composite economic disadvantage index each had associations with several chronic conditions when individual- and family-level socioeconomic status were controlled. Robert (1998) concluded that while individual-level variables are stronger predictors of health, community-level indicators appear to have significant associations with health.

LeClere, Rogers, and Peters (1998) used multilevel analysis to assess neighborhood effects on female heart disease mortality. Data from the National Health Interview Survey (1986 to 1990) were linked to death certificate information from the National Death Index and the 1990 U.S. census at the census tract level. Individual-level information from the National Health Interview Survey included age, race, body mass index, preexisting conditions, income, education, marital status, and employment status. Census information included percentage of families in the census tract headed by women, percentage of persons in the census tract who were Black, median family income, percentage of households who received public assistance, and unemployment rate.

For both White Americans and African Americans, heart disease rates were higher in the poorest census tracts. Adjusting for individual-level characteristics in the multilevel model, this study found women living in communities where more than one-quarter of the families are headed by women were more likely to die of heart disease compared to women who live in neighborhoods with fewer female-headed households. The authors hypothesized that neighborhoods with high proportions of female-headed households may be associated with increased financial, physical, and emotional stress. Stress and other psychosocial risk factors may contribute to heart disease either directly, through acceleration of the atherosclerotic process, or indirectly, through adverse coping behaviors such as smoking, increased caloric intake, or increased alcohol intake (Williams, Barefoot, & Schneiderman, 2003).

These studies provide evidence that the neighborhood environment exerts an effect on health independent of individual characteristics. However, as more individual characteristics are included in multilevel models, the neighborhood effects on health seem to diminish. In addition, some neighborhood effects may be more deleterious than others. Among the studies reviewed, the most commonly cited culprits are poor housing quality, exposure to toxins, and psychological stress.

#### END OF LIFE

Among older individuals, the intensity of medical care received at the end of life varies by community. McAndrew-Cooper, Wennberg, and Center for the Evaluative Clinical Sciences Staff (1999) used 1995 to 1996 Medicare billing in-

formation to compare frequency and types of care delivered to older adults in the last 6 months of life. They found that end-of-life issues “are resolved in ways that depend on where the patient happens to live, not on the patient’s preferences or the power of care to extend life.” For example, in some communities, the chance of being hospitalized at the time of death was 20%; in other communities, this proportion was 50%. During the last 6 months of life, the chance of spending a week or more in an intensive care unit also varied by community, ranging from less than 4% to over 20% of patients. The number of physicians who care for patients in the last 6 months of life, also called “intensity of care,” varies by community. In some areas, 30% of patients were seen by 10 or more physicians while in other areas, fewer than 3% received care from this number. Interestingly, variations in intensity of care reflected amount of health-care resources more than underlying levels of illness in the community. Also, variations in intensity of care did not predict improved outcomes. That is, mortality rates among older sick individuals were not lower in communities providing more intensive medical care.

McAndrew-Cooper et al. (1999) acknowledged that while mortality was not associated with intensity of care, increased spending and services at the end of life may be associated with improved comfort measures and quality of death. Comfort measures are obviously desirable, but do most people want to be in an intensive care unit at the end of life? A study of patients with life-threatening illnesses indicated that 82% would prefer to die at home rather than in the hospital if they were told by their physician they had “very little time to live” (SUPPORT, 1995). Given the results of these studies, it appears that some communities are better at allocating resources and addressing the needs and wishes of gravely ill Medicare recipients than others.

### IMPLICATIONS FOR SOCIAL WORK PRACTICE

The studies reviewed in this chapter suggest that neighborhoods can positively influence health by providing access to high-quality medical care, healthy foods, and green space for exercise, as well as by minimizing exposure to crime, toxins, and infectious disease. Neighborhoods can also negatively influence health through poor housing stock, exposure to chemical and biological pathogens, decreased access to medical care, promotion of adverse health behaviors, and through ambient psychological stressors. These effects raise important questions for social work practice. For example, from a social work perspective, is it more efficient to help individuals improve their living situation on a case-by-case basis or through community-wide interventions? If a neighborhood is physically or psychologically unhealthy, does it make more sense to help individuals move out of the neighborhood or to advocate community change? The answers to these questions are reflected in the diversity of strategies currently taken by social workers. That is, some social workers address problems at the individual level, others work for change at the community level, and still others do both. Neighborhood improvement is a slow process and often requires political, administrative, and community organizing abilities. Providing services to individuals also requires administrative ability as well as knowledge of resources and persistence. Both community- and individual-level development strategies are essential, and both should be supported to a greater extent by public policy.

MacIntyre, MacIver, and Sooman (1993) believe neighborhood improvement has received short shrift in the policy arena. They argue that unhealthy behaviors and many diseases arise from adverse environments and that improvements in the physical and social environment can lead to improved health behaviors and health. Instead of encouraging working-class populations to act more like middle-class populations, MacIntyre and colleagues believe public policy should foster the transformation of working-class neighborhoods into middle-class neighborhoods.

However, garnering support for investment in low-income communities is time-consuming and is often viewed as a low priority among private and public institutions. Even when support is obtained and a plan is in place for community improvement, several pitfalls must be avoided. One of them is the population displacement that can occur with gentrification. For example, a recent \$150 million proposal to build 550 new single-family homes in Chicago's economically depressed Englewood neighborhood is being opposed by some working-class and senior residents who are concerned that rent and property tax increases will force them out. Although about 20% of the proposed homes will be set aside for low-income families, most observers believe housing costs in the other units will be too high for local residents (Olivo, 2004). Therefore, while neighborhood improvement is beneficial for many, the unintended consequences for low- and fixed-income residents must be considered.

Assisting individuals or families to find housing in healthy environments is an important service provided by many social workers. In some cases, such assistance can mean the difference between health and illness or even life and death. But relocation also has pitfalls. Moving to a new neighborhood can lead to disruption of social networks and loss of support systems. Minorities or individuals with lower incomes may also feel stressed in high-income neighborhoods, especially if there is little ethnic or economic diversity. Analyzing 11 years of data from Alameda County, California, Yen and Kaplan (1999) found that low-income individuals living in a neighborhood with high socioeconomic status had significantly higher mortality rates compared to low-income individuals living in neighborhoods with low socioeconomic status. The authors hypothesize that differential access to resources and psychological stress contributed to this disparity. The implication for social workers and other service providers is that relocation is not without cost, and every effort should be made to help individuals access services and develop support networks in their new communities.

An additional cost of relocation can be incurred by those who remain in impoverished communities. Typically, individuals who leave economically depressed neighborhoods are either employed or have higher levels of education and job skills. Out-migration of human capital means that those who remain have fewer community resources and fewer successful role models (Wilson, 1996). This can result in further community deterioration, including loss of educational and health-care services and exacerbation of health problems among those left behind.

This problem is partially mitigated if all members of a community leave or are relocated. For example, the Chicago Housing Authority is in the process of relocating all residents of the Robert Taylor Homes (a series of 28 high-rise public housing buildings on Chicago's South Side) to subsidized housing throughout the city. The subsidized housing includes mixed-income units being constructed on the site of the former Robert Taylor Homes. In contrast to neighborhoods that have suffered from out-migration of social capital, this program will result in the

evolution of an impoverished area into a middle-class community. However, it will occur at the expense of near complete turnover of neighborhood residents and the disruption of many family and social network ties.

Neighborhood change in the other direction (from middle class to working class) can also occur when economic and ethnic integration occurs too rapidly. The early history of Chicago's Englewood neighborhood is an example. In the first half of the twentieth century, Englewood was a popular destination for German, Swedish, and Irish immigrants pursuing the American dream of home ownership. When African American residents moved to Englewood to pursue the same dream in the 1960s and 1970s, "White flight" ensued and the population decreased from 90,000 in 1960 to 40,000 in 2000 (Kouvelis, Harper, & Thomas, 2003). Majority exodus when a tipping point is reached is a common problem and presents a recurring challenge for politicians and community planners. How can neighborhoods be integrated without inducing rapid turnover and without incurring property tax and rent increases that overburden low-income residents? In her study of the history of integration, Cashin (2004) notes that rapid neighborhood turnover is less likely to occur when the minority percentage does not exceed a certain proportion or when three or more ethnic groups coexist, none more dominant than the other. While integration control is not always necessary, many communities closely monitor the status and effects of integration. Some have done so to enhance integration while others have done so to discourage it. Working at planning and administrative levels, social workers can monitor and help influence patterns of integration in their own communities. They can also help families and individuals negotiate the often arcane rules of subsidized housing and ensure that new residents have access to community resources.

Another strategy to improve neighborhoods is through Empowerment Zones—economic development programs begun during the Clinton administration. Through this initiative, urban Empowerment Zones and Enterprise Communities receive federal tax credits and Block Grants to design and fund economic development, housing, job training, and social programs (Dixon, 2000). Since 1993, this program has had several successes, including the creation of new businesses, job training programs, and new or rehabilitated housing for the homeless. However, a perception exists that ineffective oversight and improper handling of funds have limited the success of this program (McDavid, 1998). Many community residents report Empowerment Zone funds have not reached the street level where it is needed most (Dixon, 2000). In collaboration with administrators and community leaders, social workers can help ensure that Empowerment Zone jobs and resources reach the street level and provide resources to small business owners, entrepreneurs, and job seekers. All citizens should take an interest in taxpayer-funded programs such as the Empowerment Zone initiative. Social workers have the training and skills to monitor and deploy them as originally designed.

Placing cash in the hands of community residents through increased employment and wages may represent the best strategy for community transformation. That this so rarely happens illustrates the challenges of this approach. Recent U.S. economic indicators suggest wage increases have occurred at a much greater rate among the wealthy compared to the poor. Between 1979 and 2000, after-tax incomes increased by 201.3% among the top 1% of wages earners while the increase was only 68.3% among the highest fifth and 8.7% among the lowest fifth (Greenstein & Shapiro, 2003). Some argue that relative differences in in-

come are more important to health than actual differences (Wilkinson, 1999). Health data from Cuba are consistent with this notion as life expectancy in Cuba is equivalent to that in the United States while per capita GDP and income disparities are a fraction of that in the United States.

Utilizing progressive taxation policies, many nations in Europe have had more success in pursuing economic parity. These policies have enhanced social security and reduced income-related health differences. Published in 1998, Britain's Acheson report on health disparities recommends specific steps to reduce these disparities further, including increased cash and services to poor women, expectant mothers, children, and the elderly. Additional resources for schools and job training programs as well as improved housing for the poor are also recommended (Acheson, 1998). In the United States, many politicians have recently decried the "off-shoring" of jobs to low-wage locales and have called for tax incentives to retain American jobs. Some of these efforts reflect increasing recognition of the growing disparities in employment, income, and community resources in the United States. Whether this rhetoric reflects an appreciation of the link between neighborhood characteristics and health remains to be seen, but efforts in this direction have gained momentum in other countries and should be supported in the United States.

Social workers can play a key role in advocating economic reform and directing community improvement. As professionals who work on the "front lines," social workers observe firsthand the effects of unemployment, low wages, and lack of health insurance. Inability to afford housing, strained family relationships, and deferred treatment for illnesses are just a few of the outcomes social workers encounter on a daily basis. Recognizing the need for systemic change, social workers often lead the way in bringing attention to resource-poor communities. Testifying before city and state legislatures, writing editorials in local newspapers, highlighting deficient city services, and forming community-based service organizations are just a few of the ways social workers have succeeded in raising awareness of community needs.

A large volume of evidence indicates that individual health is influenced by community characteristics and resources. Because so many communities face economic and resource challenges, the opportunities for social workers to have a significant impact are enormous. This can occur at the individual level as well as at the community and national levels. Whatever strategy is chosen, those who strive to improve the social and physical environment of others can be assured that such efforts will have long-lasting and significant health benefits.

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## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 6.1

Identify the characteristics of a local neighborhood that appear to have the most important effects on the health of its residents.

### LEARNING EXERCISE 6.2

List the physical, social, and health-care needs of individuals who live in an economically depressed community.

## LEARNING EXERCISE 6.3

Discuss why health outcomes in Cuba are comparable to those in the United States despite fewer resources.

## LEARNING EXERCISE 6.4

List the ways in which social workers can promote community development.

## LEARNING EXERCISE 6.5

Develop policy recommendations for successful integration and neighborhood improvement.

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PART II

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HEALTH SOCIAL WORK  
PRACTICE: A SPECTRUM OF  
CRITICAL CONSIDERATIONS



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## CHAPTER 7

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# Theories of Health Behavior

SARAH GEHLERT

**T**HEORIES OF HEALTH behavior have the potential to order the panoply of constructs with which health social workers are faced and provide a conceptual framework that assists in understanding why people behave as they do in terms of their health. These theories provide direction for the helping process and structure for research. They allow us to unite practice and research by providing a shared language for discussing clinical realities.

A review of the 15 health social work model syllabi selected in 1999 by jury in conjunction with the Council on Social Work Education (Copeland, Jackson, Jarman-Rohde, Rosen, & Stone, 1999) revealed a paucity of items related directly to health behavior theory. This is indeed the case, although leading social work textbooks for years have emphasized the importance of theory in social work practice and research. Hepworth, Rooney, and Larsen (2002), for example, say that “to analyze problems, persons, and situations, to plan remedial interventions, and to implement appropriate techniques requires an adequate grasp of practice theory and knowledge about human behavior in the social environment” (p. 17).

We could say that social workers in health care make ample use of theory if our definition of practice theory were limited exclusively to orienting theories, such as cognitive, behavioral, group, or family systems. Social work interventions are based on orienting theories, most of which come from the field of psychology. Sheafor and Horejsi (2006) say that “most practice theories are rooted in one or more orienting theories” and give the example of “psychosocial therapy, which is based primarily on psychodynamic theory and ego psychology” (p. 51). Social workers in health care have used orienting theories amply and creatively, such as the adaptation of cognitive and behavioral theories to produce stress inoculation (Blythe & Erdahl, 1986), a technique for preparing patients for difficult medical procedures.

This chapter argues, however, for a different category of theories that are equally important to practice, namely, theories of health behavior. Although orienting theories and theories of health behavior are related, they differ in two ways. First, orienting theories can be seen as narrower than theories of health behavior, because they focus on the origin and treatment of human problems rather



than the full constellation of human behavior. Theories of health behavior are germane to all behaviors, not just those that are problematic. They might be used to consider why people protect their health through exercise and regular physician visits, for instance. Second, theories of health behavior, while considering all types of behavior, restrict themselves to the arena of health. Orienting theories, on the other hand, are concerned with problematic behavior in many areas, including health, education, employment, and marriage.

The contention of this chapter is that adding theories of health behavior to our definition of practice theory represents the addition of valuable tools for social work practice and research in health care. After a brief discussion of the uses of theory in social work, a select group of theories of health behavior will be introduced and reviewed. Each will be discussed in terms of its past uses in health practice and research, its strengths and limitations, and empirical evidence of its ability to explain health behavior.

### CHAPTER OBJECTIVES

- Define theory in general and theories of health behavior in particular.
- Distinguish theories of health behavior from orienting theories.
- Discuss ways in which theories of health behavior could be used to advance social work practice in health care.
- Discuss ways in which theories of health behavior could be used to advance social work research in health care.
- Describe the Health Belief Model, its limitations, and the empirical evidence for its use.
- Describe the Theory of Reasoned Action, its limitations, and the empirical evidence for its use.
- Describe how the Theory of Planned Action extends the Theory of Reasoned Action and the empirical evidence for its use.
- Describe the Social Action Theory, its limitations, and the empirical evidence for its use.
- Describe the Behavioral Model of Health Services Use, its limitations, and the empirical evidence for its use.
- Distinguish among the five theories in terms of their limitations and empirical evidence available for their use.

### THE USE OF THEORY IN SOCIAL WORK PRACTICE AND RESEARCH

Kerlinger (1986) defines theory as “a set of interrelated constructs, definitions, and propositions that present a systematic view of phenomena by specifying relations among variables, with the purpose of explaining and predicting the phenomena” (p. 9). He defines constructs as concepts that have been “deliberately and consciously invented for a special scientific purpose” (p. 27). Constructs such as well-being, self-esteem, and aggression are widely used in social work. By virtue of their ability to propose relationships among constructs, theories provide order in what otherwise might be an overwhelming confusion of abstract ideas. This is especially important in social work, in which abstract, less perceptible

constructs, such as aggression and self-esteem, are considered instead of the discrete, directly measurable subjects of inquiry of the natural sciences (e.g., molecular weight or temperature). Theory helps to order the panoply of constructs with which social workers are faced, providing a conceptual framework that assists in understanding client problems and, in doing so, provides directions for proceeding with the helping process.

Theory not only provides order for what is going on with any one client situation or with clients of the same social worker, but also allows us to compare across practice situations and settings. In this way, we gain a shared understanding of the dynamics of certain constellations of behavior within the field. In addition, theory allows us to unite the arenas of research and practice by providing a shared language for discussing clinical realities.

Understanding how constructs relate to one another in the present allows us to predict how they are likely to operate in the future and, thus, to plan interventions. Glanz, Lewis, and Rimer (1997) write that "a health educator without theory is like a mechanic, or a mere technician, whereas the professional who understands theory and research comprehends the why and can design and craft well-tailored interventions" (p. 21). The knowledge that a certain action, covert or overt, will likely lead to another action makes it possible to intervene to promote behaviors that will lead to desired outcomes and decrease the likelihood of undesired outcomes. If we know for instance that people who understand their risk for acquiring a disease will be more likely to engage in preventive behaviors, interventions can be developed to focus on conveying risk.

Theories and skills are natural partners in social work practice. As the time allotted to assess and treat client problems decreases, tools that facilitate assessment and the development of effective treatment approaches increase in value. Theory represents the accumulation of knowledge about human behavior that is necessary to inform our use of skills. Relying on theories to assist in constructing interventions increases the likelihood that they will be successful. If successful interventions are implemented as soon as possible after problems are noted, the hopelessness that results from multiple treatment failures can be avoided.

An example of how theory provides guidance for practice comes from an empirical study of adults with epilepsy. Adults with epilepsy experience high rates of psychosocial problems, such as a suicide rate five times that of the population as a whole for all types of seizures combined and 25 times higher for seizures that originate in the temporal limbic system of the brain (Hauser & Hesdorffer, 1990). In attempting to understand the etiology of these psychosocial problems so that effective interventions could be designed and implemented, Gehlert (1994, 1996) hypothesized that some persons with epilepsy generalized their lack of physical control, as represented by epileptic seizures, to the social realm, causing them to have very low expectations that any of their behavioral efforts would result in foreseeable outcomes. The basis for this hypothesis was that repeated disruptions in the action-to-outcome sequence, such as when a young girl wants to succeed in school yet cannot because her parents are unable to provide her with clothing and books, led to a learned helpless state accompanied by high rates of depression and other psychosocial problems. Attribution theory (Abramson, Seligman, & Teasdale, 1978; Kelley, 1967; Weiner, 1985), which predicts depression for persons who attribute negative events in their lives, such as not being able to get or keep a job, to their own doing and positive events, such as being given a

compliment, to outside influences (e.g., other persons, fate, or luck) was helpful in making sense of how constructs such as seizure control and psychosocial problems fit together.

Although not a theory of health behavior per se, Attribution Theory (Abramson et al., 1978; Heider, 1958; Kelley, 1967) has been used widely to explain behavior. The theory holds that people, when faced with a world over which they have little control, attempt to impose control by offering explanations or causes for what happens to them. Illness is an example of a situation over which people have little control, and therefore it elicits causal explanations.

Abramson, Seligman, and Teasdale (1978) speak of three dimensions of causal attributions: (1) internality versus externality, or whether the cause is do to the person or to other persons or circumstances; (2) globality versus specificity, or whether the same explanations are used for a variety of factors or are specific to one or a few factors; and (3) stability versus instability, which has to do with whether a factor is long-lasting or transient. Pessimistic attributional style is said to occur when persons make stable, global, internal attributions for bad events.

Attributions, the dimensions of which are measured using either the Attributional Style Questionnaire (Peterson et al., 1982) or the CAVE technique (Content Analysis of Verbatim Explanations; Peterson, Bettes, & Seligman, 1985), are useful in explaining health behavior. Peterson, Seligman, and Vaillant (1988) divided 99 graduates of the 1942 to 1944 classes of Harvard University into those with optimistic and pessimistic attributional styles and followed their physical health at 5-year intervals for 30 years. They found pessimistic attributional style to predict poor health at ages 45 through 60, even when controlling for mental and physical health at age 25. The authors proposed that persons with pessimistic attributional styles might tend to become passive in the face of illness and be less able to solve problems and to have fewer supportive social networks to buffer against stress.

In the example of epilepsy, understanding how a key cognitive component of learned helplessness, termed negative attributional style, developed in persons with epilepsy helped to determine both a point and target of intervention. For example, people with epilepsy are faced with multiple messages from others that they are not as efficacious as other people. Even the most benign actions of others, such as assistance during a seizure, convey subtle messages of inefficacy and lack of control that, when internalized by persons with epilepsy over the years, lead to negative attributional style. A small group intervention in which individuals with epilepsy were helped to identify when negative thoughts are likely to occur, stop the thoughts, and substitute more realistic appraisals that have proved effective in decreasing their negative attributional style and depression (Gehlert, 1995).

#### RATIONAL CHOICE-BASED THEORETICAL APPROACHES

The first theories of health behavior to be considered hold that human behavior stems from rational, logical thought processes. People make health choices largely based on consideration of the costs and benefits of various actions. The two major versions are the Health Belief Model and the Theory of Reasoned Action. The Theory of Planned Behavior (Ajzen, 1991; Ajzen & Madden, 1986) is an extension of the Theory of Reasoned Action and not a theory in itself.

## THE HEALTH BELIEF MODEL

The Health Belief Model (Hochbaum, 1958; Rosenstock, 1960, 1966, 1974) was originally developed to explain why people failed to participate in health screening for tuberculosis, despite accommodations such as mobile vans that came into neighborhoods. The model posits two major components of health behavior: threat and outcome expectations (see Table 7.1). Threat is made up of perceived susceptibility to an ill-health condition and the perceived seriousness of that condition. In the case of risk for acquiring AIDS, for example, threat would entail believing that one was susceptible to acquiring AIDS and that it was as serious as the medical community portrayed it to be.

Outcome expectations are the perceived benefits of a specified action, such as using condoms to prevent the transmission of HIV, and the perceived barriers to taking that action. The benefit of taking action to reduce the risk of acquiring AIDS might be staying alive, whereas barriers might be the cost of buying condoms or fear that one will be rejected after asking a partner to use them.

The Health Belief Model has been used with a variety of health behaviors and conditions. These include medication compliance among psychiatric outpatients (Kelly, Mamon, & Scott, 1987), obtaining influenza vaccination by individuals at high risk for acquiring life-threatening complications of influenza (Larson, Bergman, Heidrich, Alvin, & Schneeweiss, 1982), and lower-socioeconomic-status mothers' adherence to weight-loss regimens for their obese children (Becker, Maiman, Kirscht, Haefner, & Drachman, 1977).

Empirical evidence supports the Health Belief Model's ability to predict health outcomes. Becker et al. (1977; Maiman, Becker, Kirscht, Haefner, & Drachman, 1977) were able to explain 39% of the variance in dietary adherence using the Health Belief Model's components in multiple regression analysis. This means that when components of the Health Belief Model, such as perceived susceptibility, were measured in a group of people whose dietary adherence was also measured, the model's components were relatively important to understanding dietary adherence. Although other factors must be considered to fully explain what determines dietary adherence, the Health Belief Model adds significantly to our ability to understand the phenomenon. Janz and Becker (1984) published a meta-analysis of 18 prospective and 28 retrospective applications of the Health Belief Model completed during the first 30 years of its use. The ability of each component of the Health Belief Model to predict health outcomes, such as adopting health preventive behaviors, was calculated by dividing the number of positive, statistically significant findings for a component by the number of studies

**Table 7.1**  
Major Elements of the Health Belief Model

- 
- I. Perceived Threat
    - A. Perceived susceptibility
    - B. Perceived severity
  - II. Outcome Expectations
    - A. Perceived benefits
    - B. Perceived costs
  - III. Expectations of Self-Efficacy
-

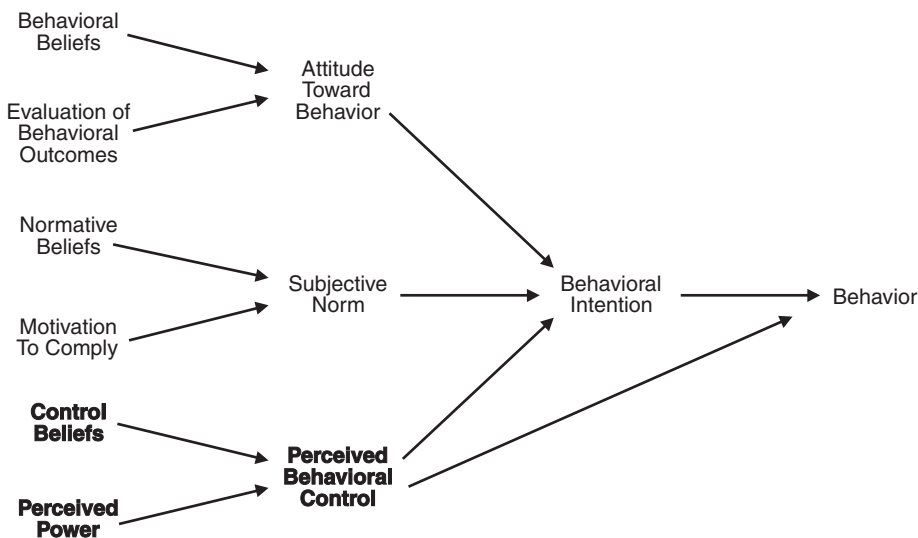
for which significant results were obtained. Perceived threat was the most and perceived costs the least significant predictor of outcomes, with perceived susceptibility and perceived benefits intermediate between the two. This suggests the perceived impediments to engaging in a behavior to improve health (whether they are real or not), such as fear of losing one's hair from radiation therapy for cancer, are more significant than other factors (perceptions of severity, susceptibility, and benefit) in determining whether a person will engage in the behavior. Perceived severity is the least significant factor in determining behavior.

#### THE THEORY OF REASONED ACTION

The Theory of Reasoned Action (Fishbein, 1967; Fishbein & Ajzen, 1975) extends the Health Belief Model to include the influences of significant others in the environment on individual health behavior. The theory assumes that behavior is immediately determined by behavioral intention (see Figure 7.1). Behavioral intention is, in turn, determined by a person's attitude toward the behavior and the influence of significant others in the environment, or *social norm*. Attitude toward the behavior consists of two things: (1) an individual's belief that if a behavior is performed, a given outcome will accrue and (2) how important the individual considers the outcome to be.

Social norm is made up of beliefs about what valued others will think about one's performing a behavior coupled with the individual's motivation to comply with their opinions. As an example, a practitioner might consider a young woman's perceptions of what her boyfriend, closest friend, mother, and physician would think about her having an abortion and her motivation to comply with their opinions in attempting to understand or predict her behavior.

The Theory of Reasoned Action has been applied to many health behaviors and conditions, including substance abuse (Beck, 1981), weight loss (Sejwacz, Ajzen,



**Figure 7.1** Combined Theory of Reasoned Action (TRA) and Theory of Planned Behavior (TPB). Components shared by the TRA and TBP are shown in regular type. Those unique to the TPB are shown in bold type.

& Fishbein, 1980), and hypertension (Norman, Marconi, Schezel, Schechter, & Stolley, 1985). Because of its inclusion of others who hold influence over the individual, the Theory of Reasoned Action has been widely used in studies of the health behavior of adolescents, often in the area of contraception decision making (Baker, 1988), abortion (Smetana & Adler, 1986), and AIDS risk behavior (Jemmott, Jemmott, & Fong, 1992). Baker (1988) was able to predict 36% of the variance in intention to use condoms with steady partners and 8% with new or infrequent partners by the use of attitude toward condom use and subjective norm among patients in a sexually transmitted disease clinic. Jemmott et al. (1992) designed an intervention for African American adolescent males that emphasized knowledge, attitudes, and skill building based on the Theory of Reasoned Action to decrease intentions to engage in AIDS risk behavior and the behavior itself. Adolescents who received the intervention reported significantly fewer occasions of coitus, fewer partners, greater use of condoms, and a lower incidence of heterosexual anal intercourse than did adolescents in the control condition.

#### THE THEORY OF PLANNED BEHAVIOR

Ajzen and Madden (1986; Ajzen, 1991) extended the Theory of Reasoned Action to include perceived control over behavior. Their idea was that intention alone could not predict behavior if the behavior was one over which the individual did not have complete control (see Figure 7.1). Perceived behavioral control is assumed to reflect past problems encountered in behavioral performance. In other words, if a person has been unsuccessful in engaging in a behavior in the past, such as losing weight, and thus has demonstrated poor control over the behavior, it is less likely that he will be able to execute it, no matter how strong his intentions.

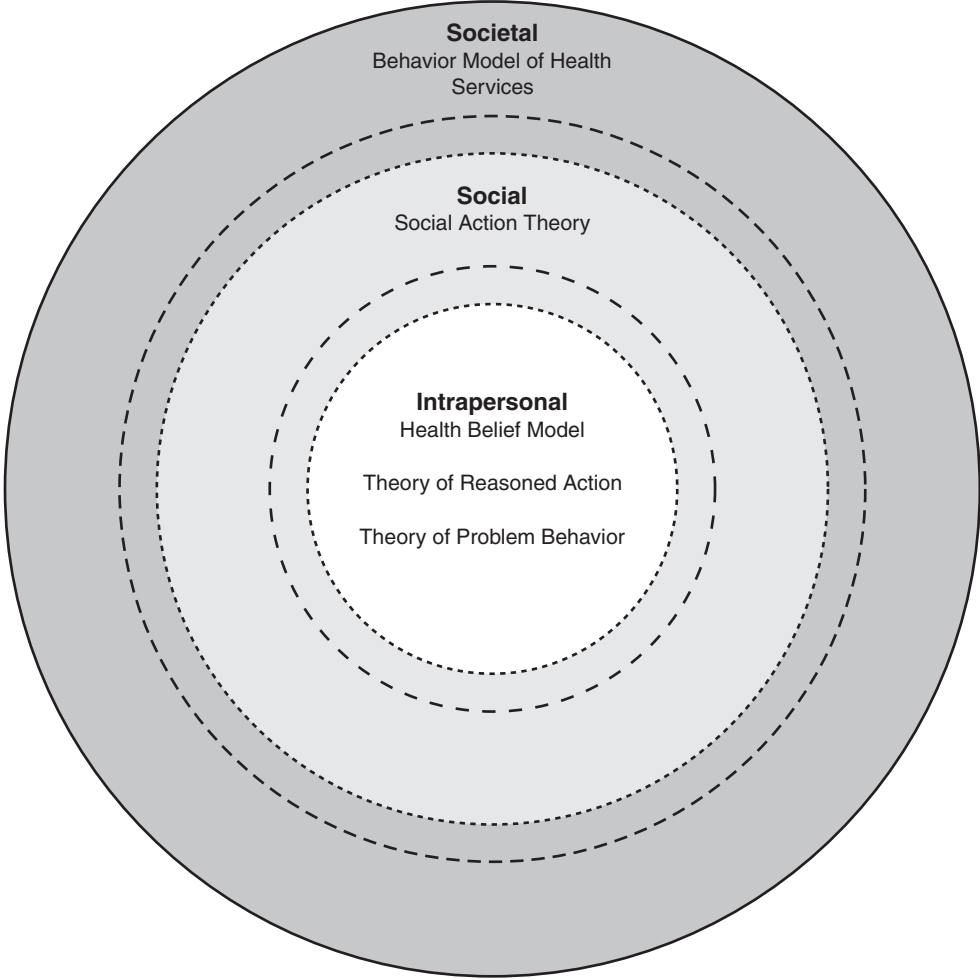
The Theory of Planned Behavior has been widely used to predict behaviors as diverse as the administration of opioids for pain relief by nurses (Edwards et al., 2001), cervical cancer screening (Sheeran & Orbell, 2000), and fighting by adolescents (Jemmott, Jemmott, Hines, & Fong, 2001). In a review of studies in which behavior was predicted via intentions alone, as in the Theory of Reasoned Action, and in combination with perceived behavioral control, as in the Theory of Planned Behavior, behaviors that required more volitional control and with which the individual had negative experiences in the past, such as losing weight and getting high grades, were better predicted by the combination of intentions and perceived behavioral control than by intentions alone (Ajzen, 1991). A meta-analysis of 96 studies found the Theory of Planned Behavior to predict condom use less accurately than did the Theory of Reasoned Action (Albarracín, Johnson, Fishbein, & Muellerleile, 2001). A recent meta-analysis of 185 studies using the Theory of Planned Behavior prior to the end of 1997 found the Theory of Planned Behavior to account on average for 27% of the variance in health behavior (Armitage & Conner, 2001).

#### SOCIAL NETWORK-BASED THEORETICAL APPROACHES

The impetus for social network-based approaches came from critiques that rational choice approaches did not adequately take into account environmental influences on behavior. The Health Belief Model is entirely intrapersonal, and even

the Theory of Reasoned Action and Theory of Planned Behavior fail to acknowledge influences on health behavior outside the individual's immediate environment. Missing is an appreciation for the influences of social networks and structures on health behavior. In a second category of theoretical approaches, social network-based approaches, the emphasis shifts from individual mental events to social relationships, recognizing the social nature of individuals (Tilly, 1984). This shift in emphasis helps to avoid another criticism of rational choice-based approaches, namely, that they ignore the influence of culture on health behavior.

If we conceptualize health decisions made by individuals as the centermost of three concentric circles, social network-based approaches add two adjacent bands or layers (see Figure 7.2). The middle layer is comprised of social networks and



**Figure 7.2** Concentric circles representing the three layers of influence on health behavior, with theories and models superimposed. The Behavioral Model of Health Services Use is on a stippled background. Social Action Theory is on a background that is dotted. The Health Belief Model, Theory of Reasoned Action, and Theory of Planned Behavior are on a clear background.



the outer layer the larger social system, which is made up of governmental and economic entities and forces. Two approaches that consider the middle and outer layers of influences on health behavior are Social Action Theory (Ewalt, 1991) and the Behavioral Model of Health Services Use (Anderson, 1968, 1995).

#### SOCIAL ACTION THEORY

Social Action Theory (Ewalt, 1991) represents a marriage of psychological and public health models and principles. The prevailing model in public health is a three-way interaction between host, agent, and environment. Whereas rational choice-based approaches are concerned exclusively with the host, Social Action Theory encourages a social-contextual analysis of personal change by suggesting pathways by which social and other environmental factors influence cognitive processes. The model contains three dimensions: (1) self-regulation as a desired action state; (2) a system of interrelated change mechanisms; and, (3) larger environmental systems that contextually determine how personal change mechanisms operate (see Box 7.1; Ewalt, 1991, p. 932). Individuals' desired states are influenced by what is necessary to achieve goals such as social influence, personal safety, material resources, and intimacy (Ewalt, 1991, p. 936).

The health routines and habits that ensue are entwined with those of others, and how these relationships develop has the potential to either promote or inhibit the goals of individuals or the prescriptions of health providers. Recommended change in diet for a child with diabetes, for instance, would require a parent to shop for and prepare different foods or serve two separate meals to the family. Health decisions, therefore, are viewed as being embedded in the social network. While the Theory of Reasoned Action views social networks as influences on health behavior, Social Action Theory considers them to be mechanisms of action. Others are viewed as active players rather than as outside influences on behavior and are thus inside the lens of inquiry.

Social Action Theory holds that social ties strongly influence the success of attempts to alter behavioral routines, such as lowering dietary fat, increasing physical activity, or engaging in less risky sexual practices. Failure to adhere to health-enhancing regimens has been linked to conflicts that arise when family members' routines are disrupted (Oldridge, 1982). This provides guidance for the choice, development, and targeting of interventions, often by specifying when and how significant others should be included in the treatment process.

#### **Box 7.1** **Social Action Theory**

##### Influences on Health Behavior

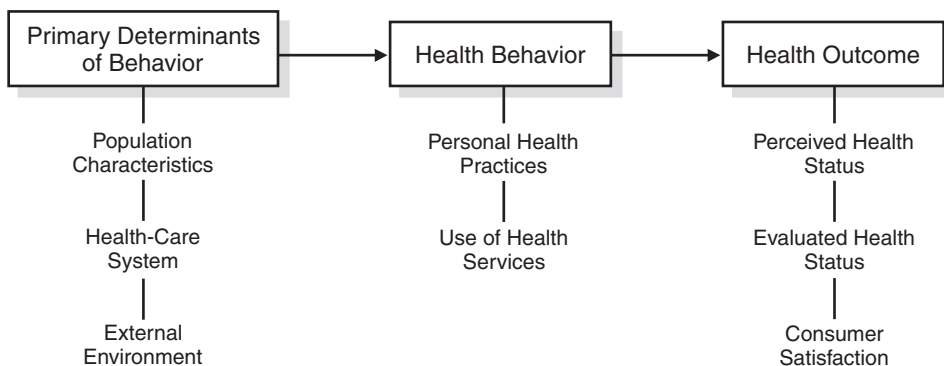
- Personal level (health habits, personal projects, action states, motivation)
- Social level (social and biological contexts, social interdependence, social interaction processes, action linkages)
- Societal level (organizational structures at the level of government; economic, educational, and health-care systems; laws; policies)

Since Social Action Theory is a fairly new approach, its applications have been fewer. McCree (1997) found high relationship closeness, favorable attitudes toward condom use, high self-esteem, and a secure attachment style to best predict condom use among a sample of African American women. This suggested interventions focused on increasing self-efficacy, improving sexual responsibility, and creating more favorable attitudes toward condom use among women and their sexual partners. Social Action Theory has also successfully been applied to the promotion of more healthful behavior and well-being after heart attacks (Ewalt & Fitzgerald, 1995).

#### THE BEHAVIORAL MODEL OF HEALTH SERVICES USE

The Behavioral Model of Health Services Use has gone through three phases since its development in the 1960s (Anderson, 1968, 1995) and fairly recently underwent another major revision, the Behavioral Model for Vulnerable Populations (Gelberg, Anderson, & Leake, 2000). The model differs somewhat from the approaches outlined previously in its emphasis on health services use and the outcomes of health behavior. Originating in medical sociology, it considers a bigger picture of the influences on health behavior, such as aspects of the health-care system.

The original model (Anderson, 1968) divided determinants of health service use into three groups of variables: predisposing, enabling, and need. Predisposing were variables such as demographic factors and health beliefs and attitudes that influenced an individual's use of health services. Enabling factors included insurance coverage, social support, and family income. Need variables usually included perceived and objectively determined health problems. The model's second phase in the 1970s (see, e.g., Aday & Anderson, 1974) saw predisposing, enabling, and need variables subsumed under the category of population characteristics and the addition of a category of variables, the health-care system, which included policy and resources and organization of the health-care system. Consumer satisfaction was included as an outcome of the use of health services. Phase three, in the 1980s and 1990s, brought the addition of the external environment to an expanded category of determinants of health behavior (see Figure 7.3). Use of



**Figure 7.3** Components of Phase 3 of the Behavioral Model of Health Services Use. *Source:* From "Revisiting the Behavioral Model and Access to Medical Care: Does It Matter?" by R. Anderson, 1995, *Journal of Health and Social Behavior*, 36, p. 7.

health services was no longer the end point of the model, but was subsumed, with personal health practice, under a new category entitled health behavior. The outcomes of health behavior became the model's new end point, which was made up of perceived and evaluated health status and consumer satisfaction (Anderson, Davis, & Ganz, 1994).

Empirical support for the Behavioral Model of Health Services Use has been strong. Anderson and Aday (1978) used the model to understand levels of health services use of a probability sample of 7,787 noninstitutionalized persons in the United States. These authors were able to explain 22% of the variance in physician visits using (a) age, race, and education of the head of household as predisposing variables; (b) family income, physician visit insurance, number of physicians per 1,000 in population, and if a particular physician was seen as enabling variables; and, (c) perceived health and number of illness symptoms in the prior year as need variables. Level of illness and age were most strongly related to the number of physician visits. The most significant policy-related variable was having a regular source of care.

The Behavioral Model for Vulnerable Populations (Gelberg et al., 2000) is an especially valuable tool for the field of social work because of its focus on the health services use of disadvantaged persons. Adding residential history, mental health, substance abuse, victimization history, and competing needs to the original model added to the efficacy of the model with vulnerable persons in a longitudinal study of homeless persons (Gelberg et al., 2000).

## DISCUSSION

In the early years of the twentieth century, Richard Cabot, the Massachusetts physician who helped to found the first hospital social work department, urged social workers to build a solid theoretical basis for their profession (Evison, 1995). With all that has been entailed in maintaining a respected profile in medicine, this advice has been largely overlooked. Building its own theoretical base is an enormous undertaking that arguably is too much to ask of health social work. Employing well-founded theoretical approaches from other disciplines, then, represents a reasonable and prudent compromise with which Cabot would likely have been satisfied.

The theoretical approaches reviewed in this chapter are all relatively sound empirically. They differ more in scope than in content. Rational choice-based approaches focus in detail on the center of a model consisting of three concentric circles, with social networks and relationships forming the middle, and societal level influences forming the outer layer (see Figure 7.2). Although they take into consideration only a part of what we know to influence health behavior, they have utility for understanding that layer well. Whereas some have criticized these approaches for focusing on the intrapersonal, it can be argued that, in certain situations, focusing on smaller constellations of behavior can be useful clinically. To gain an understanding of what goes on within an individual in decision making, a smaller frame, such as is provided by the Health Belief Model, could, for example, be very useful.

Since rational choice based approaches focus largely on the individual, it is important that the social worker does not engage in the fundamental attribution error (i.e., overlooking environmental causes of the behavior of others) or victim-

blaming, but instead embeds this microcosm of behavior within the larger arena of environmental influences on behavior.

A major strength of Social Action Theory is that it considers in detail influences on behavior from an individual's social network (the middle of our three concentric circles of influence). This provides a useful tool in pinpointing how others in the environment are facilitating or impeding the efforts of patients and providers to implement health behavior change. The Behavioral Model extends our analytic lens to include several systems levels (e.g., the health-care system). Although less useful for focusing in on individual decision making or the influence of others in the social network on health decisions, that it accounts for all possible influences on behavior makes it useful in planning. The principal disadvantage of social network-based approaches is that their inclusiveness renders them more cumbersome to implement in practice and research.

Behavioral theory is a powerful tool that allows us to apply existing knowledge of internal and external determinants of health behavior to the clinical situations with which we are faced. The Health Belief Model offers insight into individual's health decision making. The Theory of Reasoned Action extends that insight to include anticipated opinions of valued others. The Theory of Planned Behavior increases the power of the Theory of Reasoned Action when the behavior in question requires a great deal of volition, such as in weight loss or smoking cessation. Social Action Theory is particularly useful when the behavior (rather than opinions) of others is a factor in an individual's behavior change. The Behavioral Model of Health Services Use, by virtue of its taking into consideration influences at various systems levels, provides assistance in health planning. Taken together, the set of theories and models is a resource that can heighten the ability of health social workers to succeed in an increasingly demanding health-care environment.

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### SUGGESTED LEARNING EXERCISE

The purpose of this exercise is to apply the theories of health behavior discussed in this chapter to a specific health issue or problem. Students should select a current topic of interest in which individuals or groups engage in a behavior known to impact health negatively (e.g., smoking among youth or unprotected sex with strangers) or fail to engage in healthful behavior (getting flu shots when at risk or getting mammograms after age 40, especially for individuals with a strong family history of breast cancer). Instructors may want to provide an article or set of articles to students (this can be any recent discussion in the print media of a health situation or problem, such as why adolescents choose to smoke or to have sex without birth control). After selecting a health problem or situation, students should select two theories that they think allow an understanding of the health behavior described in the article. Next, they should analyze the health behavior in terms of each of the two theories. Last, students should make a strong case for which of the two theories best accounts for why the health behavior is as it is (e.g., why teens ignore health warnings about smoking).

First, briefly outline each of the two theories and the issue (written succinctly, but providing sufficient information to assess individual student's level of under-

standing of each). Next, provide a detailed analysis of how the theory fits the situation described. Are all of the salient elements of the situation described covered by the theory? Is the theory adequate to explain the behavior? Does the theory allow for a better understanding of the behavior discussed in the article than would an atheoretical analysis? If not, why not? This should be the meat of the paper. The implications for practice of using this theory to try to understand the behavior described in the two articles should be addressed. Last, the student should make a choice as to which of the two theories best explains the behavior in question and why.

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## CHAPTER 8

# Physical and Mental Health: Interactions, Assessment, and Intervention

MALITTA ENGSTROM

INTERACTIONS BETWEEN PHYSICAL and mental health are among the most complex issues that are brought to social workers in health-care settings. The complexity stems from the dynamic mind-body relationship; the numerous possible combinations of physical and mental health conditions; the consideration of possible psychological reactions to physical illness, psychological effects associated with physical conditions and treatments, and psychiatric disorders; intervention during mental health crises; and the provision of ongoing intervention to support physical and mental well-being. While considering these issues, the social worker is responsible for the formulation of assessments and interventions that reflect the unique family and ecological contexts of people in their environments. With particular focus on differential assessment, this chapter provides guidance for social workers navigating these complexities.

It is important to recognize the limitations inherent in using the terms *physical health* and *mental health* (U.S. Department of Health and Human Services [DHHS], 1999, p. 5). This language implies a false division of these related elements of overall health (Angell, 2002; DHHS, 1999; Kerson, 2002). In fact, these two elements are not only interrelated, but also exert “mutual influence” on each other (Rolland, 1994; J. S. Rolland, personal communication, June 16, 2004). While recognizing this mutual influence and that information continues to emerge about the mind-body connection, this chapter uses these terms for both illustrative purposes and toward the goal of developing knowledge with adequate specificity so

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that practitioners can effectively engage in evidence-based assessment and intervention (Angell, 2002; J. Williams, 1998).

## CHAPTER OBJECTIVES

- Provide a framework for considering the intersections of ecological factors (such as race, ethnicity, cultural background, gender, socioeconomic status, sexual orientation, family relationships, and social support), psychosocial well-being, and health.
- Discuss differential assessment of psychological reactions to physical illness, psychological symptoms associated with physical illness or treatment, and clinical mood and anxiety disorders.
- Provide background information and tools for the assessment of suicide risk and for intervention in this area.
- Highlight general intervention strategies to support overall health, coping, and well-being and targeted intervention strategies to assist people experiencing psychological distress associated with depression and anxiety disorders in health-care settings.

## PSYCHOSOCIAL CONDITIONS AND INCREASED RISK OF ILLNESS

Psychological distress is associated with numerous negative health outcomes across a wide range of illnesses (Institute of Medicine [IOM], 2001). Psychological distress can include stress, anger, hostility, depression, worry, and anxiety. The role of stress, in particular, has been well documented in its relationship to the risk of numerous health problems, including cardiovascular disease, cancer, autoimmune and inflammatory disorders, and wound healing (IOM, 2001; Krantz, Sheps, Carney, & Natelson, 2000; Ng & Jeffrey, 2003). While stress and its effects on physiology can have benefits as they enable a person to respond to a threat, “to fight or flight” (IOM, 2001, p. 40), in the face of chronic exposure to undefined stress, which is not resolved and in which the stress response cannot be turned off, an individual will experience allostatic load. As described by the IOM (2001), “Allostatic load is the wear and tear the body experiences as a result of repeated allostatic response” (p. 42). Allostasis involves the body’s physiological responses to stressors in order to foster adaptation to challenge and to maintain homeostasis. However, as the body continues to engage in allostasis, allostatic load results. Allostatic load is influenced not only by chronic stress, but also by behavioral factors, including “diet, alcohol and tobacco use, physical activity, and sleep,” and by genetic and developmental variations in an individual’s ability to adapt to routine experiences such as the cycle of sleeping and waking (IOM, 2001, p. 42).

There are two primary ways to consider the relationship between stress and health. First, through a biological pathway, stress directly influences the body’s physiology. Responding to stress releases hormones that influence the central nervous, cardiovascular, and immune systems (IOM, 2001). Exposure to chronic stress, in particular, has a negative influence on the immune system (Segerstrom & Miller, 2004). Second, coping with stress may lead to engaging in behaviors,

such as eating a higher fat diet, smoking cigarettes, and reducing exercise, which increase the risk of illness (Ng & Jeffrey, 2003). Through both physiology and behavior, stress may intersect with health. Additionally, the psychosocial and physical demands of illness may increase stress and warrant intervention to address potential biological and behavioral elements of its impact on overall health.

Social workers in health-care settings are well positioned to assist people who are experiencing psychological stress. One powerful framework for guiding intervention in this area is Lazarus and Folkman's (1984) model of stress, appraisal, and coping. This model and its implications for physical and mental health are further discussed in the Interventions section of this chapter.

Social networks, support, integration, and capital also have strong implications for physical and mental health (IOM, 2001; McGinnis, Williams-Russo, & Knickman, 2002). Social networks generally refer to the composition of a person's social relationships (e.g., number of people, types of relationships, relationships among the people in a social network), while social support generally refers to a person's sense of feeling warmly regarded and respected or to the type of support available (e.g., emotional support, material assistance, instrumental or practical support; Cobb, 1976; House & Kahn, 1985; IOM, 2001). Social integration can be conceptualized as the number of intimate relationships a person has with both individuals (including family and friends) and with groups (including voluntary and religious organizations); social capital reflects a societal conceptualization of its members' integration. Measures of social capital can include reported trust among people and degree of civic participation (IOM, 2001). In sum, "more socially integrated societies seem to have lower rates of crime, suicide, mortality from all causes, and better overall quality of life" (p. 164).

From survival in infancy to buffering stress in life transitions, to increasing one's ability to fight off a cold, to reducing advancement of carotid atherosclerosis, to slowing the decline of immune functioning in HIV, and to supporting lower levels of allostatic load, social ties and support are far-reaching in their power to strengthen health. Alternatively, isolation, loss, conflict within relationships, and the potential for disease transmission are aspects of social ties that can negatively affect health and mental health (IOM, 2001). For social workers in health-care settings, these findings highlight the importance of exploring available social support, augmenting it when needed, and enhancing interactions and communication among social network members as indicated by one's assessment. Additionally, social workers can play an important role in preventing disease transmission through psychoeducation and counseling efforts.

#### PHYSICAL ILLNESS AND THE ROLE OF MENTAL HEALTH

Among people who are experiencing physical illness, mental health can play an important role in physical outcomes across the life span. For example, among adolescents, nonadherence to oncology regimens may be influenced by depression, low self-esteem, and parent-child conflict (Kennard et al., 2004). Among adults who have had myocardial infarction, research suggests that depression, state anxiety, and psychological distress are associated with increased risk of 5-year cardiac-related mortality (Frasure-Smith & Lesperance, 2003). Among older adults, treating depression appears to reduce intensity of pain and disability as-

sociated with osteoarthritis (E. Lin et al., 2003). Additionally, among older women with cancer, depression has been shown to be associated with reduced likelihood of receiving appropriate treatment and increased risk of death (Goodwin, Zhang, & Ostir, 2004).

The following example of research among women living with HIV is provided to illustrate the relationship between mental and physical health, to take into account possible pathways through which they interact, and to consider the implications for social work practice. Among women living with HIV, Ickovics et al. (2001) found that those with chronic depression were twice as likely to die as those with limited or no depressive symptoms. Additionally, when controlling for sociodemographic background, clinical status, and substance use, chronic depression significantly predicted decline in CD4 cell counts among women in the study. While the causal mechanisms in this relationship remain unclear, the authors propose four possible explanations:

1. Depression's previously established impact on morbidity and mortality via changes in neuroendocrine and immunological functioning may have an interaction effect in combination with the medical illness (see also Cohen & Herbert, 1996; Kemeny et al., 1994; G. Miller, Cohen, & Herbert, 1999).
2. Depression may contribute to the engagement in risk behaviors such as alcohol and tobacco use and to the disengagement in health care, which may negatively influence health status.
3. Depression's negative impact on medication adherence among people living with HIV may contribute to declines in health.
4. Although protease inhibitors have been shown to be significantly associated with reductions in symptoms of depression, less than half the women in the study received highly active antiretroviral therapy (HAART) medications for HIV (Ickovics et al., 2001; Low-Beer et al., 2000). With suboptimal treatment experiences, women may have reduced access to both the physical and mental health gains associated with protease inhibitor treatment.

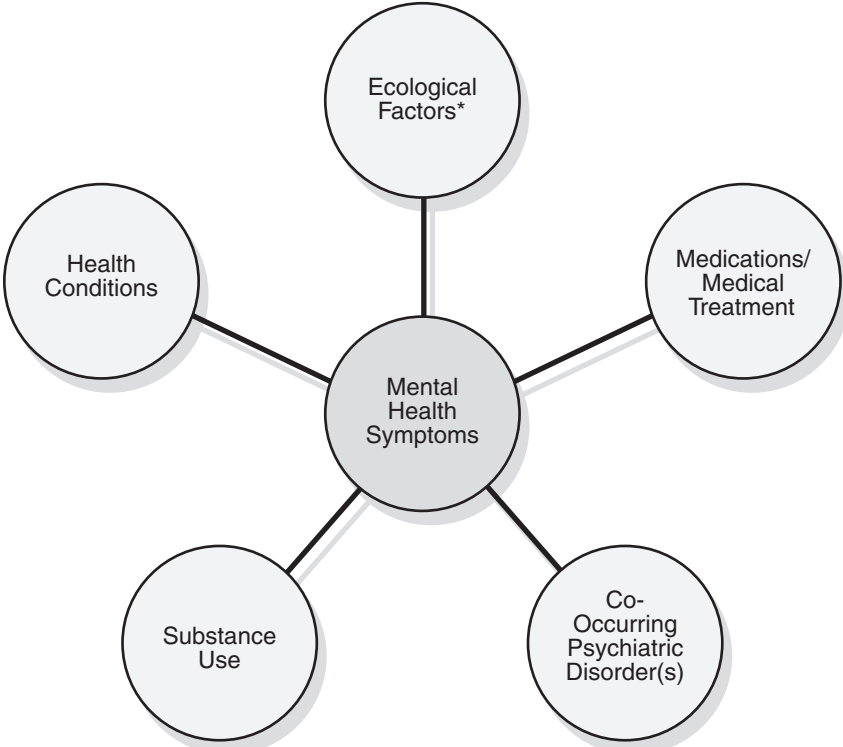
This example of the relationship between depression and mortality among women living with HIV underscores both the relevance of mental health in physical health outcomes and the complexity of possible pathways between them. While medical intervention to address physical illness may be the priority among the health-care team, mental health assessment and intervention is likely to be closely linked with physical health outcomes. In terms of social work practice, this linkage highlights the critical role of assessing psychosocial conditions, including mental health and risk behaviors, and formulating interventions that can support individuals' overall health.

#### ASSESSING PSYCHOSOCIAL CONDITIONS IN HEALTH-CARE SETTINGS

At the heart of effective social work intervention is accurate assessment. As described by Meyer (1993), assessment involves "the thinking process that seeks out the meaning of case situations, puts the particulars of the case in some order, and leads to appropriate interventions" (p. 2). In health-care settings, social workers are likely to encounter people with a range of mental health experiences. Some people may be experiencing mild psychological distress and may benefit from

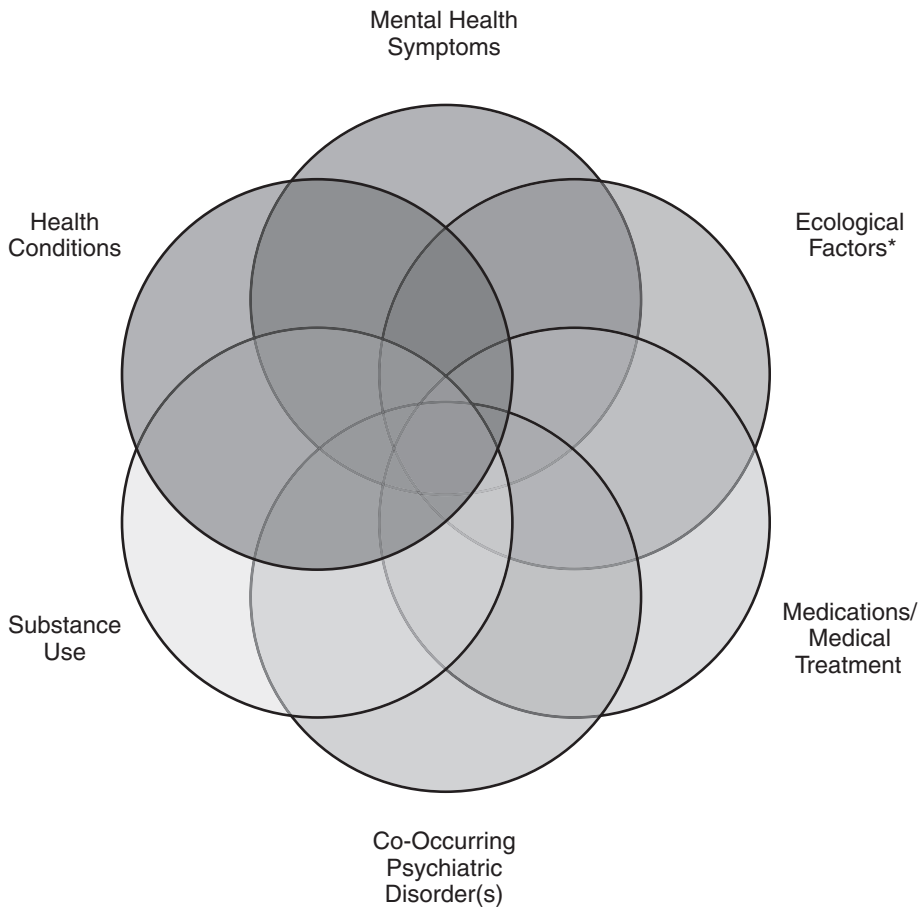
psychoeducation regarding their physical conditions and supportive counseling to enhance coping and stress management; for others, who may be experiencing significant psychological distress, more intensive psychosocial interventions, including psychotherapy and psychopharmacology, may be indicated (DHHS, 1999; IOM, 2001). The process through which a social worker considers the nature of the client’s mental health issues and their influencing factors is called *differential assessment*. To guide differential assessment and, therefore, appropriate intervention, this discussion covers several intersecting domains, including ecological factors, mental health symptoms, physical conditions, medications, and substance use. Figure 8.1 illustrates various domains related to mental health symptoms; however, a more real-world depiction of the complex intersections between each of these domains is provided in Figure 8.2.

*Ecological Factors* Although conceptualizations of the connections between the person and the environment have varied, social workers have a longstanding history of recognizing the importance of a person-in-environment perspective (Berlin & Marsh, 1993; Germain & Gitterman, 1980; Hollis, 1939; Jordan & Franklin, 1995; Kondrat, 2002; Perlman, 1957; Richmond, 1917). Ecological systems theory (Bronfenbrenner, 1977, 1979, 1989) provides a lens through which to employ this perspective as we consider the transactional intersections of ecologi-



\* For example, race, ethnicity, cultural background, socioeconomic status, employment status, sexual orientation, spiritual background, family, social support, gender, and age.

**Figure 8.1** Domains Related to Mental Health Symptoms.



\*For example, race, ethnicity, cultural background, socioeconomic status, employment status, sexual orientation, spiritual background, family, social support, gender, and age.

**Figure 8.2** Mental Health Symptoms.

cal factors and physical and mental health. According to ecological systems theory, each individual experiences life within a unique intersecting web of systems. These intersecting systems can include the microsystem (e.g., individual activity, roles, physical and mental health status), broaden to the mesosystem (e.g., relationships with family, significant others, peers), then to the exosystem (e.g., work, neighborhood, community), and last, to the macrosystem (e.g., culture and dominant patterned processes that inform numerous configurations, including politics, government, education, and law). This perspective is provided in order to consider the relationships between physical and mental health within the context of relationships with significant others and peers; interactions with community, school, work, or unemployment; and connections to broader cultural frameworks and governmental institutions.

The importance of this perspective rests not only in its consistency with social work practice, which recognizes that individuals and their environments exist in dynamic, mutually influencing interaction (Kondrat, 2002), but also in the conclusion reached by the seminal report from the Institute of Medicine (2001) that

focuses on the interactions between biology, behavior, and social influences. After reviewing evidence gathered across numerous disciplines, the report concludes that “health and behavior are influenced by factors at multiple levels, including biological, psychological, and social. Interventions that involve only the person—for example, using self-control or willpower—are unlikely to change long-term behavior unless other factors, such as family relationships, work situation, or social norms, happen to be aligned to support a change” (p. 27). To formulate an accurate assessment that will lead the social worker in the direction of effective intervention, multisystemic influences should be considered. Lack of attention to the various components of an ecologically informed assessment may lead the social worker to focus in error on either individual characteristics or environmental factors; excessive attention to one or the other may lead to faulty explanations regarding how best to be helpful (Berlin & Marsh, 1993). Additionally, as described by the IOM report (2001), “Interventions must recognize that people live in social, political, and economic systems that shape behaviors and access to the resources they need to maintain good health” (p. 8). The ecological framework provides an efficient way of considering the numerous systems with which individuals interact and the mutual influence with physical and mental health.

This overview of an ecological approach to assessment begins with the macrosystem for two reasons. First, macrolevel factors of race and culture have multifaceted, pivotal intersections with health and mental health. Second, this overview moves us through multisystemic considerations and their interactions with physical and mental health toward a comprehensive framework for assessing and intervening to support mental health in health-care settings. This discussion begins at the broadest level in considering these dynamic multisystemic interactions and concludes with in-depth attention to aspects of the microsystems of physical and mental health. Rather than solely focusing on individual level components of health, this comprehensive framework aims to reinforce that the physical and mental health experiences of individuals intersect in powerful ways with their social and environmental contexts.

*Macrosystems* Beginning at the broadest level, the macrosystem, McGoldrick (1982) states that neither physical nor mental health problems can be appropriately assessed without understanding “the frame of reference of the person seeking help. . . . The language and customs of a culture will influence whether or not a symptom is labeled a problem” (p. 6). Additionally, cultural influences may shape the experience and communication of pain, expected or desired treatment, understanding of illness causes, coping styles, and perspectives regarding who to turn to for help, for example, primary care physician, mental health provider, traditional healer and clergy (DHHS, 2001a; McGoldrick, 1982). In the context of assessing and intervening to address mental health in health-care settings, these considerations become particularly salient in several ways.

As supported by McGoldrick (1982), the ways in which symptoms are experienced and described will intersect with the social worker’s understanding of what is the matter and “what can be done about it” (Berlin & Marsh, 1993, p. 35). Generalized statements regarding culture and cultural norms, values, and expectations run the risk of conveying stereotyped information that may obscure individual differences and experiences in connection with a person’s cultural background and may overlook diversity within a culture (Yellow Bird, Fong,



Galindo, Nowicki, & Freeman, 1996); however, such information, when provided and used appropriately, can broaden the social worker's cultural knowledge base and inform efforts to reach a shared understanding of the client's experiences (Kerson, 2002). With this caveat in mind, somatization, the expression of feelings of distress through physical symptoms, reflects an important intersection between culture, health, and mental health (DHHS, 2001a). Powerful influences are likely to contribute to somatization across cultural groups, including the culture's understanding of the connection between mind and body, culturally accepted ways of expressing distress, and culturally informed stigma regarding mental illness (DHHS, 2001a). For example, a limited body of research suggests that among people who are American Indian and Alaska Native, there is not a clear distinction between mind and body and there is likelihood of expressing distress in both somatic and psychological terms (DHHS, 2001a). Among several Asian cultures, mental illness carries significant stigma; the weight of this stigma may influence the likelihood of people from Asian backgrounds expressing psychological distress in physical symptoms (DHHS, 2001a), as might cultural perspectives regarding the connection between mind and body (K. Lin & Cheung, 1999); however, when asked explicitly about mental health, research suggests that Asian clients will report symptoms in psychological terms (DHHS, 2001a; K. Lin & Cheung, 1999).

Common examples of somatization among people who are Puerto Rican American, Mexican American, and White American include stomach-related problems, chest pain, and palpitations; among people in Africa and South Asia, somatization may involve sensations of "burning hands and feet," "worms in the head," or "ants crawling under the skin"; and among some Asian groups, somatization may involve blurred vision, dizziness, and vertigo (DHHS, 2001a, p. 11). In terms of social work practice in health-care settings, the possible somatization of psychological distress underscores the importance of routine screening for mental health symptoms.

In order to provide culturally competent assessment and intervention, it is critical that social workers become informed about their own and their clients' cultural beliefs in the context of experiences of physical and mental health (DHHS, 2001a; Pinderhughes, 1989; Rolland, 1994). Such competence is vital to recognizing and supporting normative coping in the midst of physical or mental illness and to avoiding misassessment of physical and mental health symptoms (K. Lin & Cheung, 1999). Some strategies to assist social workers with increasing their cultural competence in addressing mental health in health-care settings are:

- Becoming more mindful of your own cultural beliefs about health and mental health may enhance meaningful self-awareness (Pinderhughes, 1989; Rolland, 1994). Consider specific ways in which a person's cultural background influences his or her values about expressing distress and about mental and physical illness. One particularly significant domain in the assessment of mental health pertains to cultural expectations regarding expression of emotion. To what degree does a person's cultural background encourage open expression of emotion or limit its direct expression? A social worker's own beliefs about expected displays of emotion are likely to influence the lens through which the client's experience is assessed. For example, a social worker whose cultural background encourages direct expression

of emotion may view a person who is reserved in her emotional expression as having a restricted range of affect, when, in fact, the behavior is consistent with her cultural context and does not reflect a problem in emotional expression. Awareness of this lens can foster reflection regarding culturally informed assessment that recognizes that “cultural differences are not deviances” (Pinderhughes, 1989, p. 17). Additional salient domains for social workers to consider in the intersection between culture and physical and mental health pertain to their own culturally informed expectations regarding how people respond to physical pain and values regarding mental illness.

- Exploring the client’s cultural identity with him can inform considerations regarding the implications of culture in the client’s presenting concerns, including culturally informed ways of expressing distress and preferred types of help, and considerations regarding culture, immigration, and acculturation, as salient elements of an ecologically informed assessment (American Psychiatric Association, 1994).

- Becoming better informed about the cultures of the people they serve and about evidence-based interventions that are culturally relevant to them can be important avenues to enhancing intervention effectiveness (Carlton-LaNey, 1999; DHHS, 2001a; Pinderhughes, 1989).

- As outlined in Chapter 9 of this *Handbook*, exploring clients’ beliefs about their illnesses and goals for intervention may be facilitated by using the following questions (Kleinman, Eisenberg, & Good, 1978, p. 256):

What do you think has caused your problem?

Why do you think it started when it did?

What do you think your sickness does to you? How does it work?

How severe is your sickness? Will it have a short or long course?

What kind of treatment do you think you should receive?

What are the most important results you hope to receive from this treatment?

What are the chief problems your sickness has caused for you?

What do you fear most about your sickness?

- Becoming better attuned to issues of commonality and difference, including race, ethnicity, culture, socioeconomic status, gender, sexual orientation, physical ability, and power between you and the clients you serve may facilitate addressing these elements within the helping relationship (American Psychiatric Association, 1994; Pinderhughes, 1989).

- Actively considering clients’ spiritual beliefs can contribute to the provision of culturally competent services. As described by Kerson (2002), “Spiritual beliefs . . . are integral to health beliefs and need to be approached in the same manner as other cultural beliefs” (p. 162). Walsh (2004) further describes the role of prayer, meditation, and faith in numerous positive health outcomes including stress reduction, decreased blood pressure and cortisol levels, improvements in managing chronic pain, reduced problems with alcohol or other drugs, and reduced depression. Walsh (2004) also asserts that “Over 350 studies point to religion as the forgotten factor in physical and mental health” (p. 198). Beliefs may

provide a powerful source of cognitive assistance to support coherence, making meaning, and “a sense of control” (Walsh, 2004, p. 198) as people are experiencing physical and mental health difficulties. In addition to supporting a worldview that facilitates meaning, Musick, Traphagan, Koenig, and Larson (2000) provide three further pathways through which religion may positively influence health: supporting positive health behaviors (e.g., healthier diets, reduced drinking and smoking, and increased physical activity); fostering social integration and support (e.g., shared beliefs, larger social network, opportunities for conversation, learning, and support); and providing comfort (e.g., emotional and instrumental support, religious rituals for assistance in difficult times, source of hope and coping). While spirituality and religion may be important resources, assessment should be sensitive to these topics as potential sources of conflicted or negative feelings (Gotterer, 2001). Open-ended inquiry that is sensitive to the diversity of experiences people may have regarding these issues and that elicits the client’s unique experiences may be a useful starting point for actively considering spiritual beliefs in the context of culturally relevant services.

Consulting Chapter 9 of this *Handbook* may be useful in considering these issues further; the chapter addresses in greater detail ways in which culture intersects with health, including the ways in which bodily sensations are recognized as symptoms of illness.

While cultural competence facilitates the recognition of strengths of cultural influences and coping in the midst of health issues (McGoldrick, 1982), the influences of racial health disparities are particularly salient in the context of assessment and intervention in the intersections between physical and mental health. The extent of race-related disparities in physical and mental health is staggering. For example, people who are African American are more than twice as likely to experience infant mortality, to give birth to a low-weight baby, and to have had no prenatal care in the first trimester of their pregnancies, in comparison to their White American counterparts; they also have considerably higher prevalence of tuberculosis and syphilis, greater exposure to unhealthy air, and considerably higher death rates associated with heart disease, stroke, all cancers, and homicide (Keppel, Percy, & Wagener, 2002; Weir et al., 2003). In addition to increased risk of dying from cardiovascular disease, people who are African American experience increased risk of burden associated with the condition than do people who are White Americans (Hahn, Heath, & Chang, 1998; Office of Minority Health, Centers for Disease Control and Prevention, n.d.; Parmley, 2001). While epidemiological studies indicate increased prevalence of risk factors for cardiovascular disease among people who are African American, for example, physical inactivity, overweight, hypertension, diabetes mellitus, and combined risk factors (Hahn et al., 1998), it is also important to consider the ways in which such disparities are shaped by structural inequities that influence access to health care and to resources that support health, including safe living environments, “heart-healthy food choices, smoke-free environments in the workplace, and safe and convenient places to exercise” (Keppel et al., 2002; Winkleby, Kraemer, Ahn, & Varady, 1998, p. 361; Wyatt et al., 2003; also see Chapter 6 in this *Handbook*). Additionally, given the connection between race and socioeconomic status, it is likely that race and socioeconomic inequalities mutually influence each other although additional research is needed to identify the extent to which race and socioeconomic

status contribute to race-related health disparities (Krieger, 2003). Last, by virtue of their high prevalence of chronic illness and their overrepresentation in at-risk groups, for example, people experiencing poverty, incarceration, and inpatient hospitalization, and African Americans are at increased risk of mental health problems compared to White Americans (DHHS, 2001a).

Racial discrimination is another salient macrolevel consideration in the intersections between physical and mental health and health disparities (Krieger, 2003; D. Williams, Neighbors, & Jackson, 2003). Discrimination is associated with health problems, and, in particular, with mental health problems (D. Williams et al., 2003); however, the mechanisms through which discrimination influences health, and therefore, the implications for social work intervention, are still being explored and research in this area is limited (Krieger, 2003; D. Williams et al., 2003). One conceptualization of this relationship posits that experiencing discrimination is a source of stress that, as discussed previously, can negatively influence health through physiological pathways and through behaviors that increase illness risk (D. Williams et al., 2003). This conceptualization has been further developed by examining the mediating role of coping in the relationship between discrimination and health (Noh & Kaspar, 2003). As described by Noh and Kaspar (2003), this body of research has examined differences in health based on whether people exposed to discrimination employ emotion-focused coping or problem-focused coping. *Emotion-focused coping* generally includes cognitions that aim to reduce distress, including minimization, avoidance, distancing, and finding positive elements of negative circumstances (Lazarus & Folkman, 1984, p. 150). *Problem-focused coping* generally includes steps to solve a problem, including problem definition, identification of possible solutions, consideration of their strengths and limitations, selection of a solution, and then action (Lazarus & Folkman, 1984, p. 152). Noh and Kaspar (2003) assert that the effectiveness of coping is likely shaped by the nature of the stressor and the individual's resources, social context, cultural background, and degree of acculturation. Their assertion is based on divergent findings about the efficacy of emotion- or problem-focused coping in supporting health in the face of discrimination among members of different culture and gender groups.

Another conceptualization of the possible mechanisms through which discrimination negatively affects health comes from the work of Nancy Krieger. Krieger (2003) argues that the influence of racism on health should be examined through research on the following issues: "(1) economic and social deprivation; (2) toxic substances and hazardous conditions; (3) socially inflicted trauma . . .; (4) targeted marketing of commodities that can harm health, such as junk food and psychoactive substances . . .; and (5) inadequate or degrading medical care" (p. 196). While Krieger recognizes the role of individual- and community-level coping and action to counter discrimination, these five potential pathways underscore systemic and multilevel influences of racism on health. Although this body of knowledge is nascent, implications for social work practice include attention to individual coping strategies to manage stress and support health and to systemic factors that negatively influence physical and mental health. Additional considerations on how to support psychological well-being and coping when experiencing serious illness (Folkman & Greer, 2000) are addressed in the Intervention Strategies section of this chapter.

*Exosystems* Exosystem issues regarding socioeconomic status, including income, education, and employment, are also likely to intersect with microlevel physical and mental health issues. In fact, as described by McGinnis, Williams-Russo, and Knickman (2002), "for the population as a whole, the most consistent predictor of the likelihood of death in any given year is level of education; persons ages 45 to 64 in the highest levels of education have death rates 2.5 times lower than those in the lowest level" (p. 81). Individual poverty and societal inequality of income distribution also negatively affect mortality among people with lower income (McGinnis et al., 2002). In addition to mortality risks associated with lower socioeconomic status is an increased risk of mental health problems (DHHS, 1999; Siefert, Bowman, Heflin, Danziger, & Williams, 2000). Comparisons between people in the extremes of socioeconomic status suggest that annual prevalence of mental disorders among people at the lower end are approximately twice that of those at the higher end (World Health Organization, 2001). The increased prevalence of mental health problems among people with lower socioeconomic status has been explained in two primary ways. First, the increased risk of acute and chronic stressors among people living in poverty may contribute to their increased risk of mental health problems (Siefert et al., 2000). This explanation is referred to as *social causation*, in which social circumstances have a causal link with mental health problems. The second explanation, referred to as *social selection*, argues that mental health problems cause people to move downward in socioeconomic status (Dohrenwend et al., 1992; Saraceno & Barbui, 1997). Social causation appears most relevant for women experiencing depression and for men experiencing antisocial personality and substance use disorders, while social selection appears most relevant among those experiencing schizophrenia (Dohrenwend et al., 1992; Siefert et al., 2000). Among children, recent research suggests that social causation may be most relevant for youth experiencing oppositional or conduct disorders and that parental monitoring mediates this relationship such that changing poverty level is associated with increased parental monitoring which, in turn, is associated with decreased mental health symptoms (Costello, Compton, Keller, & Angold, 2003). This study did not find that social causation was as relevant for symptoms of anxiety and depression among the participants.

Socioeconomic status is also associated with the course of mental health problems. Numerous factors may influence this relationship, including obstacles related to access to care, lack of health insurance, and lack of culturally and linguistically appropriate services (World Health Organization, 2001). For social workers addressing mental health issues in health-care settings, the increased risk of physical and mental health problems among people with lower socioeconomic status underscores the importance of designing and delivering services to reach this population.

Research on stress and coronary artery disease provides an example of the specific ways in which socioeconomic status intersects with mental and physical health. Krantz, Sheps, Carney, and Natelson (2000) discuss factors that may contribute to the inverse relationship between socioeconomic status and cardiac morbidity and mortality, including limited access to health care, increased prevalence of risks (e.g., smoking, high blood pressure), inadequate nutrition, and social and environmental stress. To illustrate this point and to consider implications for social work practice, the following hypothetical case is offered.



### Case Example

Joseph is a 52-year-old, heterosexual, single man of Italian-American ancestry who has worked in various construction positions for the past 20 years. While Joseph has earned enough money to pay most of his monthly bills, his employment has not provided health insurance and his income exceeds the eligibility criteria for Medicaid. Joseph recently presented in the emergency department reporting chest pains and shortness of breath, which were ultimately diagnosed as symptoms of myocardial infarction. Upon consultation with the health-care team, Joseph was encouraged to begin a medication regimen and urged to reduce his work hours, to reduce the stress in his life, and to improve his eating habits, because he generally relied on low-cost, high-fat takeout for lunch and dinner. On his discharge from the hospital, Joseph agreed to follow the health-care team's recommendations and enrolled in the hospital's stress management program.

Within 2 weeks of beginning the stress management program, Joseph reported that his bills were accumulating with his efforts to work fewer hours and that he had just received a hefty bill for his hospital services, in addition to high co-payments for his prescribed medications. Joseph said that he felt better since reducing his work hours and attending the stress management program, but feared he would be unable to pay his bills and might lose his house and his medical benefits if he did not return to his prior work schedule. He also said that he thought returning to work might reduce his general level of stress, because much of it originated with financial pressures and pressure from his boss to work longer days. Joseph feared his boss might replace him with another worker who could maintain the demanding hours.

As this case depicts, supporting Joseph's physical and mental well-being would involve consideration not only of individual coping and stress management strategies, but also of broader systems including health insurance and socioeconomic resources.

*Mesosystems* Consideration of clients' familial and social contexts defines the mesosystem from an ecological perspective. Numerous empirical studies support the vital role of family and social support in physical and mental health outcomes (For examples see Allgöwer, Wardle, & Steptoe, 2001; Bagner, Fernandez, & Eyberg, 2004; DiMatteo, 2004a; McFarlane et al., 1995; for reviews see Campbell, 2003; Weihs, Fisher, & Baird, 2002). In considering issues of health and mental health in the context of family and social relationships, it is important to pay attention to the meaning, diversity, and strengths of these relationships in clients' lives. In her discussion of the course of psychotherapeutic intervention with a lesbian woman struggling with infertility, Brown (1991) describes that "during the process of infertility treatments and fertility testing, Carla [the client] always had to anticipate having to explain to yet another person where her husband wasn't and who Susan [her partner] was" (p. 25). Such anticipation of a heterosexist bias is likely to fuel a client's emotional disengagement from the health-care team and unlikely to facilitate effective intervention to support the mesolevel intimate relationships in the client's life. To support clients in their intimate relationships and to support their physical and mental health, information gathering should proceed with open-ended, inclusive questions that do not presume particular responses.

Additionally, as previously described, it is likely that macrosystemic issues, such as homophobia, may interact with microsystem physical and mental health conditions. Brown (1991) describes this complexity in the context of dominant cultural expectations of women to be wives and mothers. Women who are lesbian and struggling with infertility may confront complex issues regarding their identity in this dominant cultural context. These intersecting cultural and personal experiences may create “difficulties both in valuing herself and being valued by others, difficulties that may be distressing enough to merit psychotherapeutic intervention” (Brown, 1991, p. 15). In Chapter 11 of this *Handbook*, Rolland and Werner-Lin discuss the relationships between individuals, families, and health, and ways in which social workers can intervene to foster coping and positive health outcomes among families in health-care settings.

Informed by relational theory, the research of Kayser and Sormanti (2002a), suggests that women’s psychosocial response to cancer is likely to be influenced by close connections with others and that these connections are interwoven with women’s sense of identity. Additionally, their research suggests that experiencing cancer may influence identity by influencing the way in which women who are mothers alter their priorities (Kayser & Sormanti, 2002b). For example, women in Kayser and Sormanti’s study described enjoying their families and their lives with greater intensity; learning about their identities apart from their functions as workers, partners, and mothers; finding deep personal strength and self-efficacy; experiencing greater empathy and authenticity in their relationships; and examining the balance between caring for self and others.

Interventions to assist people experiencing changes in their sense of identity in the face of illness and to support their social relationships are important aspects of the social worker’s role in health-care settings and are likely to have important implications for positive health outcomes. In fact, social isolation is said to increase the risk of mortality by two to five times in comparison to the presence of relationships with family, friends, and community (McGinnis et al., 2002). Given that numerous mental health conditions may contribute to social withdrawal and social isolation (American Psychiatric Association, 1994), individuals experiencing co-occurring physical and mental health conditions may be a particularly vulnerable group. As part of a comprehensive assessment to inform intervention, social workers should explore client’s social support, including attention to composition and size of the person’s social network, types of social support available, positive and negative components of available support, and strengths and obstacles to engaging with others and sharing support.

## MICROSYSTEMS

Bearing in mind the complex intersections between the multiple systems in the ecological framework, this discussion now turns to microsystems of physical and mental health.

### PREVALENCE, DETECTION, AND SCREENING: ANXIETY AND MOOD DISORDERS

According to the Surgeon General’s Report on Mental Health, each year, approximately 1 in 5 people of all ages is likely to experience psychiatric symptoms that meet criteria for a diagnosable mental health condition (DHHS, 1999). Anxiety



disorders, which can include posttraumatic stress disorder, simple phobia, social phobia, agoraphobia, generalized anxiety disorder, panic disorder, and obsessive-compulsive disorder, have the highest annual prevalence among children (ages 9 to 17), adults (ages 18 to 54), and older adults (over age 55), at 13.0%, 16.4%, and 11.4%, respectively (DHHS, 1999). Among children, disruptive disorders follow in annual prevalence, with an estimated 10.3% of children meeting diagnostic criteria and experiencing mild global impairment (DHHS, 1999). Annual prevalence of mood disorders, which can include major depressive episode, unipolar major depression, dysthymia, and bipolar disorder, is estimated to be 6.2% among children, 7.1% among adults, and 4.4% among older adults (DHHS, 1999). Psychiatric and substance use disorders are often described and classified based on the diagnostic criteria of the *Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition (DSM-IV)*; American Psychiatric Association, 1994), as described in Box 8.1.

Among people with serious and persistent illnesses, prevalence rates of mental health conditions that meet *DSM-IV* diagnostic criteria are likely to be elevated (Aben, Verhey, Strik, Lousberg, Lodder, & Honig, 2003; American Psychiatric Association, 1994; Bing et al., 2001). For example, among a large, representative sample of adults engaged in HIV-related medical care, prevalence of psychiatric disorders was 47.9%, which is more than twice the prevalence among community participants (Bing et al., 2001; DHHS, 1999). Among those living with HIV, major depression and dysthymia were the most common conditions and 21% experienced both conditions; generalized anxiety disorders and panic attacks followed in prevalence (Bing et al., 2001). Prevalence estimates of depressive symptoms and major depression among people experiencing cancer vary considerably, between 1% and 42% (Patrick et al., 2003); prevalence estimates of anxiety disorders also encompass a broad range, from 10% to 30%, based on large-scale research that employed standardized interviews and diagnostic criteria (Stark et al., 2002). Methodological limitations likely contribute to these wide ranges; however, the National Institutes of Health's State-of-the-Science Panel (Patrick et al., 2003) describes that, "the most common symptoms of cancer and treatments for cancer are pain, depression, and fatigue" (p. 110). Among people experiencing stroke or myocardial infarction, new cases of depression were identified in 38.7% and 28.4% of a group of people receiving care in the Netherlands; when adjusted for age, sex, and degree of disability, the rates were comparable (Aben et al., 2003). Given the high prevalence of anxiety and mood disorders across all age groups and their increased prevalence among people experiencing chronic illnesses, they will be the primary focus of this discussion of assessment and intervention. Implications for assessment and intervention with children experiencing co-occurring conduct disorder and health conditions are discussed in Box 8.2. Further information that focuses entirely on older adults can be found in Chapter 14 of this *Handbook*.

In addition to general consideration of highly prevalent disorders of anxiety and mood, it is important to consider trauma specifically. Lifetime exposure to trauma, including exposure to seeing someone being seriously injured or killed; a fire, flood, or natural disaster; a life-threatening accident; combat; physical attacks; and sexual assaults, is estimated to occur among 61% of men and 51% of women in the United States (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995); however, in the current context of post-9/11 experiences, a global war on terror and homeland security alerts within the United States, perceived risk or threat to one's safety and related psychological sequelae may be more prevalent than

### Box 8.1 The DSM-IV and Multiaxial Assessment

A commonly used method for describing and classifying the types of mental health symptoms a person is experiencing, along with additional information regarding other health conditions, environmental stressors, and their overall functioning, is the multiaxial assessment contained in the *Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition (DSM-IV)* (American Psychiatric Association, 1994). While there are numerous critiques of the DSM (Kirk & Kutchins, 1992; Mechanic, 1999; Saleebey, 2002; Wakefield, 1999), its wide usage as a classification and communication system in health and mental health settings supports developing familiarity with it (Kerson, 2002; Williams, 1998). This presentation of the DSM-IV multiaxial assessment aims to introduce the components of this assessment tool. More detailed information and the most recent text revisions of the DSM-IV can be found in the *Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition, Text Revision (DSM-IV-TR)* (American Psychiatric Association, 2000).

The DSM-IV multiaxial assessment (American Psychiatric Association, 1994, 2000) generally focuses on describing and communicating the problems people are experiencing; however, social workers have a commitment to recognize and to build on people's strengths (Saleebey, 2002). In multiaxial assessment, it is important to be attuned to, to recognize, and to formulate interventions that build on clients' strengths. No matter how dire a situation may be, people have strengths that have fueled their perseverance and survival to the point at which they come into contact with you as a social worker. Actively reflecting on and engaging people's strengths, which may include their knowledge, capacities, and resources, are arguably central components of clients "achieving their goals and visions and . . . [having] a better quality of life on their terms" (Saleebey, 2002, pp. 1–2). Formulating a specific notation regarding client strengths as part of the multiaxial assessment may provide a useful tool for active consideration of and engagement with clients' strengths.

Multiaxial assessment according to the DSM-IV includes the following domains:

- Axis I: Clinical Disorders
- Other Disorders That May Be a Focus of Clinical Attention
- Axis II: Personality Disorders
- Mental Retardation
- Axis III: General Medical Conditions
- Axis IV: Psychosocial and Environmental Problems
- Axis V: Global Assessment of Functioning (American Psychiatric Association, 1994, p. 25; American Psychiatric Association, 2000, p. 27)

This discussion of the differential assessment of physical and mental health focuses primarily on Axis I, Clinical Disorders, such as Major Depressive Episode or Generalized Anxiety Disorder; Axis III, General Medical Conditions, such as cardiovascular disease or HIV; and Axis IV, Psychosocial and Environmental Problems, such as homelessness, longstanding poverty, or recent loss. Because social workers have specialized training in addressing the interactions between people and their environments, they are likely to have particular ability to intervene to address Axis IV-related issues; however, it is worth noting that in addition to this expertise, estimates suggest that there are more social workers in the psychotherapy workforce (192,814) than psychologists (73,018), psychiatrists (33,486), and psychiatric nurses (15,330)

(Continued)

combined (Center for Mental Health Services, 2001; Insel, 2004). As described throughout this chapter, social workers' attention to the interface between the person and environment is an important aspect of both differential assessment and intervention in mental and physical health; however, the ability to understand and to intervene to address these complex co-occurring issues also requires substantive background and training in additional psychotherapeutic interventions, some of which are discussed in the Interventions Section of this chapter.

Axis II identifies personality disorders and mental retardation. There are 10 specific personality disorders (Paranoid Personality Disorder, Schizoid Personality Disorder, Schizotypal Personality Disorder, Antisocial Personality Disorder, Borderline Personality Disorder, Histrionic Personality Disorder, Narcissistic Personality Disorder, Avoidant Personality Disorder, Dependent Personality Disorder, and Obsessive-Compulsive Personality Disorder). Personality disorders that do not meet diagnostic criteria for any of the 10 types identified are categorized as Personality Disorder Not Otherwise Specified (NOS). People with a personality disorder generally experience "an enduring pattern of inner experience and behavior that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment" (American Psychiatric Association, 2000, p. 685). As with the clinical disorders recorded on Axis I, the *DSM-IV* provides specific diagnostic criteria for each of the personality disorders.

Axis V, which focuses on the Global Assessment of Functioning (GAF) scale, provides notation of the clinician's assessment of the client's overall functioning based on psychological, social, and occupational domains; the influence of physical and environmental conditions is not considered in the GAF. The GAF is a constructed continuum in which functioning associated with mental health is ranked on a scale from 1 to 100 (a ranking of 0 indicates inadequate information). A GAF rating of 10 is associated with "persistent danger of severely hurting self or others"; a GAF rating of 50 is associated with "serious symptoms (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) or any serious impairment in social, occupational, or school functioning" (e.g., unable to maintain employment); and a GAF rating of 91 is associated with "superior functioning in a wide range of activities" (American Psychiatric Association, 2000, p. 34). Detailed information and guidance regarding how to formulate a GAF rating can be found in the *DSM-IV-TR* (American Psychiatric Association, 2000).

earlier estimates (Susser, Herman, & Aaron, 2002). Estimates from 1995 suggest that approximately 5.0% of men and 10.4% of women, ages 18 to 54, experience psychological effects of trauma that meet the diagnostic criteria for posttraumatic stress disorder (PTSD) in their lifetimes (Kessler et al., 1995). Posttraumatic stress disorder is considered a type of anxiety disorder (American Psychiatric Association, 1994).

The connections between trauma and health are numerous. First, preexisting trauma exposure and its related psychological sequelae are likely to interact with experiences of physical illness. Second, people may be seeking medical care as a direct result of a traumatic experience, such as a motor vehicle accident, sexual assault, or other physical attack. Third, consistent with the traumatic events identified in the *DSM-IV* as potential precipitants of PTSD (American Psychiatric Association, 1994), Mundy and Baum (2004) underscore the utility of broadening the definition of trauma to include some medical conditions, for example, myocardial infarction,

**Box 8.2**

**Intersections between Disruptive Disorders and Health Conditions: Assisting Parents and Children**

Approximately 1 out of 10 children is likely to experience a disruptive disorder such as, attention deficit/hyperactivity disorder, conduct disorder, or oppositional defiant disorder, each year (DHHS, 1999; Shaffer et al., 1996). The symptoms associated with disruptive disorders, including significant difficulties following directions, limited tolerance for frustration, impulsive behavior, and opposition to authority figures, pose particular challenges for children who may be experiencing co-occurring health conditions. Additionally, children's ability to benefit from health-care services may be limited by their difficulties following through with adult requests to adhere to medical recommendations (e.g., diet, medicine, and other treatment) and to avoid behaviors that worsen illness or interfere with treatment (e.g., engaging in restricted activities, removing bandages, moving around during exams or treatment; Bagner, Fernandez, & Eyberg, 2004; Matthews, Spieth, & Christopherson, 1995). While the study that follows focuses on a child experiencing a disruptive disorder and bladder cancer, it likely has relevance for children experiencing other conditions commonly seen among children in health-care settings, including asthma, diabetes, and epilepsy, in conjunction with experiencing a disruptive disorder.

Based on a case study of a 4-year-old boy, "Robert Smith," experiencing oppositional defiant disorder and bladder cancer, Bagner, Fernandez and Eyberg (2004) suggest that parent-child interaction therapy (PCIT) holds promise as an effective intervention to address co-occurring disruptive behavior and persistent physical illness. On referral for psychological services, Robert was screaming, yelling, and hitting during medical visits. His behavioral difficulties were exacerbated when he began chemotherapy. In one instance, he swung the bag filled with his chemotherapy over his head, resulting in its spilling on his mother and on one of the nurses.

The two phases of PCIT include an initial focus on child-directed interaction (CDI) that aims to enhance the relationship between the parent and child, the degree of positive parental communication with the child, and the child's social skills through play therapy. In the CDI phase, parents are guided to use nondirective skills outlined by the acronym PRIDE: Praise for the child, Reflection of the child's statements, Imitation of the child's play, Description of the child's behavior, and Enthusiasm in the play (Bagner, Fernandez, & Eyberg, 2004, p. 3). Parents are coached during this phase to employ PRIDE skills while ignoring negative behaviors and avoiding criticism, questions, and commands directed toward the child. The second phase focuses on parent-directed interaction (PDI); similar to behavioral intervention, this phase aims to enhance parenting skills in the following domains: expectations of their children, limit-setting ability, and consistent discipline.

After 12 sessions of PCIT, Robert displayed numerous clinically significant improvements in his behavior as measured by the Child Behavior Checklist and the Eyberg Child Behavior Inventory and his behavior was no longer consistent with a diagnosis of Oppositional Defiant Disorder. Additionally, Ms. Smith experienced clinically significant reduction in her parenting stress. Last, Robert's behavioral gains transferred to medical visits as noted by his physician and social worker who described increased adherence and an absence of aggression in his behavior.

While this case example describes but one illustration of the effectiveness of PCIT with a child experiencing co-occurring oppositional defiant disorder and a serious health condition, its efficacy with several other populations of children experiencing disruptive behaviors and disorders (Brestan & Eyberg, 1998; Eisenstadt, Eyberg, McNeil, Newcomb, & Funderburk, 1993; Hood & Eyberg, 2003; McNeil, Eyberg, Eisenstadt, Newcomb, & Funderburk, 1991; Nixon, Sweeney, Erickson, & Touyz, 2003; Schuhmann, Foote, Eyberg, Boggs, & Algina, 1998), further suggests that PCIT may be useful for clinicians, parents, and children to address such co-occurring health issues.

which may be considered traumatic events, because they represent significant threat to a person's life. Fourth, research examining PTSD and health-care usage suggests significantly elevated rates of medically related hospitalization, visits to the emergency department, and visits to a medical provider among people experiencing PTSD compared to people with no psychiatric condition (Stein, McQuaid, Pedrelli, Lenox, & McCahill, 2000). Given the high prevalence of exposure to traumatic events, their powerful intersection with individual health and medical care, and the potential for people to experience clinically significant symptoms of posttraumatic stress, even if they do not meet *DSM-IV* diagnostic criteria for PTSD (American Psychiatric Association, 1994), this chapter includes discussion of PTSD in health-care settings.

*Detection* In light of the high prevalence of depression and anxiety in the general population and among people with serious and persistent physical illnesses; the significant number of people, particularly people from ethnic minority backgrounds, who seek health care solely through primary care services; the high prevalence (30% to 50%) of people experiencing psychiatric disorders who go undetected in usual primary care; and the potential negative impact of psychiatric disorders on health outcomes, routine mental health screening is relevant for social workers in health-care settings (DHHS, 2001a; Lecrubier, 2004; Pignone et al., 2002; Regier et al., 1993). In addition, trauma, which can have significant implications for health, may go undetected in primary care (Lecrubier, 2004). However, research suggests that when brief screening questions explore trauma among people presenting with depression and anxiety, PTSD detection rates may be improved (Lecrubier, 2004; Samson et al., 1999). Although this research underscores the importance of exploring trauma among people presenting with symptoms of depression and anxiety, the National Center for PTSD recommends routine screening for posttraumatic stress disorder, because it may be associated with physical health and may go undetected.

Depression and anxiety can be expressed in health-care settings in a variety of ways. For example, a parent may comment to a social worker or other health-care provider that his teenage son does not seem to be himself. The parent says that his son has been short-tempered lately, is sleeping more than usual, has experienced a decline in his grades, and has lost interest in social activities that formerly interested him. The parent has attempted to offer him incentives to improve his academic performance and to encourage him to spend time with friends to no avail. Another individual describes feeling fatigued, having sore muscles, and experiencing difficulty falling asleep, but attributes these symptoms to recent stress at work. As part of conducting a comprehensive assessment, the social worker would recognize that depression among children and adolescents may present as irritability (American Psychiatric Association, 1994), and that symptoms of anxiety which are attributed to normalized conditions, such as stress at work, may not be accurately detected (Culpeper, 2003; D. Kessler, Lloyd, & Lewis, 1999). Equipped with the knowledge that detection of mood or anxiety disorders requires the consideration of atypical presentation of symptoms or behaviors, the social worker would understand that further assessment would be warranted for both people.

In health-care settings, depression and anxiety may also be expressed through physical changes, such as weight gain or loss or sleeping problems, and



frequent medical visits (more than five per year; Institute for Clinical Systems Improvement, 2002). Anxiety, in particular, may be expressed through medically unexplained physical symptoms, such as chest pain, gastrointestinal problems, headache, or dizziness (Culpeper, 2003; Institute for Clinical Systems Improvement, 2002). Physical concerns, rather than explicit concerns about anxiety, are frequently expressed by people experiencing panic disorders (Institute for Clinical Systems Improvement, 2002). While it is important not to invalidate an individual's physical symptoms, recognizing that such symptoms may have a relationship to mental health issues and, as previously discussed, may reflect culturally informed somatization of distress, can provide important avenues to appropriate intervention and relief. At the same time, some medical conditions, including coronary insufficiency, chronic obstructive pulmonary disease, pancreatic tumor, hypoparathyroidism, pheochromocytoma, pulmonary emboli, certain cases of coronary artery disease, and certain epilepsies may be eclipsed by symptoms of anxiety and would warrant assessment by a physician. Culpeper (2003) suggests that if a person over age 35 without prior anxiety symptoms and in prior good health describes new-onset of anxiety, evaluation for possible medical conditions should be obtained. Such medical evaluation would also be indicated when a client presents with symptoms of anxiety without a personal or family history of anxiety and in the absence of a stressful life event or possibly in situations where the client describes a high level of concern about the feelings of anxiety, which may suggest the presence of a physical condition rather than a mental health condition. Social workers are well-situated both to refer clients for appropriate physical care and to further explore mental health issues that may be manifested in physical symptoms. In addition to asking open-ended questions to inquire about the client's mood, coping strategies, and daily functioning, two structured ways in which social workers might explore mental health in health-care settings include using screening instruments and conducting a mental status exam.

*Screening Instruments* Screening instruments, which identify mental health symptoms warranting additional assessment, may facilitate the detection of mood, anxiety, and trauma-related disorders in health-care settings. Such instruments can include standardized scales with numerous items or may consist of just a few questions. They are often used in health-care settings in which certain psychosocial responses are seen and in which their early detection is thought important for the achievement of optimal outcomes of care.

According to the U.S. Preventive Services Task Force (2002), the following screening questions may identify the majority of adults experiencing depression and are likely to be as effective as more detailed instruments: (1) Over the last 2 weeks, have you felt down, depressed, or hopeless? and (2) Have you felt little interest or pleasure in doing things? (p. 760). Positive responses to these brief questions suggest that additional assessment of depression should be conducted.

Screening for specific anxiety disorders may be facilitated by the following questions proposed by Levinson and Engel (1997; cited in Feldman, 2000). Each question aims to screen for a particular anxiety disorder. A positive response to any of these questions would warrant further assessment of anxiety and of its impact on the individual's daily life (Institute for Clinical Systems Improvement, 2002).

- Would you describe yourself as a nervous person? Do you feel nervous or tense? (Generalized Anxiety Disorder)
- Have you ever had a sudden attack of rapid heartbeat or rush of intense fear, anxiety or nervousness? (Panic Disorder)
- Have you ever avoided important activities because you were afraid you would have a sudden attack like the one I just asked you about? (Agoraphobia)
- Some people have strong fears of being watched or evaluated by others. For example, some people don't want to eat, speak or write in front of people for fear of embarrassing themselves. Is anything like this a problem for you? (Social phobia)
- Some people have strong fears, or phobias, about heights, flying, bugs, or snakes. Do you have any phobias? (Specific phobia)
- Some people are bothered by intrusive, silly, unpleasant, or horrible thoughts that keep repeating over and over. For example, some people have repeated thoughts of hurting someone they love even though they don't want to; that a loved one has been seriously hurt; that they will yell obscenities in public; or that they are contaminated by germs. Has anything like this troubled you? (Obsession)
- Some people are bothered by doing something over and over. They can't resist the urge, even when they try. They might wash their hands every few minutes, or repeatedly check to see that the stove is off or the door is locked or count things excessively. Has anything like this been a problem for you? (Compulsion)
- Have you ever seen or experienced a traumatic event when you thought your life was in danger? Have you ever seen someone else in grave danger? What happened? (Acute Stress and Posttraumatic Stress Disorder [PTSD]; pp. 2–3).

The National Center for PTSD (n.d.) suggests routine screening for symptoms of PTSD because such symptoms can be associated with physical health problems and may not be identified as PTSD. Lecrubier (2004) further asserts that PTSD is likely to be a "hidden diagnosis" in primary care settings and that routine screening regarding trauma histories may facilitate appropriate intervention. To screen for PTSD in primary care and other health-care settings, the National Center for PTSD suggests the following, yes-no, self-reported screening questions which can be completed via paper and pencil by the client:

In your life, have you ever had any experience that was so frightening, horrible, or upsetting that, *in the past month*, you . . .

1. Have had nightmares about it or thought about it when you did not want to?
2. Tried hard not to think about it or went out of your way to avoid situations that reminded you of it?
3. Were you constantly on guard, watchful, or easily startled?
4. Felt numb or detached from others, activities, or your surroundings? ([http://www.ncptsd.org/screen\\_disaster.html](http://www.ncptsd.org/screen_disaster.html))

Any positive response to these screening questions would warrant further follow-up to assess for PTSD. The National Center for PTSD provides detailed information regarding proceeding with further assessment and intervention.



*Mental Status Exam* The mental status exam is a systematic, semistructured method for gathering information about and describing a person's mental health status at the current time. It includes observation and inquiry to assess a person's mental status and frequently involves a written summary of the examination. Unlike a biopsychosocial assessment, the mental status exam does not explore comprehensive elements of the person-in-environment and her history, but focuses primarily on the person's mental status at that time. Additionally, the mental status exam involves not only eliciting the client's perspective, but also actively drawing on and incorporating the social worker's observations (Lukas, 1993). Last, while not a diagnostic tool, the mental status exam may alert the social worker to mental health problems that warrant further assessment (Trzepacz & Baker, 1993).

The mental status exam addresses the following domains: appearance, attitude, and activity (sometimes simply referred to as appearance and behavior); mood and affect; speech and language; thought processes, thought content, and perception; cognition; and insight and judgment (Trzepacz & Baker, 1993). A mental status examination may be conducted as a discrete assessment or interwoven with a clinical interview. For example, as a worker begins talking with an older adult client he may describe recent difficulties with remembering to take his medication and a recent event in which he forgot where he parked his car at the grocery store and wandered around the parking lot for an hour. His description would be a cue to pursue exploration of his cognitive capacities and of his memory in particular. Especially when a client introduces an area that is worthy of further exploration through a mental status examination, it can be useful to empathically follow-up with the client, to explain the nature of the questions you will ask, and then to proceed with the mental status exam. This sort of follow-up conveys both attentiveness to the client and your professional capacity to further assess and intervene appropriately (Shea, 1988).

*Appearance, Attitude, and Activity* The mental status exam typically begins with the social worker's observations of the client's appearance, attitude, and activity (Lukas, 1993; Trzepacz & Baker, 1993). This part of the mental status exam includes attention to the following considerations:

- Client's degree of consciousness (Is the person alert? Does she respond to stimuli?)
- The congruence between the client's age and appearance (Does she appear to be her "stated age?" Does she seem older or younger?)
- The client's posture and position (Does the client's posture appear rigid or relaxed? Is the client in a hospital bed? Is the client able to sit down during the interview?)
- The client's attire and personal hygiene (Is the client dressed appropriately for the season? Are there any significant observations regarding the client's personal hygiene?)
- Any notable physical characteristics, in addition to race, ethnicity, and sex
- The client's attitude toward the social worker and toward the interview (How does the client respond to you? Are there changes in this response during your meeting?)
- Any significant movement or paralysis (Does the client have difficulty sitting still? Does she seem to move quickly or slowly? Does she appear to have any tremors or involuntary movements?)

*Mood and Affect* Consideration of the client's mood and affect generally follows these observations in the mental status exam. Mood commonly refers to the client's subjective report of his emotional state in general or in the present moment, while affect commonly refers to the social worker's observations of the ways in which the client demonstrates his emotional state during the clinical interview (Lukas, 1993). Exploration of the client's mood can begin with open-ended questions such as, "'How have you been feeling lately?' or 'How do you feel right now?'" (Trzepacz & Baker, 1993, p. 40). It is important to listen closely to clients' descriptions; to follow-up with questions that elicit greater detail and specificity regarding their mood, especially its intensity and the degree to which it reflects their usual mood; and to include direct phrases from the client whenever possible in a mental status exam summary. The following hypothetical interaction illustrates such follow-up:

SOCIAL WORKER: Can you tell me about how you've been feeling lately?

CLIENT: I've been very nervous.

SOCIAL WORKER: In what ways have you been feeling nervous?

CLIENT: I feel sick to my stomach. I can't eat. I feel very restless and uneasy. I'm tired, but I can't sleep. I sleep a short time and then I'm up again. I can barely focus at work.

SOCIAL WORKER: Is feeling this way new for you or have you been feeling this way for a while?

CLIENT: Sometimes I worry, but it wasn't like this until I got sick. Waiting for all of the test results is very stressful and it's got me very worried.

SOCIAL WORKER: How intense are the feelings that you're having?

CLIENT: Like I said, I worry now and then, but I've never felt anything like this.

SOCIAL WORKER: It seems like this worry is pretty intense for you. If you were to rank how you're feeling right now on a scale of 1 to 10 where 1 is the best you've ever felt and 10 is the most nervous you've ever felt, what would be your ranking?

CLIENT: I feel pretty far from the best I've ever felt (laughs). I would probably say that my nervousness feels like it's about an 8. It could go higher depending on what the test results say.

SOCIAL WORKER: It sounds like this nervousness feels very intense and out of the ordinary for you. It also sounds like you feel it quite physically, in your stomach, with your sleep, and in the restlessness you describe; and it sounds like it's affecting your concentration at work.

In this situation, in addition to the information the client provided regarding his mood, the social worker likely would observe that his affect appeared congruent with his mood; he appeared tense and nervous as he talked about feeling worried. Through the injection of humor, the client may have also displayed a range of affect even while predominantly expressing anxiety. Last, the psychological distress the client is experiencing would warrant additional assessment to inform appropriate intervention.

*Speech and Language* When observing speech and language social workers focus on how information is being expressed and what is being said. Of particular interest is the speed with which a person speaks, any notable aphasia (difficulty ex-

pressing and understanding language which may be evidenced in word-finding problems and more severe inability to express oneself), comprehension of language, volume of speech, prolonged silences, and any significant speech-related impairment (Lukas, 1993; Trzepacz & Baker, 1993). Comprehension can be assessed by asking the person to complete tasks that begin simply and increase in complexity. Sample questions can include: "Point to your eyes. . . [then] . . . Touch your left hand to your right ear" . . . [and finally] a three-staged command of otherwise unrelated activities can be tried, for example: "Pick up the paper clip, put it on the table, and cross your arms" (Trzepacz & Baker, 1993, p. 69). Asking clients to name objects in the room or in a complex picture is a way in which to assess aphasia. Clearly, the assessment of mental status, and of speech and language in particular, should be informed by an awareness of the client's primary language and should be conducted with linguistic competence (Trzepacz & Baker, 1993). A person whose primary language is Spanish may display limited comprehension and difficulty naming objects; however, this may be due to limited fluency in English rather than a mental health issue. Linguistic competence is a central component of accurate assessment. When a social worker's language ability hinders provision of linguistically competent services, professional interpreters who are able to facilitate communication and cultural understanding are needed (Hepworth, Rooney, & Larsen, 2002).

The information gathered by assessment of speech and language serves to inform inferences regarding possible mental health issues a person may be experiencing. For example, a client experiencing symptoms of depression may speak slowly and quietly, with long pauses in the rhythm of his or her speech. A person who has recently experienced a stroke, severe head trauma, brain surgery, or an infection may demonstrate difficulty finding words, but may still evidence comprehension or the person may demonstrate loss of the ability to understand or express language. Additionally, with the range of difficulties associated with aphasia, individuals may have variable awareness of their language difficulties. When individuals evidence aphasia, collaboration with the transdisciplinary health-care team will be a key element of ongoing assessment and intervention. Last, when individuals are experiencing aphasia related to Alzheimer's disease and other progressive dementias, they will likely demonstrate gradual deterioration in language ability (Trzepacz & Baker, 1993). Routine assessment of mental status among older adults provides a way in which to monitor changes in mental status over time and to engage in early intervention (Rabins, 1991).

*Thought Processes, Thought Content, and Perception* When assessing thought processes, content, and perception, social workers are primarily focusing on "how a person thinks and . . . what a person thinks about," (Lukas, 1993, p. 20) as well as any perceptual difficulties (e.g., hearing ability, eyesight, hallucinations, illusions) the person is experiencing (Lukas, 1993; Trzepacz & Baker, 1993). Thought processes are assessed by attending to the "organization, flow, and production of thought" (Trzepacz & Baker, 1993, p. 84). Specifically, the social worker attends to the degree of tangentiality, circumstantiality, flight of ideas, and looseness of associations in the person's verbal expressions. The primary areas of interest regarding thought content focus on the presence of obsessions, compulsions, paranoia, delusions, and violent ideation (Lukas, 1993; Trzepacz & Baker, 1993). Given the increased prevalence of risk of suicide associated with

physical illnesses that are chronic or terminal (Trzepacz & Baker, 1993), an entire section of this chapter is dedicated to suicide assessment and intervention. In terms of risk of injury to another person, either through homicide, abuse, or neglect, social workers should familiarize themselves with their organization's protocols regarding intervening to assist the individual and to prevent harm to another person; additionally, they should familiarize themselves with state laws regarding their mandates to warn third parties in the event of risk of imminent harm to an identified person and their mandates to report suspected abuse or neglect of children or elders (Lukas, 1993; Trzepacz & Baker, 1993). If a social worker has reason to believe that a person may be at risk of harming someone, it is important to consult with a supervisor and to formulate a plan to assist the person with staying safe.

*Cognition* Assessment of cognition focuses on orientation, perceived level of intelligence, concentration, memory, and abstract thinking (Lukas, 1993; Trzepacz & Baker, 1993). A phrase frequently used in mental status exams is, "the person is oriented X 3." This statement indicates that a person is oriented to person (she knows who she is; knows immediate family members), to place (she knows where she is, both specific setting and city and state), and to time (she knows the time, day, date, and season; Trzepacz & Baker, 1993). In the mental status exam, perceived level of intelligence is based on the social worker's assessment of the client's apparent intelligence, described as average intelligence or as above or below average intelligence (Lukas, 1993). Concentration is typically assessed by asking the person to engage in a task such as counting backward from 20; counting down from 100 by 7s (this request is called "serial seven subtractions"); or to spell "WORLD" backward; with these tasks, the person should be encouraged to complete the task without the use of paper, pencil, or other tools (Lukas, 1993; Trzepacz & Baker, 1993; pp. 128–129). Short-term memory can be assessed by asking a person to remember three words; telling the person the words; asking her to repeat the words (which indicates that information has been registered); and then asking her to recall the words after five minutes have passed (Trzepacz & Baker, 1993). Long-term memory can be assessed by inquiring about significant aspects in the person's past, for example, the city where she grew up, or details of major life events (Lukas, 1993; Trzepacz & Baker, 1993).

Last, asking the person to interpret a proverb can be a way to assess abstract thinking. For example, an interpretation of the phrase, "The grass is greener on the other side," that demonstrates abstraction would be, "Things that seem better elsewhere are not necessarily so," while a more concrete interpretation would be, "His lawn is greener than mine" (Trzepacz & Baker, 1993, p. 144). Numerous factors may influence the degree to which a person can abstractly interpret a proverb, including age, cultural relevance, level of education, IQ, psychosis, delirium, injury to the head, damage to the frontal lobe, and dementia (Trzepacz & Baker, 1993).

*Insight and Judgment* The final component of the mental status exam, which attends to insight and judgment, assesses the person's awareness of a problem and her ability to pursue action with awareness of consequences (Lukas, 1993; Trzepacz & Baker, 1993). The mental status exam enables the social worker to assess comprehensive elements of a person's mental status and can facilitate detec-

tion of mental health problems warranting further assessment. Once mental health issues are identified, the social worker proceeds with the process of differential assessment in order to formulate an appropriate intervention.

#### DIFFERENTIAL ASSESSMENT: ANXIETY AND MOOD DISORDERS

Feelings of sadness and worry are part of the human experience (American Psychiatric Association, 1994) and are likely to accompany numerous physical illnesses, including cancer, HIV, stroke, diabetes, heart disease, and Parkinson's disease (National Institute of Mental Health [NIMH], 2002a, 2002b, 2002c, 2002d, 2002e, 2002f). Psychological distress associated with physical illness is likely to range from transient worry and sadness to clinical mood and anxiety disorders. This discussion focuses on differentiating feelings of sadness and worry from more persistent mental health problems, including those which meet *DSM-IV* diagnostic criteria (American Psychiatric Association, 1994) for anxiety and mood disorders in order to formulate appropriate intervention to assist individuals and their families. As described earlier, interventions may range from psychoeducation and supportive counseling to support positive coping when faced with illness to psychotherapy and psychopharmacology to assist people who are experiencing more persistent and severe mental health issues (DHHS, 1999; IOM, 2001). This discussion aims to equip social workers with the ability to assess an individual's mental health experiences and then to formulate interventions based on the assessment to support overall well-being. While people experiencing co-occurring physical and psychiatric conditions may be particularly vulnerable to social isolation, medication nonadherence, and negative health outcomes (DiMatteo, 2004a; Frasure-Smith & Lesperance, 2003; Ickovics et al., 2001; IOM, 2001), it is also important that social workers reach people whose mental health conditions do not meet *DSM-IV* diagnostic criteria (American Psychiatric Association, 1994). For example, a meta-analysis of 37 studies published between 1974 and 1997 suggests that psychoeducational interventions focusing on stress management and health education with people with coronary disease are associated with reduced risk of cardiac mortality and of subsequent myocardial infarction, as well as improvements in dietary habits, smoking, exercise, cholesterol, and blood pressure (Dusseldorp, van Elderen, Maes, Meulman, & Kraaij, 1999). Additionally, research suggests that quality of life, social support, and group therapeutic interventions that focus on education, coping, support, and stress management are associated with increased cancer survival (Butow, Coates, & Dunn, 1999; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Fawzy et al., 1993; Spiegel, Sephton, Terr, & Stites, 1998). Attending to psychosocial elements of overall health is a valuable role for social workers in health-care settings in order to support positive health outcomes.

While understanding the unique situation of the individual in his ecological context is at the core of assessment, among the most significant additional components involved in differentiating emotional reactions associated with adjustment to various health conditions from psychiatric disorders pertain to severity, daily functioning impact, and duration of psychiatric symptoms. Differentiating between physical and mental health conditions is challenging; considering the etiology of the mental health symptoms is critical (J. Williams et al., 2002). The following section provides an overview of steps involved in differentiating the etiology of mental health symptoms so that appropriate intervention can be



formulated. The steps are based on the decision trees of the *DSM-IV*, which consider the possible contribution of medical conditions or substances in the mental health difficulties a person is experiencing (American Psychiatric Association, 1994). This discussion builds on the decision trees of the *DSM-IV* by also addressing the potential contribution of ecological factors to a person's mental health difficulties.

*Medical Conditions* Once mental health symptoms have been detected, the decision trees of the *DSM-IV* can provide helpful guidance regarding initial steps in the differential assessment process; the first step is to determine whether or not the symptoms may be due to a general medical condition. Many medical conditions have an underlying association with depression or anxiety. For example, Cushing disease or hypothyroidism can cause symptoms of depression (American Psychiatric Association, 1994; J. Williams et al., 2002). As described previously, numerous physical illnesses may be obscured by symptoms of anxiety (Culpeper, 2003). Because of the vast number of potential health conditions people may experience, collaborating with the transdisciplinary health-care team (e.g., nurses, physicians, and others with specialized training in the particular area) and obtaining condition-specific information will be central to making this determination. If it is determined that the mental health symptoms are due to an underlying medical condition, then intervention should first address that condition and mental health symptoms should be reassessed following such intervention. When physical conditions are associated with, rather than causing, psychological distress, for example, diabetes mellitus, coronary heart disease, and autoimmune disorders, intervention should concurrently target both the physical and psychological difficulties the person is experiencing (J. Williams et al., 2002).

*Medications* If mental health symptoms do not appear to be due to a medical condition, the next step is to assess whether or not the symptoms are due to ingesting or withdrawing from a substance, either a prescribed medical treatment, a toxin, alcohol, or other drugs (American Psychiatric Association, 1994). Side effects of numerous medications, including interferon alfa, anabolic steroids, glucocorticoids, and reserpine in high dosage, may involve psychological distress (Strader, Wright, Thomas, & Seeff, 2004 ; J. Williams et al., 2002). These medications are generally prescribed to treat Hepatitis B and C; anemia, pain associated with osteoporosis, and problematic weight loss after trauma, injury, or illness; endocrine disorders, asthma, and nasal symptoms of allergies; and high blood pressure, respectively (Strader et al., 2004; Thomson PDR® Electronic Library, n.d.; U.S. National Library of Medicine and National Institutes of Health, n.d.). Again, collaboration with the transdisciplinary health-care team and gathering medication-specific information are key elements in making this determination and considering options for intervention.

*Substance Use* The use of alcohol and other drugs may also influence mental health symptoms. Alcohol use is widely prevalent, with an estimated 51.0 % of people age 12 and over in the United States reporting current use; 22.9% report binge drinking at least once in the past 30 days (Substance Abuse and Mental Health Services Administration [SAMHSA], 2003). The highest rates of both heavy and binge drinking are found among young adults, 18 to 25 years old, at 40.9% and 14.9%, respectively (SAMHSA, 2003). Although the effect of alcohol in

small amounts mimics stimulants and produces feelings of alertness, confidence, and a positive mood, alcohol is a central nervous system depressant that leads to slowed reaction, reflexes, and muscular response. Additionally, higher doses of alcohol lead to greater slowing of the central nervous system, which typically results in sleep followed by feelings of shakiness, headaches, depression, and difficulty concentrating upon waking (Weil & Rosen, 1993).

Cigarette smoking is also widely practiced. Nearly 1 in 3 people age 12 and over in the United States uses tobacco (SAMHSA, 2003). Tobacco is a stimulant plant, whose active ingredient, nicotine, is highly addictive and has significant pharmacological effects on the brain (Henningfield, 1998; Weil & Rosen, 1993). As a stimulant, nicotine may lead some people to feel more energized and alert while others may feel jittery and nervous. Stimulants may also affect sleep and eating. Following the use of stimulants, a person is likely to feel sleepy, fatigued, and depressed (Weil & Rosen, 1993). Additionally, the National Institute on Drug Abuse (n.d.) describes numerous psychological effects associated with withdrawal and cravings of nicotine (e.g., impairments in psychomotor and cognitive functions).

This discussion of the physiological effects of alcohol and tobacco in relation to mental health symptoms provides just two examples of the numerous ways in which substance use and mental health symptoms may intersect. As part of a comprehensive assessment of a person's mental health symptoms, the social worker should consider the potential influence of substances on these symptoms. For example, a person recently diagnosed with lung cancer who has been a long time smoker, may describe difficulty concentrating. With further exploration, you identify that he recently stopped smoking. While this recent discontinuation of smoking is not likely to be the only factor contributing to his psychological distress, it would be an important consideration in a comprehensive assessment. Similarly a person seeking assistance with feelings of depression may also describe heavy alcohol consumption. As a central nervous system depressant, consuming alcohol may be contributing to her feelings of depression.

However, this conceptualization of the relationship between mental health and substance use suggests a unidirectional, causal relationship, in which substance use predates and causes the mental health symptoms a person is experiencing. This type of relationship between mental health symptoms and substance use is but one of several ways in which substance use and mental health symptoms may intersect. For example, it is possible for a person to experience mental health difficulties that predate her substance use and the substance use may not meet criteria for a diagnosis of abuse or dependence (American Psychiatric Association, 1994; Hien, Zimberg, Weisman, First, & Ackerman, 1997). Alternatively, a person may experience concurrent mental health and substance use disorders that are independent of each other and do not necessarily share etiology, however, increased symptoms of either disorder may intensify and prompt increased symptoms of the other disorder (Hien et al., 1997). For social workers engaged in differential assessment, teasing apart the relationship between mental health and substance use issues involves obtaining a comprehensive history of the person's mental health symptoms, substance use, and the relationship between them. This comprehensive history may facilitate identification of the etiology of the client's current difficulties and inform appropriate action, including mental health services, if psychological distress seems primary, substance use intervention if that seems primary, or integrated mental health and substance use intervention if the



person seems to be experiencing each condition with equal weight (DHHS, 1999). In this *Handbook*, further information can be found in Chapter 13 that provides comprehensive guidance for addressing substance use in health-care settings.

*Ecological Context* Although the *DSM-IV* does not identify ecological factors in its decision trees to inform differential diagnosis of psychiatric disorders (American Psychiatric Association, 1994), the centrality of the person in environment perspective in social work suggests that a comprehensive assessment of factors contributing to a person's mental health symptoms should include explicit consideration of her ecological context as possibly contributing to the mental health difficulties she may be experiencing. Inadequate housing, nutrition, financial resources, health insurance, access to medical care, and social support are likely to contribute to feelings of stress, sadness, and worry, as well as to negative health outcomes.

In fact, research suggests that adults who are homeless have greater risk for mental illness, substance use disorders, physical illness, lack of health insurance, and death than the U.S. general population (Barrow, Herman, Cordova, & Streuning, 1999; Fischer & Breakey, 1991; Hibbs et al., 1994; Hwang et al., 1998; Kessler et al., 1994; Kushel, Vittinghoff, & Hass, 2001; Regier et al., 1993). Further, Kushel et al. (2001) found that lack of health insurance coverage was associated with increased difficulty in receiving needed care and adhering to medications. Additionally, research with mothers receiving welfare suggests that increased environmental and social risks (such as living in an unsafe neighborhood, not having enough food, experiencing domestic violence, and stressful life experiences associated with meeting basic needs) are associated with increased risk of depression, while social support and a sense of control over one's life are associated with reductions in this risk (Siefert et al., 2000). This research further supports the importance of social workers' attention to helping clients meet basic needs (e.g., housing, nutrition, financial resources, health insurance), as well as to support their social relationships and coping. If upon comprehensive assessment of a person's environmental context it appears that ecological factors are contributing to a person's mental health difficulties, clearly intervention should target those factors to support the client's access to basic needs, to familial and social support, and to strategies to support coping in order to relieve the mental health problems that may be associated with them. Identifying potential resources and services, discussing them with the client, and facilitating referrals are important aspects of both the social worker's role to link people to resources (Hepworth et al., 2002) and of addressing ecological factors that may be fueling mental health symptoms.

Once medical conditions, substance use, and ecological factors are addressed as potential contributors to the client's mental health symptoms, the process of differentiating feelings of sadness and worry as aspects of the human experience from those which indicate a psychiatric disorder resumes. As described earlier, John Williams and colleagues (2002) summarize the primary components of this differential assessment as "intensity, duration, and impact on daily functioning" (p. 1161). These components reflect elements of the diagnostic criteria for psychiatric disorders according to the *DSM-IV*.

*DSM-IV and Diagnostic Criteria* For a person to be diagnosed with a particular condition, the *DSM-IV* identifies clusters of mental health symptoms for each disorder and thresholds for the number of symptoms that must be met, their du-

ration, and their impact on functioning. When inquiring about a person's mental health experiences, it is useful to explore the nature of the difficulty a person is having, its intensity, its history, any associated precipitating event or stressor, and any prior mental health difficulties or prior treatment, while bearing in mind ecological factors of the person-in-environment. As an example, a diagnosis of major depressive disorder would be made if a person's symptoms meet the following criteria: daily or near daily experiences of symptoms over 2 weeks causing significant distress or impaired functioning. The symptoms would not be due to a medical condition, substance, or bereavement. The symptoms would include depressed mood (in children and adolescents, it may be irritable mood) or loss of pleasure or interest in activities and at least four additional symptoms outlined next:

1. Significant change in weight or appetite
2. Insomnia or hypersomnia
3. Psychomotor agitation or retardation
4. Fatigue or loss of energy
5. Feelings of worthlessness or excessive or inappropriate guilt
6. Impaired concentration or indecision
7. Recurrent thoughts of death, suicidal ideation, suicide attempt (American Psychiatric Association, 1994, p. 327)

A person experiencing fewer symptoms with less impact on functioning may meet the criteria for minor depression, however this research diagnostic category is currently under investigation and is not formally included as a diagnosis in the *DSM-IV*. Other diagnostic categories that may be considered when a person presents with symptoms of depression that are not due to a general medical condition or substance, include dysthymia, which involves depressed mood and two additional symptoms of depression for more than 2 years that cause significant distress or impairment; and adjustment disorder with depressed mood, which involves symptoms of depression following a stressful life event in conjunction with significant distress or impaired functioning (American Psychiatric Association, 1994; J. Williams et al., 2002).

Anxiety disorders not due to a general medical condition or to a substance include generalized anxiety disorder, panic attack and disorder, phobias, obsessive-compulsive disorder, acute stress disorder, posttraumatic stress disorder, and anxiety disorder not otherwise specified (American Psychiatric Association, 1994). For illustrative purposes, the diagnostic criteria for generalized anxiety disorder and posttraumatic stress disorder are outlined here; additional information can be found in the *DSM-IV*. With both of these conditions, the attention to "intensity, duration, and impact on daily functioning" (J. Williams et al., 2002, p. 1161) is again part of differentiating worry that might be part of the human experience from generalized anxiety disorder, or differentiating responses that might be expected based on exposure to a traumatic event from posttraumatic stress disorder (American Psychiatric Association, 1994). In the case of generalized anxiety disorder, in addition to experiencing excessive worry or anxiety that is difficult to control for 6 or more months, the person also experiences at least three (only one required with children) of the following symptoms:

1. Restlessness or feeling keyed up or on edge
2. Being easily fatigued
3. Difficulty concentrating or mind going blank
4. Irritability
5. Muscle tension
6. Sleep disturbance (difficulty falling or staying asleep; p. 436)

Last, the anxiety is generalized and not focused on a single domain; the symptoms fuel significant distress or impairment in functioning and are not due to a general medical condition or substance.

Diagnostic criteria for posttraumatic stress disorder include exposure to a traumatic event in which the person experienced "intense fear, helplessness, or horror" which, among children, may be expressed as agitation or disorganization of behavior (p. 428). Additionally, the person reexperiences the traumatic event, avoids stimuli associated with it or experiences numbed responsiveness evidenced in at least three symptoms, and experiences heightened arousal evidenced in at least two symptoms. Last, the symptoms are present for more than 1 month and involve significant distress or impairment in functioning (American Psychiatric Association, 1994, pp. 428–429).

Finally, it should be noted that when a person's symptoms overlap across conditions, the diagnosis that holds a higher place in the diagnostic hierarchy of the *DSM-IV* (e.g., explanations of mental health symptoms due to a general medical condition or to substances are addressed first) or which has greater pervasiveness (e.g., secondary symptoms related to the primary diagnosis are not diagnosed as separate conditions) is applied (J. Williams, 1998). Exclusion criteria found in each diagnostic category of the *DSM-IV* will facilitate the application of these principles (American Psychiatric Association, 1994; J. Williams, 1998). As described by Janet Williams (1998), "A small forest of decision trees is provided to make the differential diagnostic process easier by helping clinicians understand the organization and hierarchic structure of the classification" (pp. 37–38).

## SUICIDE

Suicide is a serious, preventable public health issue and is ranked as the 11th overall cause of death in the United States (DHHS, 1999, 2001b; NIMH, 2003; Hoyert, Kung, & Smith, 2005). Numerous risk factors are associated with suicidal behavior and completed suicide, including differences by gender, age, race, and marital status (Moscicki, 1997). In general terms, women are more likely to attempt suicide, while men are more likely to complete suicide. Firearms represent the most prevalent method of suicide among both men and women (NIMH, 2003).

People over age 65 are at high risk of suicide and the highest rate of suicide is found among White American men over age 85 (NIMH, 2003). Young adults ages 15 to 24 are also at risk. For this group, suicide has been decreasing since 1993, but continues to be the third cause of death and, in 1996, accounted for more deaths among teenagers and young adults than "cancer, heart disease, AIDS, birth defects, stroke, pneumonia and influenza, and chronic lung disease *combined*" (U.S. Public Health Service, 1999, p. 3, emphasis in the original; Anderson & Smith, 2005; Hoyert, Kung, & Smith, 2005; Joe & Marcus, 2003). African American male adolescents appear to be at increasing risk as their rates of suicide attempts more than doubled between 1991 and 2001 (Joe & Marcus, 2003).

Among males and females of all ages, suicide as a cause of death ranked highest in 2002 among people from American Indian (8th) and Asian or Pacific Islander (8th) backgrounds, followed by White Americans (10th), Hispanic Americans (11th) and African Americans (16th; Anderson & Smith, 2005). Two important considerations should be noted in reviewing these data. First, Anderson and Smith (2005) advise using caution regarding reports for groups other than African American or White American due to race-related misreports on death certificates. Second, although suicide did not appear in the first 10 causes of death among all sexes and ages among people who were African American or Hispanic American, this ranking differed by age and by gender in both groups. Last, in her review of epidemiologic studies to identify risk factors for suicide, Moscicki (1997) identifies research suggesting that rates of suicide among people who are divorced or widowed are higher than among people who are married across age groups.

In addition to differences in prevalence of suicidal behavior and completed suicide by age, gender, race, and marital status, there is a growing body of literature regarding increased risk of suicidal behavior among gay, lesbian, and bisexual youth. While there appears to be general agreement that gay, lesbian, and bisexual youth experience increased risk of suicidal ideation and attempts (Fergusson, Horwood, & Beautrais, 1999; Frankowski & the Committee on Adolescence, 2004; Jesdale & Zierler, 2002; Remafedi, 1999; Russell & Joyner, 2001) due to methodological limitations, the literature is less conclusive regarding increased risk of completed suicide among gay, lesbian, and bisexual youth in comparison to their heterosexual counterparts (Jesdale & Zierler, 2002; Remafedi, 1999; Zametkin, 2002). While the empirical literature on sexual orientation and completed suicide is limited, a prior suicide attempt is considered a significant risk factor for suicide (Gliatto & Rai, 1999; Moscicki, 1997; Zametkin, Alter, & Yemini, 2001). Accordingly, health-care professionals should be aware of the potential for heightened suicide risk among gay, lesbian, and bisexual youth.

Research suggests an increased risk of suicide associated with several physical illnesses, including "HIV/AIDS, Huntington's disease, malignant neoplasms, multiple sclerosis, peptic ulcer, renal disease, spinal cord injuries, and systemic lupus erythematosus" (Moscicki, 1997, p. 511); however, "there is no evidence that medical disorders are *independent* risk factors for suicide outside the context of depression and substance abuse" (p. 511, emphasis in the original). In terms of social work practice in health-care settings, these findings suggest that strategies to address mental health conditions among people with physical illness, including routine screening, assessment, and intervention, are central components of suicide prevention.

Experiencing a psychiatric or substance use disorder is associated with attempted and completed suicide; the risk increases with experiencing more than one disorder, and especially with co-occurring psychiatric and substance use disorders (Kessler, Borges, & Walters, 1999; Moscicki, 1997). Other widely recognized risk factors for suicidality include:

- Hopelessness
- Previous suicide attempts
- Firearms in one's home

- Recent loss
- Significant stressful events (including terminal illness diagnosis, loss of employment, financial or legal difficulties)
- Limited social support
- Social isolation
- Living alone
- Family history of mood or substance use disorders or suicidal behavior
- Familial stress
- Physical or sexual abuse in childhood
- Models of suicidal behavior among one's family or peer group, or among celebrities
- History of impulsive behavior
- Stigma or other obstacles to seeking help (DHHS, 2001b; Hirschfeld & Russell, 1997; Ivanoff & Smyth, 1992; Moscicki, 1997; NIMH, 2003; Sanchez, 2001; Shaffer et al., 2001; U.S. Public Health Service, 1999; Zametkin et al., 2001)

In addition to these considerations, suicide risk factors among youth include domestic violence, rejection, disciplinary stress, and incarceration (Moscicki, 1997; Zametkin et al., 2001).

The National Cancer Institute (2005) asserts that people with cancer may be at increased risk for suicide and that additional suicide risk factors to consider include the following:

- Oral, pharyngeal, and lung cancers (often associated with heavy alcohol and tobacco use)
- Advanced stage of disease and poor prognosis
- Confusion/delirium
- Inadequately controlled pain
- Presence of deficit symptoms (e.g., loss of mobility, loss of bowel and bladder control, amputation, sensory loss, paraplegia, inability to eat and to swallow, exhaustion, fatigue; <http://www.cancer.gov/cancertopics/pdq/supportivecare/depression/HealthProfessional/page4>)

The presence of a suicide risk factor does not mean that a person will engage in suicidal behavior (Ivanoff & Smyth, 1992); however, if a person is experiencing numerous factors, the risk may increase (Moscicki, 1997). Assessment of suicidality begins with an awareness of risk factors, but then proceeds with an individualized assessment. At its core, suicide assessment involves employing relevant knowledge and finely tuned skills to assess a person's ability to stay safe and to refrain from self-harm. In this process, generalized information should be considered in the context of the unique experiences of each particular individual.

*Assessment of Suicide* The first step in suicide assessment is the identification of suicidal ideation. As noted by Gliatto and Rai (1999), prior research suggests that people had seen a physician within months of completing suicide and that frequently physicians were not aware of clients' history or risk of suicidality (Murphy, 1975a, 1975b). Recent research indicates that 98% of people participating in services in an urban outpatient medical setting supported routine inquiry by physicians about mental health during medical visits; though the finding was not statistically significant, more people with a history of suicidality (55%) sup-

ported such inquiry at each visit in comparison to people without such history (37%; Zimmerman et al., 1995). While some individuals may readily identify their thoughts about suicide, others may keep them to themselves or may convey them in indirect language. Indirect communication may include expressions of hopelessness, an inability to see a solution to a problem, a feeling that others might be better off without them, a desire to give up, or a feeling that current problems are insurmountable (Ivanoff & Smyth, 1992).

Direct inquiry about suicidal ideation has not been shown to cause suicidal behavior (J. Williams et al., 2002; Zimmerman et al., 1995). Particularly in settings where people may be at high risk of suicide, Ivanoff and Smyth (1992) recommend routine inquiry as part of a mental health assessment in which a person would be asked about history of thinking about or doing something to hurt himself or herself. Direct inquiry that is coupled with empathy can provide an inroad into assessing suicidal ideation and intention. For example, interwoven with a discussion in which a client expresses hopelessness and difficulty identifying solutions to a pressing problem, a follow-up question might be, "it sounds like you've been feeling pretty discouraged, and maybe a bit desperate, have you thought about hurting yourself?" Or another follow-up question might be, "it sounds like you're having a hard time finding a way out of this situation and that you're feeling like you have no options. You mentioned wanting to give up. Have you thought about wanting to die?" If the client reports wanting to die, then the social worker could follow-up by asking, "You've described feeling so down you've wanted to die. Have you thought about hurting yourself?" (For additional examples see Gliatto & Rai, 1999; Hirschfeld & Russell, 1997; Ivanoff & Smyth, 1992; Lukas, 1993; Shafer et al., 2001).

If a client reports suicidal ideation, the social worker's next questions aim to gather additional information regarding components of the ideation (e.g., content, timing, onset, frequency, intensity) and to identify the level of imminent risk associated with it (American Psychiatric Association, 2003; Hirschfeld & Russell, 1997; Ivanoff & Smyth, 1992). Bearing in mind the risk factors previously discussed, the imminence of suicide risk increases in the presence of the following factors:

- A developed plan for hurting one's self, with particular attention to plans which involve violence or irreversibility
- Access to the means to carry out the plan
- Intention to harm one's self or to carry out the plan
- Consideration of efforts to avoid being discovered or interrupted
- Completion of or in process of completing suicide note
- Alcohol or other substance use
- Presence of psychotic symptoms, with particular attention to command hallucinations that may be instructing the person to engage in self-harm
- Hopelessness (American Psychiatric Association, 2003; Hirschfeld & Russell, 1997; Ivanoff & Smyth, 1992)

Making a determination regarding a client's level of suicide risk can be facilitated by several additional factors. First, gathering specific information in the course of the suicide assessment will enable the social worker to further consider the person's level of risk, to describe it to others from whom consultation may be



sought, and to coordinate services as indicated (Lukas, 1993). Second, consultation with a supervisor or with colleagues is often a vital element in making this assessment and in formulating appropriate intervention. Third, in advance of conducting a suicide assessment, a social worker should familiarize herself with her organization's policies and procedures regarding assessment and intervention with clients at risk of suicide; she should also familiarize herself with the state laws and regulations in this area. Fourth, while a social worker should be mindful of the potential negative aspects of inpatient hospitalization (e.g., stigma, loss of control) and the centrality of supporting clients' self-control (Ivanoff & Smyth, 1992; Lukas, 1993), Lukas (1993) asserts, "you should make a practice—both for the client's well-being and your own—of never letting a client leave your office until you have used all necessary resources to satisfy yourself that she is not at imminent risk of trying to kill herself" (p. 119). Last, clear, thorough documentation can be useful in recording events, decisions made, and action taken and in serving as a risk management practice (Ivanoff & Smyth, 1992).

*Interventions to Address Suicide Risk* If a client is at immediate risk of suicide, intervention should focus on physical safety (Hirschfeld & Russell, 1997; Ivanoff & Smyth, 1992); however, throughout the process, Ivanoff and Smyth (1992) recommend "a bias toward maintaining the client's sense of self-control and personal management whenever possible" (p. 123). This stance suggests that social workers should pursue collaboration and empowerment, rather than unilateral action and disempowerment when working with clients at risk for suicide to the extent possible. In social work practice, this perspective would involve seeking clients' input regarding available intervention options and empowering them to take action, for example, voluntarily pursuing inpatient hospitalization rather than involuntary commitment. However, if a person is unable to pursue action that will uphold her safety and there is imminent risk of suicide, it is the responsibility of the social worker, or other direct service provider, to intervene to support her physical safety.

When a client is at imminent risk of suicide, someone should remain with him, and in most cases, an evaluation for inpatient hospitalization should be made (Hirschfeld & Russell, 1997). If the contact with the client is over the phone, the social worker should remain on the phone with the client and the client should not be placed on hold (Millman, Strike, Van Soest, Rosen, & Schmidt, 1998). It may be helpful to involve a reassuring person to stay with the client so that he is not left alone and so that emotional support can begin to be mobilized (Ivanoff & Smyth, 1992). If the client states that he has a gun or pills during the phone contact, Millman et al. (1998) recommend that he should be asked to place the gun (unloaded) in another part of the room or, likewise, to move pills, to dispose of them in the toilet, or to ask another person to keep them temporarily. Contacting emergency medical services or the police would be warranted if a suicide attempt has occurred or is in the process of occurring or if needed to transport the client for inpatient hospitalization evaluation (Hirschfeld & Russell, 1997; Ivanoff & Smyth, 1992). A client in need of evaluation for inpatient hospitalization should not drive himself there (Holkup, 2002).

Shaffer et al. (2001) further specify that with children and adolescents experiencing suicidality, the social worker should be in contact with the client's family and should address treatment's importance, as well as its feasibility and family preferences. Additionally, they recommend gathering information from multiple



sources (e.g., interviews with the client and people who know the client, observation of behavior, completion of standardized scales) and consulting with the client's caregiver. Consultation with the client and caregiver should focus on the following topics: restricting access to alcohol or drugs due to their disinhibiting effects; securing or removing any firearms or lethal medications; identifying that someone supportive will be at home; discussing stressful situations that may precipitate suicidality and coping strategies to address them; and confirming that an appointment for follow-up care has been made.

Verbal and written safety contracts are often made with clients and their families when their risk of suicide is found not to be imminent (American Psychiatric Association, 2003; Shaffer et al., 2001). These contracts typically include an agreement that the client will not harm himself and that the client will take action to stay safe, including contact numbers and whom to call if he is not able to stay safe (Holkup, 2002; Ivanoff & Smyth, 1992). Written contracts are typically signed by both the client and the social worker and each retains a copy (Holkup, 2002). While such contracts may be widely used, there are important caveats to consider in their use. Perhaps most important, no research exists to examine their efficacy (Shaffer et al., 2001) and the American Psychiatric Association (2003) cautions against their use as evidence of a client's ability to stay safe or of his eligibility for discharge from outpatient services or inpatient hospitalization. Additionally, the American Psychiatric Association (2003) does not recommend the use of safety contracts with clients who display impulsivity, agitation, psychosis, or substance intoxication or with clients who are not well known to the provider or who are seen in emergency contexts. Last, when the client is at risk for suicide, but not imminently, recommended interventions include mobilizing the person's support system by asking the client's permission to contact and involve a person with whom the client has a close relationship; acting to restrict the client's access to any firearms, ammunition, lethal medication, or other potentially lethal method of self-harm; thoroughly following-up with the client through additional contacts (including phone contact, visits, letters, or scheduled meetings); and providing appropriate intervention or referral to address any co-occurring psychiatric or substance use disorders the person may be experiencing (Hirschfeld & Russell, 1997; Ivanoff & Smyth, 1992; Shaffer et al., 2001).

Evidence-based information to guide intervention with people engaged in suicidal behavior is limited, although aspects of effective strategies generally include intensive follow-up and a combination of psychotherapy and pharmacotherapy (American Psychiatric Association, 2003; Hirschfeld & Russell, 1997; Ivanoff & Smyth, 1992; Shaffer et al., 2001). Cognitive-behavioral therapy and interpersonal psychotherapy may be useful with persons experiencing depression and suicidality; dialectical behavior therapy and psychodynamic therapy may be useful with persons experiencing borderline personality disorder, which is often associated with suicidal and self-harming behavior (American Psychiatric Association, 2003, 1994). Recent research with older adults experiencing depression suggests that interpersonal psychotherapy and medication (primarily citalopram, a selective serotonin reuptake inhibitor) provide more timely relief from suicidal ideation than does usual care, while also facilitating improvements in depression (Bruce et al., 2004). In some cases when a person is experiencing severe unremitting depression, electroconvulsive therapy may be indicated (American Psychiatric Association, 2003; Hirschfeld & Russell, 1997). Again, collaboration with a physician is warranted.

Most of the limited research regarding effectiveness of interventions to address suicidality has focused on adults. In fact, Zametkin et al. (2001) assert that only one example of research with adolescents who have attempted suicide is available. This study, conducted with participants 15 to 45 years old, showed greater effect of interpersonal problem-solving training in comparison to a brief, problem-oriented intervention (McLeavey, Daly, Ludgate, & Murray, 1994). In their practice parameters for intervention with children and adolescents experiencing suicidality, Shaffer et al. (2001) draw on research with adolescents experiencing depression to cite evidence for the use of the following approaches: cognitive-behavioral therapy; interpersonal psychotherapy; dialectical behavior therapy; and family psychoeducation (Brent, Poling, McKain, & Baugher, 1993; Brent et al., 1997; A. Miller, Rathus, Linehan, Wetzler, & Leigh, 1997; Mufson, Weissman, Moreau, & Garfinkel, 1999).

Shaffer et al. (2001) also discuss several psychopharmacological interventions to assist children and adolescents experiencing suicidality, including lithium, valproate, carbamazepine, and selective serotonin reuptake inhibitors (SSRIs), fluoxetine in particular; however, only SSRIs have been empirically validated with this age group. Concerns regarding the potential increased risk of suicidality with the use of fluoxetine (also known as Prozac) inform Shaffer et al.'s (2001) recommendations that close monitoring, routine inquiry regarding suicidality, and attention to akathisia, a side effect which seems to increase risk of suicidality, accompany fluoxetine intervention among this population. Additionally, recent concerns have been raised regarding increased risk of suicidal ideation and attempts associated with the use of paroxetine (also known as Paxil or Seroxat), a selective serotonin reuptake inhibitor, among children and adolescents (Wooltorton, 2003). Based on these concerns, the U.S. Food and Drug Administration (2003) issued a statement clarifying that among people under age 18, paroxetine is not recommended treatment for major depressive disorder or approved for use among this age group and that an individual's physician should be consulted prior to discontinuing use of the medication. The limitations in applying interventions with effectiveness among adults to intervention with adolescents underscore the importance of further research with the population (Zametkin et al., 2001). Research is underway that focuses on school-based and emergency department interventions to reduce the risk of suicide among adolescents. Further information can be found in the *National Strategy to Prevent Suicide* (DHHS, 2001b).

For social workers in health-care settings, these findings suggest that depending on your role and setting, training in the provision of cognitive-behavioral, interpersonal, psychodynamic, and dialectical behavior therapies or referring clients to such therapies may be indicated. Additionally, collaboration with physicians who can evaluate the use of psychotropic medications, in particular medications that are not lethal in overdose, would be warranted (Hirschfeld & Russell, 1997; Murphy, 1975a).

#### PSYCHOSOCIAL INTERVENTION STRATEGIES IN HEALTH-CARE SETTINGS

Social work practitioners strive to match intervention strategies to individuals in their ecological contexts and to the identified problems (Berlin & Marsh, 1993). In addition, they strive to match the person-in-environment and problem in con-

junction with the best available evidence and the client's preferences for intervention (Culpeper, 2003; Gambrill, 2000; J. Williams et al., 2002). Comprehensive assessment enables social workers to consider fully the range of factors that may be contributing to the problem and the range of interventions that may effectively resolve it; and to discuss intervention options with the client (Gambrill, 2000). As described previously, differential assessment involves identifying the type of mental health issue a person is experiencing, its possible influences, and possible ways in which to address it. The psychosocial interventions described next focus on strategies to support coping and overall well-being and then address strategies to assist people who are experiencing depression and anxiety disorders.

#### ROUTINE SCREENING OF PSYCHOSOCIAL CONDITIONS

Given the significant implications of mental health in health-care settings, including the relationships between psychological distress and mental and physical health conditions, the role of behavior in shaping health, the importance of suicide prevention, and the power of social ties in supporting health, routine screening of psychosocial conditions is highly relevant in health-care settings. Program planning and policy level initiatives are warranted to ensure the availability of this core element of overall health care.

#### TRANSDISCIPLINARY COLLABORATION AND COORDINATION OF SERVICES

Another central component of supporting mental health in health-care settings involves transdisciplinary collaboration with the team of providers working with the client. Transdisciplinary collaboration is particularly relevant in understanding the intersection of mental health and the client's physical condition, the possible etiologic role of the physical illness, the interactions of medications and treatment with psychosocial conditions, the coordination of care with numerous providers, and underscoring the importance of mental health in physical health conditions and outcomes. When a client is experiencing psychological distress that warrants consultation for psychopharmacological intervention, transdisciplinary collaboration can be helpful in accessing this service and in considering the possible interactions between psychotropic medications and any medications the client is currently taking for another condition.

Social workers also serve as brokers of services (Hepworth et al., 2002). In this role, social workers can facilitate referrals and access to needed resources, including components of medical and mental health care, health insurance coverage, and community-based case management when indicated. Gambrill (2000) underscores the importance of being aware of the effectiveness of services to which clients are referred. Beyond simply linking a client to a given service, the social worker attends to the overall quality of that resource when making a referral. In some communities, available resources may be limited, which may highlight the need for macrolevel advocacy to adequately meet the needs of people within the community. Additionally, beyond simply providing a phone number or a contact name, the social worker may help facilitate the referral by obtaining written consent from the client to contact the referral agency, following-up with

the agency directly, and then following-up with the client to ensure that the linkage was made.

#### INFORMATION AND PSYCHOEDUCATION

Whether focused on physical or mental health conditions, information and psychoeducation are central components of assisting individuals and families with understanding the condition, including its course, expected outcome, treatment, and psychosocial components (Johnson, Sandford, & Tyndall, 2003; Rolland, 1994). The provision of information through education or through psychoeducation typically differs in scope, focus, and qualifications of the service provider. Education generally focuses on providing information about an illness, including expected course, treatment, and components of self-care by a person who may not necessarily have professional training, while psychoeducation generally builds on these components by also drawing on psychotherapeutic strategies, such as behavioral and cognitive frameworks, led by a person with professional training in mental health services (Lukens & Thorning, 1998). The inclusion of psychoeducational approaches allows for the emotional and cognitive processing of the information and may assist people with developing a psychosocial understanding of the condition and its meaning in their lives (Rolland, 1994). Based on a review of studies that compared the usefulness of written and verbal information for parents of children discharged from acute hospitals, Johnson et al. (2003) concluded that increased satisfaction and knowledge were associated with the provision of both written and verbal information. Additionally, they underscore the potential for client involvement in creating the written information, the importance of culturally relevant presentation of it, and attention to the literacy level of written material. The provision of written and verbal information, in addition to psychoeducational interventions, are important components of facilitating knowledge and coping with physical and mental health conditions. Additionally, as described in the subsequent section on Stress Management and Health Supporting Behaviors, such interventions may also play an important role in reducing health risks and promoting longevity.

#### ADHERENCE COUNSELING

Adherence to medication and treatment are key elements of health outcomes; however, nonadherence is highly prevalent, impacting approximately one in four people (DiMatteo, 2004b). Social workers are often key participants in assisting people with adherence to medications and treatment. For comprehensive guidance to support adherence in health-care settings, see Chapter 18 in this *Handbook*, which provides a systematic model of adherence counseling.

#### STRESS MANAGEMENT AND HEALTH SUPPORTING BEHAVIORS

Several strategies have shown promise in helping people to manage stress and to support overall health, including mindfulness-based stress reduction (Kabat-Zinn, 2003; Weissbecker, Salmon, Studts, Floyd, Dedert, & Sephton, 2002), exercise, and relaxation training, although there have been mixed findings about the

effectiveness of some relaxation training and stress management interventions among people with cardiac problems (IOM, 2001). A comprehensive review of 36 studies by Rees, Bennett, West, Davey, and Ebrahim (2004), 18 of which examined the effectiveness of stress management strategies, suggested that psychological and stress management interventions among people with coronary heart disease were associated with some decreased depression and anxiety; however, findings did not demonstrate reductions in cardiac mortality, which may be due to methodological limitations of the published research and the range of interventions included in the review. In contrast to these findings, as previously discussed, a meta-analysis of 37 studies found that stress management and health education interventions were, in fact, associated with reduced risk of cardiac mortality, as well as reductions in associated risk factors, such as smoking, dietary habits, cholesterol, and blood pressure (Dusseldorp et al., 1999). These findings, in conjunction with research conducted with people experiencing cancer, seem to suggest that stress management interventions are best partnered with psychoeducation to reduce risk factors and to enhance coping and survival (Butow, Coates, & Dunn, 1999; Dusseldorp et al., 1999; Fawzy et al., 1993, 1995; Spiegel et al., 1998).

Smoking cessation, healthful eating, and weight management are key behaviors that can help support health (IOM, 2001). Engaging people in the change process and facilitating motivation to change behavior are central elements of supporting such health behaviors. Two paradigms, the transtheoretical/stages-of-change model (Prochaska & DiClemente, 1983) and motivational interviewing (W. Miller & Rollnick, 1991, 2002) have received considerable attention as models to inform assisting people with behavior change efforts. While empirical research has prompted questions regarding the theoretical validity of Prochaska and DiClemente's (1983) transtheoretical/stages-of-change model (IOM, 2001; Littell & Girvin, 2002) and further research suggests that perceptions of self-efficacy, expectations about the outcomes, and self-control of behavior may more effectively predict behavioral changes, the stages-of-change model may provide utility as a framework for conceptualizing readiness for change (IOM, 2001).

The stages-of-change model proposes that a person's readiness for behavior change can be understood in the context of five stages: precontemplation, contemplation, preparation, action, and maintenance (Prochaska, DiClemente, & Norcross, 1992). The stages reflect the degree of awareness a person has about making a behavioral change (e.g., a move from precontemplation to contemplation reflects increasing awareness of a behavior to be changed and increasing consideration of the possibility of change); the time frame in which behavioral change will happen (e.g., a move from contemplation to preparation reflects increased intention to take action in the near future); and the action a person is taking to achieve behavioral change (e.g., preparation involves planning for change, action involves active modification of behavior or environment to support behavioral change, and maintenance involves steps to uphold change; Prochaska et al., 1992). Together, W. Miller and Rollnick's (1991, 2002) model of motivational interviewing and the stages-of-change model may provide useful tools for conceptualizing and enhancing motivation and helping people to change behaviors (IOM, 2001). Both of these models are discussed in detail in Chapter 13 in this *Handbook*. However, as noted earlier, individually focused interventions to support positive health behaviors, without attention to familial, social, and environmental factors,



including access to safe places to exercise and availability of healthful food, will likely be limited in their effectiveness (IOM, 2001).

#### COPING ENHANCEMENT

A large body of research suggests that interventions to enhance coping can assist people experiencing psychological stress (Noh & Kaspar, 2003). Rather than focusing on specific mental health symptoms among people experiencing physical illness, Folkman and Greer (2000) focus on "psychological well-being and the coping processes that support it" (p. 11). Informed by Lazarus and Folkman's (1984) cognitive model of stress and coping and relevant research that focuses on elements of effective coping while experiencing illness, Folkman and Greer (2000) propose the model described next to support coping when faced with illness. In essence, this model focuses on continuing to seek goals that matter; facing the inspiring, yet potentially scary possibility that the goal may or may not be realized; and taking action to achieve the goal. Implicit in this model is the notion that pursuing goals which matter, and which are not necessarily illness-specific, can be an important mechanism for fostering coping and continued engagement with positive aspects of life in the midst of illness.

First, the social worker focuses on creating "conditions for challenge," which reflect "an appraisal of the opportunity for meaningful mastery or gain" (Folkman & Greer, 2000, p. 16). The importance of challenge in this model is based on the premise that such appraisal holds the possibility of achieving a meaningful goal through one's efforts and of enhancing one's sense of control and ability. In this challenge rests the exciting possibility of achieving the goal and the potentially worrisome risk of striving without achieving the goal, of possibly "falling short" (p. 16). Normalizing this combination of emotions may be helpful. To create the conditions for challenge, Folkman and Greer (2000) suggest exploring what matters to the client, whether it relates to one's illness or to other parts of one's life. The social worker "needs to help the patient define what is important now, what matters most" (p. 16). Probing recent events and specific aspects of them that have meaning and that matter to the client will help create conditions for challenge. Identification of what matters to the client may also be fostered even as clients discuss negative events, which can be explored, and then followed with inquiry regarding positive events or personal strengths. Folkman and Greer (2000) offer the following specific questions, "'Tell me about a time when something happened that made you feel good,' or 'tell me about a time when things were really going well. What was going on?'" (p. 16). Other sample questions might include, "what are some of your strengths? When was a time that you used that strength?" Exploration of what was involved in those times, of how the client was feeling, and of "what mattered" to the client can help identify what is important to the client (p. 16).

Identifying what matters to the client then informs "a meaningful goal that is realistic" (p. 16). The goal may be created independently by the client or with input from the social worker or from significant others. Most relevant is that the goal has meaning for the client and that it emphasizes personal control. Folkman and Greer (2000) describe the goal of a person experiencing metastatic bowel cancer to make tea for his companion although he was feeling weak physically and somewhat powerless emotionally. They go on to describe that in setting this goal and considering steps to achieve it "the patient realized that there were still things he could control, and this helped lift his spirits" (p. 16). Goals may involve



reading a book to a loved one, having a conversation with a friend, pursuing a cherished hobby, formulating a system to manage medical treatments or side effects, writing a letter to a partner; what is central is that the goal matter to the client and that it strengthen a sense of control.

The next step focuses on encouraging the client's achievement of the goal, including continued encouragement or possible revision of the goal if the task seems overwhelming. Key elements of this step include active engagement of the client in pursuing a goal that has meaning to him, focusing on steps to achieve the goal, and continuing to create the conditions of positive challenge. The final component of the model involves maintaining "background positive mood" (p. 17), which may include asking clients to talk about positive happenings in their lives and encouraging clients to plan activities that yield feelings of enjoyment and accomplishment (Folkman & Greer, 2000).

This theoretically-informed and research-guided model may provide a framework to enhance coping and psychological well-being when a person is experiencing serious illness. Key elements of this model include its attention to normative coping and to supporting a sense of control and mastery in the context of illness. Through this model, Folkman and Greer (2000) suggest that well-being may be enhanced in the midst of significant illness.

#### FAMILY AND SOCIAL SUPPORT AND SPIRITUAL RESOURCES

Psychosocial responses to illness among individuals and their families are likely to vary according to the timing, onset, course, degree of incapacitation, and anticipated outcome of the illness (Rolland, 1994). Family and social support influence health outcomes via the following pathways: direct biology (including airborne, bloodborne, and genetic conditions); health behavior (including lifestyle, caregiving, and medical adherence support); and psychophysiology (including physiological effects of emotions and cognitions). Generally, evidence-based family interventions include illness-specific education and psychoeducation to support knowledge and coping, and, as indicated, therapy to address relational problems (Campbell, 2003). Multiple family groups, ongoing assessment of psychosocial experiences of the family to support normative coping and early intervention in the event of psychological distress, self-help, or professionally facilitated support groups, and structuring services to actively involve families are also recommended (IOM, 2001; Fobair, 1998; Rolland, 1994; Weihs, Fisher, & Baird, 2002). Enhancing social support and coping skills through support groups and peer support is also likely to improve quality of life and health status. Last, involvement in religious organizations is linked with positive health outcomes (IOM, 2001). Additional information regarding families and health can be found in Chapter 11 in this *Handbook* and information regarding spiritual resources among families can be found in Walsh (1999).

#### TARGETED INTERVENTIONS TO ASSIST PEOPLE EXPERIENCING DEPRESSION AND ANXIETY DISORDERS

There is a growing body of evidence to guide intervention with people experiencing depression and anxiety disorders (DHHS, 1999). Unfortunately, most people in the United States who likely need care do not receive appropriate treatment, even when "appropriate treatment" is defined based on minimal recommended

levels of antidepressant medication or at least four meetings focusing on mental health with a mental health specialist or primary care provider (Young, Klap, Sherbourne, & Wells, 2001). With a nationally representative sample of those likely experiencing a depressive or anxiety disorder, only 30% received appropriate treatment, although 83% had seen a health-care provider. Likelihood of not receiving appropriate care was associated with being male, African American, less well educated, less than 30 years old, or over 59 years old. Income and insurance status were not associated with appropriate treatment, although insurance was associated with seeking care. No difference in accessing care was found between people who were White American or African American, but appropriate treatment was less likely to be received by African Americans; this discrepancy underscores the importance of addressing cultural competence in mental health care. Additionally, the importance of addressing mental health-care disparities associated with race and socioeconomic status is also underscored in this research (DHHS, 2001a; Young et al., 2001).

The following treatment recommendations to assist people experiencing depression and anxiety disorders are informed by consensus statements and available evidence (Ballenger et al., 2000, 2004; DHHS, 1999; Hollon et al., 2002; Young et al., 2001). For depression, cognitive-behavioral therapy (CBT) and interpersonal psychotherapy (IPT) are evidence-based psychotherapeutic interventions that have demonstrated effectiveness with adolescents, adults, and older adults, although there appears to be a larger body of evidence for IPT than CBT among older adults. Additionally, antidepressant medications are evidence-based psychopharmacologic interventions that may be helpful. When people are experiencing severe unremitting depression for which other treatments are not effective or which co-occur with psychotic symptoms, consideration of electroconvulsive therapy (ECT) may be indicated (DHHS, 1999; Hollon et al., 2002). For people experiencing generalized anxiety or panic disorder, cognitive-behavioral therapy has demonstrated effectiveness, as have several antidepressant and anti-anxiety medications (DHHS, 1999; Young et al., 2001). Psychodynamic or interpersonal therapies may be beneficial to people experiencing anxiety disorders, however, their evidence base is limited (DHHS, 1999).

Recommended intervention for people experiencing PTSD differs based on when the traumatic event occurred. Immediately following the traumatic event, recommendations include attending to safety, providing education about trauma, accessing natural support systems, and providing supportive counseling (Ballenger et al., 2000; Foa, Hembree, Riggs, Rauch, & Franklin, 2005; National Center for PTSD, n.d.). Psychoeducation regarding trauma, normal responses, coping strategies, and when indicated, psychotherapeutic and psychopharmacologic interventions, may be particularly useful in primary care. Neither single-sessions of critical incident stress debriefing nor benzodiazepines are recommended as early intervention strategies (Ballenger et al., 2004). These authors underscore the importance of encouraging clients who may access Internet information to pursue it from reputable health-care or advocacy organizations, rather than commercial, nonspecialist, or chat room sites.

People experiencing high levels of distress with psychological or somatic symptoms should be assisted with relief of symptoms; cognitive-behavioral therapy may be useful in reducing the risk of later PTSD (Ballenger et al., 2004). If after 3 or 4 weeks and two assessment sessions, the client continues to experience significant distress and symptoms of PTSD, treatment that includes either selec-

tive serotonin reuptake inhibitors (SSRIs), cognitive-behavioral treatment, or a blend of these strategies, is recommended. Further research is needed to address possible relapse upon completion of treatment. People experiencing persistent PTSD may benefit from medication regimens of 1 year or more; cognitive behavioral treatment may help enhance gains during pharmacotherapy and sustain gains after treatment concludes (Ballenger et al., 2004).

While recommended interventions with children and adolescents experiencing PTSD also include attention to cognitive-behavioral strategies and social support, there is limited evidence regarding the effectiveness of psychopharmacologic interventions among this population. As such, it is recommended that intervention with children and adolescents begin with psychotherapy and include medication, typically SSRIs or imipramine, as needed, depending on the symptoms they are experiencing. Last, psychoeducation with caregivers is recommended to facilitate their coping, to provide information about PTSD, and to aid their efforts to support the child or adolescent (Cohen et al., 1998).

## CONCLUSION

This chapter considered myriad intersections between physical and mental health in health-care settings. In many ways, we end where we started: with the recognition of the complexity of the mutual influences between health, mental health, and ecological contexts. While the general information provided can contribute to one's theoretical and evidence-based practice knowledge, it is critical that any knowledge base be informed by the individual preferences and ecological contexts of the people served. To cross the myriad intersections between physical and mental health in health-care settings, proceed with engaged, thoughtful attention to assessment and intervention which reflects competence to serve individuals and families across culture, race, ethnicity, socioeconomic status, sexual orientation, spiritual background, physical ability, gender, and age. This engaged, thoughtful attention to the individuals and families served, in conjunction with leading edge evidence-based practice knowledge, will enable social workers to provide the high-quality services they deserve.

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## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 8.1

What is the relevance of addressing the intersections between physical and mental health?

### LEARNING EXERCISE 8.2

How does your cultural background and the cultural background of your clients influence mental health assessment and intervention in your health-care setting?

### LEARNING EXERCISE 8.3

How might you proceed in direct practice with Joseph, who was described in this chapter? What additional information might you need to inform your assess-

ment? What goals might be collaboratively set with Joseph? How might you intervene to address these goals?

#### LEARNING EXERCISE 8.4

How would you engage in differential assessment and subsequent intervention in the following hypothetical cases?

#### Case Example 8.1

Darren is a 25-year-old man of African American background. He and his wife, Paula, have been married for 2 years. Last year he was diagnosed with HIV and Hepatitis C. He was recently prescribed a combination of protease inhibitors and interferon alfa. He was referred to the social worker by his physician because his feelings of depression are causing him distress; he feels easily fatigued and has recently missed several days of work because “he could not get going.” He is worried about his job and about being able to pay his bills if he doesn’t go to work. He describes having experienced feelings of sadness and worry as a teenager, but prior to 2 months ago, those feelings had not surfaced in several years.

#### Case Example 8.2

Sandy is a 40-year-old woman of Native American background. She and her partner of 15 years, Racquel, have two children, ages 11 and 9. Sandy has experienced asthma since her early 20s; with exacerbated symptoms, she entered the hospital yesterday. While talking with you, she describes intense fears about the possibility of another asthma attack. She also describes that she felt increased difficulty breathing over the past couple of weeks. She was so busy with household and child-care responsibilities, that she did not have time to see the doctor to adjust her medication regimen. She describes feeling worried and restless when you meet with her. She has no prior history of mental health difficulties or of mental health treatment.

After dividing the class into small groups, ask some of the groups to develop a principled argument in support of the utility of the *DSM* and some of the groups to develop a principled argument against the utility of the *DSM*. Bring all of the groups back together to discuss the strengths and limitations of the *DSM* in direct social work practice.

How is the strengths perspective reflected in your direct practice with clients? What are the challenges to implementing the strengths perspective in your practice?

What would be involved in your assessment of Georgina’s suicide risk in the hypothetical case below? What might short- and long-term intervention involve?

#### Case Example 8.3

Georgina is a 45-year-old widowed woman of Mexican American background who was diagnosed with breast cancer 5 years ago. At that time, she had a mastectomy followed by reconstructive surgery, radiation, and chemotherapy. She has recently been diagnosed with a recurrence of cancer. Georgina describes a deep sense of sadness and hopelessness about this diagnosis. She fears feeling pain,

going through chemotherapy, and losing her hair again, and believes “it won’t do any good anyway.” She also describes feeling alone. Although her son and her daughter live nearby, they are both busy with their families and jobs. Georgina and her longtime companion separated 6 months ago. Georgina feels overwhelmed by her hopelessness, does not feel it will get better, and says that she wants to die. She has thought about notes that she would write to family to say goodbye and she has stored pain medication at her home that she plans to take.

What additional information would be helpful for you to learn to enhance the effectiveness of your assessment and intervention skills to assist people experiencing physical and mental health difficulties?

## SUGGESTED RESOURCES

### CONDITION-SPECIFIC ORGANIZATIONS

- American Cancer Society (<http://www.cancer.org/docroot/home/index.asp>)
- American Heart Association (<http://www.americanheart.org>)
- Bureau of Primary Health Care (<http://bphc.hrsa.gov/bphc/related.htm>)
- National Alliance for the Mentally Ill (<http://www.nami.org>)

### CULTURAL COMPETENCE

- Association of Black Cardiologists, Inc. (<http://www.abccardio.org>)
- Cross Cultural Health Care Program (<http://www.xculture.org>)
- Cultural Competence in Care with Older Adults (<http://www.stanford.edu/group/ethnoger>)
- Office of Minority Health (<http://www.hrsa.gov/OMH/competence.htm>)

### DIFFERENTIAL ASSESSMENT

- Algorithm for Assessing Major Depression, Panic, and Generalized Anxiety Disorders (<http://www.guideline.gov/algorithm/2576/FTNGC-2576.html>)
- Cancer and Depression ([http://www.nci.nih.gov/cancerinfo/pdq/supportive-care/depression/healthprofessional#Section\\_172](http://www.nci.nih.gov/cancerinfo/pdq/supportive-care/depression/healthprofessional#Section_172))
- Depression and Primary Care: The MacArthur Initiative on Depression and Primary Care at Duke and Dartmouth (<http://www.depression-primarycare.org>)
- Depression and Stroke, Heart Disease, Cancer, Parkinson’s Disease, HIV/AIDS ([http://health.nih.gov/result.asp?disease\\_id=183&category\\_id=16](http://health.nih.gov/result.asp?disease_id=183&category_id=16))

### EVIDENCE-BASED PRACTICE

- Evidence-Based Practice in Health Care-Cochrane Collaboration (<http://www.cochrane.org/index0.htm>)
- Practice Guidelines for Consumers and Patients (<http://www.ahrq.gov/consumer>)
- Practice Guidelines-National (<http://www.guideline.gov>)

Practice Guidelines-UCSF (<http://medicine.ucsf.edu/resources/guidelines/index.html>)

#### GAY, LESBIAN, BISEXUAL, AND TRANSGENDER RESOURCES

Gay and Lesbian Health-American Public Health Association ([http://www.apha.org/public\\_health/glh.htm](http://www.apha.org/public_health/glh.htm))

Gay and Lesbian Medical Association (<http://www.glma.org>)

Parents, Families, and Friends of Lesbians and Gays (<http://www.pflag.org>)

Suicide Risk among Gay and Lesbian Youth ([http://www.lambda.org/youth\\_suicide.htm](http://www.lambda.org/youth_suicide.htm))

#### GOVERNMENT ORGANIZATIONS

Agency for Health Care Quality and Research (<http://www.ahrq.gov>)

Bureau of Primary Health Care (<http://bphc.hrsa.gov/bphc/related.htm>)

National Institute of Mental Health (<http://www.nimh.nih.gov>)

Office of Minority Health (<http://www.hrsa.gov/OMH>)

Substance Abuse and Mental Health Services Administration ([www.samhsa.gov](http://www.samhsa.gov))

#### MEDICATION INFORMATION

U.S. National Library of Medicine and National Institutes of Health (<http://www.nlm.nih.gov/medlineplus/aboutmedlineplus.html>)

#### SCREENING INSTRUMENTS

Center for Epidemiological Studies Depression Scale for Children (CES-DC; [http://www.brightfutures.org/mentalhealth/pdf/professionals/bridges/ces\\_dc.pdf](http://www.brightfutures.org/mentalhealth/pdf/professionals/bridges/ces_dc.pdf))

Geriatric Depression Scale (<http://www.stanford.edu/~yesavage/GDS.html>)

NIMH Information (Depression Screening Questions; <http://menanddepression.nimh.nih.gov/infopage.asp?ID=20#1>)

#### SUICIDE

Suicide Prevention-National Institute of Mental Health (<http://www.nimh.nih.gov/suicideprevention/index.cfm>)

Suicide Prevention-Substance Abuse and Mental Health Services Administration (SAMHSA; National Suicide Prevention Lifeline: 1-800-273-TALK; [www.suicideprevention.org](http://www.suicideprevention.org))

#### SUBSTANCE USE INFORMATION

Commonly Used Drugs (<http://www.drugabuse.gov/Drugpages>)

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## CHAPTER 9

# Communication in Health Care

SARAH GEHLERT

**G**OOD COMMUNICATION IS central to the provision of effective health care. If patient and provider are able to communicate in a way that leads to the accurate exchange of information, health outcomes will be enhanced in several ways. Diagnosis is more accurate, for example, when social workers and other health-care providers are able to establish rapport with patients, take cues from them, and pose questions in a way that is understandable. Likewise, when patients are able to express their symptoms and concerns in a way that can be understood by providers, it is more likely that their conditions will be diagnosed and problems assessed with accuracy. Treatment plans based on those assessments will be more effective, because they will better reflect patients' unique health-care and social needs. It therefore is easy to agree with Fisher's (1992) assessment that the best scientific knowledge in the world is insufficient if communication between patient and provider is flawed.

In this chapter, the goal of health communication is defined as: To obtain and disseminate the maximum amount of information with the minimum amount of distortion and discomfort for the communicators. The chapter's purpose is to describe: (a) the negotiations inherent in health-care encounters, (b) common sources of communication error, and (c) ways in which communication can be enhanced in a variety of clinical settings.

### CHAPTER OBJECTIVES

- Convey the structure and dynamics of the clinical encounter between patient (or patient system) and provider in health-care settings.
- Convey how health beliefs impact health communication.
- Determine how group differences by race, ethnicity, gender, religion, and geography can affect health beliefs.
- Discuss the dynamics of health-care teams as small groups and the place of social workers on health-care teams.
- Outline evidence-based methods for improving how health messages and information are communicated to patients and their families and information solicited by health-care providers.



- Outline evidence-based methods for improving how patients and families present information to and question health-care providers.
- Distinguish interpretation from translation.
- Provide guidelines for accurate translation of health-care information between patients and providers in health-care settings.

This chapter is designed to be used in concert with other chapters in this *Handbook*, especially those on physical and mental health (Chapter 8), chronic illness (Chapter 18), and alternative health (Chapter 22). Active cross-referencing of these chapters by readers will optimize their learning of how communication can be enhanced to maximize health-care outcomes.

### THE STRUCTURE AND DYNAMICS OF THE CLINICAL ENCOUNTER IN HEALTH CARE

In a seminal article on communication in health care, Kleinman, Eisenberg, and Good (1978) described the clinical encounter between patient and provider as a negotiation between two cultural constructions of reality that yields clinical reality. The authors defined clinical reality as the interactions between patients and providers that occur during the health-care encounter and the outcomes that accrue from those interactions. Outcomes may include: (a) the development of treatment plans; (b) adherence to those plans; (c) health consequences, such as reduction in asthma attacks or seizures; and, (d) social consequences, such as a child's ability to return to school.

Kleinman et al. (1978) noted that patients bring to their encounters with providers sets of beliefs, expectations, values, and goals that are culturally constructed in the sense that they are determined by each individual's life experiences. The authors note that illness is shaped by cultural factors governing the perception, labeling, explanation, and evaluation of discomforting experiences, the latter of which are analogous to symptoms. These processes are embedded in complex family, social, and cultural nexuses. Prior experience with the illnesses of family members and how these illnesses were managed, for instance, have a significant effect on the way in which individuals approach or deal with their own illnesses and those of their families. These prior experiences can be as subtle as a child's overhearing her parents talk about the serious illness of a family member.

As described by Rolland and Werner-Lin in their chapter on families and chronic illness (Chapter 11), families vary greatly in their approaches to illness. They vary in the extent to which and how they work together to deal with the management of an illness, how they work with providers, and how they communicate with one another and others about the illness. The parents of a child with epilepsy in one family, for instance, may not talk about the condition within the family, attempt to hide seizures from others, and take a passive role with the child's physician. Another set of parents might organize the family around the child's seizures, talking freely about the condition, with all members responsible for monitoring symptoms, becoming active in advocacy groups, and joining the child at clinic visits. A third family may have integrated the child's seizures into family life, so that the condition is neither hidden nor dominates activities. Each of these three approaches to dealing with a child's epilepsy would likely have a unique effect on the lifetime responses to illness of the child with epilepsy and

his siblings. Determining an individual's family illness history can thus be a powerful tool for health social workers because it provides valuable insights into how prior experiences might have shaped the individual's cultural construction of reality.

Pachter (1994) says that patients' cultural constructions of reality almost never differ entirely from the biomedical constructions held by health-care providers, but instead vary on a continuum between lay or ethnocultural constructions on one end and biomedical constructions on the other. Most patients' cultural constructions of reality in fact represent combinations of "ethnocultural beliefs, personal and idiosyncratic beliefs, and biomedical concepts" (p. 690). The further that patients' constructions diverge from providers', the greater is the likelihood that communication problems will occur.

Providers, too, bring to clinical encounters sets of beliefs, expectations, values, and goals that are shaped by their own unique life experiences as well as the professional cultures into which they have been socialized. Professional cultures, such as those of physicians, nurses, health social workers, and physical therapists entail shared language, rules of behavior, dress, and ways of acknowledging status. Rosenthal (1993, p. 3) described the socialization of medical students, for instance, by saying "from the beginning, medical students are told that they are in school to learn to think like a doctor. And when they emerge 4 years later, many will have adopted a professional demeanor such that they not only think like one, but talk like one, and dress like one, too."

#### HEALTH BELIEFS AND COMMUNICATION

Health beliefs are components of cultural constructions of reality that guide health behavior and communication. They are guided by culture and dictate: (a) how symptoms are identified and which are considered appropriate to take to providers; (b) how patients understand the causes and treatment of their illnesses; (c) what patients expect of providers; and, (d) what personal and moral meanings patients ascribe to their illnesses and how they address questions such as "Why me? What did I do to deserve this?" (Weston & Brown, 1989, p. 77).

Leventhal (1985) adds that the natural history of illnesses can shape patients' health beliefs and constructions of reality in much the same way that culture shapes health beliefs. This is particularly true with chronic illnesses. Patients' awareness and understanding of illness increase through time, as they are exposed to health information and become more familiar with how their bodies respond to chronic illness. This heightened awareness can influence how symptoms are evaluated and in which situations patients deem it appropriate to seek formal treatment. A patient who initially was frightened by symptoms and sought treatment frequently may in time feel capable of illness self-management as he becomes more familiar with the pattern of his symptoms.

From a global perspective, illness is seen as due either to natural causes, such as infection or accident, or supernatural causes, such as spirit aggression, sorcery, witchcraft, or mystical retribution (Erasmus, 1952; Foster, 1976; see Table 9.1). Though supernatural causes may seem exotic to many, they are part of the health belief systems of many residents of the United States, especially those who were born outside the country. In 2000, one in 10 U.S. residents (28.4 million persons) was born outside the country (Lollock, 2001). According to data from the 2000

**Table 9.1**  
Four Theories of Supernatural Causation by Region of the World

Theory	Definition	Region
Spirit aggression	Aspiration to the direct, hostile, arbitrary, or punitive action of some malevolent or affronted supernatural being, such as nature spirits, disease, demons, departed ancestors, or ghosts	East Asia, Insular Pacific, South America
Sorcery	Ascription of impairment of health to the aggressive use of magical techniques by a human being, either independently, or with the assistance of a specialized magician or shaman	North America
Witchcraft	Ascription of impairment of health to the suspected voluntary or involuntary aggressive action of a member of a special class of human beings believed to be endowed with a special power and propensity for evil	Circum-Mediterranean
Mystical retribution	Acts in violation of some taboo or moral injunction causing disease indirectly	Africa

U.S. census (Spector, 2004), 51% were from Latin America, 25.5% from Asia, 15.3% from Europe, and 8.2% from other areas. These figures do not include undocumented immigrants. Although their numbers are difficult to estimate, around five million undocumented immigrants were thought to be living in the United States in 1996 (Spector, 2004).

Health beliefs, like cultural constructions of reality in general, are learned through socialization. They are often long-held cultural beliefs that remain with a group, especially one that is cut off from mainstream society for socioeconomic, religious, geographic, or political reasons. Religious and political groups might, for example, have reason to hold on to certain beliefs and to eschew mainstream constructions. Jehovah's Witnesses, for example, hold strong beliefs against the sharing of blood products, and come into conflict with health-care providers who prescribe transfusions during surgery or after accidents. A number of high-profile court cases have resulted from situations in which parents who are Jehovah's Witnesses refused to allow their children to receive transfusions prescribed by physicians. Orthodox Jews who observe strict dietary laws may come into conflict with staff members when admitted to hospitals that are not equipped to provide kosher meals.

Geography can act to maintain traditional health beliefs by limiting access to mainstream sources. Rural areas of the United States are characterized by lower population density, fewer specialized health-care providers, and greater distance between health-care facilities (Coward, 1998). Because exposure to mainstream culture is likely to be limited to media sources, fewer mainstream health messages are received, and traditional health beliefs are less likely to be challenged.

Residents born outside the United States are more likely than their native-born counterparts to live in the center of cities and to live in poverty (Lollock, 2001). They, like many native-born residents of inner cities, often live in homogeneous groups with strong within-group social network ties. These strong ties are beneficial to health in that they provide opportunities for support from other group members. If others in the group are similarly impoverished, however, they might not be able to provide financial support in times of need or assist with travel to health-care facilities. Also, strong within-group ties are often at the expense of weak ties to mainstream culture, which represent important sources of health information (Pescosolido & Levy, 2002). Women with weak ties to mainstream culture, for example, are much less likely to receive information on breast self-examination and where to obtain free mammograms. Parents with weak ties to mainstream culture are less likely to know about health-care funding opportunities for their children (see Chapter 5 in this *Handbook*).

Loudell Snow in her book *Walkin' Over Medicine* (1993) describes the impact of patients' health beliefs on their health behavior, observed during her work at a community health clinic serving predominantly African American patients in Lansing, Michigan. Clinic providers were concerned about nonadherence to prescribed medications, such as medications to lower blood pressure (called antihypertensive medications). Through interviews with clinic patients, Snow found that a number of patients included anemia under the rubric of "low blood." Many patients in this group had discontinued their medications after providers made statements such as "congratulations, you've brought your blood pressure down. It's low now!" What seemed to providers to be a healthy state (i.e., low blood pressure among those prone to hypertension) seemed unhealthy to patients, causing them to discontinue taking their medications.

In another example, Snow (1993) was consulted on high rates of unplanned pregnancy among young African American women. As part of clinical practice, women were being prescribed oral contraceptives and trained in the rhythm method of contraception. Through interviews, Snow determined that the two means of birth control conflicted with the beliefs of a number of women that menstruation was important to health, because it allowed toxins and pollutants to be eliminated that might otherwise cause ill health. Oral contraceptives were viewed as deleterious to health, because they diminished menstrual flow. The rhythm method similarly was seen as dangerous to health, because of its prescription that sex should occur near menstruation, a time when women felt that their bodies were particularly open and thus more vulnerable to toxins and pollutants. The group's health beliefs dictated the days most distant from menstruation as safest for sex, because the body was least open. This was problematic because days distant in time from menstruation are when women ovulate, and thus are most likely to become pregnant.

In both of these examples, a clinical reality could be negotiated that addressed the incongruities between the health beliefs of patients and providers. In the case of antihypertensive medications, the task was as simple as identifying the two meanings of "low blood," and advising providers to use instead "normal blood pressure" or "good blood pressure." In the case of conflicting views of birth control, methods that neither restricted menstrual flow, as was the case with oral contraception, nor involved having sex during menstruation, when women considered the body to be particularly vulnerable, as with the rhythm method, were emphasized.

Numerous empirical studies have supported the link between health beliefs and success of behavior change efforts. Patterson, Kristal, and White (1996) measured the baseline beliefs about the association between diet and cancer of a population-based sample of 607 persons in the state of Washington. They found those with stronger beliefs significantly decreased their percentage of fat consumed and significantly increased their fiber intake. In a second study, low-income, rural, African American women who did not believe themselves to be at risk for breast cancer, whether or not they had positive family histories, were less likely to get mammograms than women who believed themselves to be at risk (West et al., 2003).

#### ILLNESS VERSUS DISEASE

The clinical encounter can be seen as a set of transactions or negotiations between patients and providers. Success is at least in part determined by the extent to which the two can reach a measure of congruence. In general, the more dissimilar the cultural constructions of reality of the two, the more difficult will be the negotiation. A gross example of dissimilarity between the patient's and the provider's cultural constructions of reality is that patients suffer illness while physicians treat disease. Disease is defined by Kleinman et al. (1978, p. 251) as abnormality in the structure and function of body organs and systems. Helman (1985, p. 923) says that a disease construction reduces ill-health to physicochemical terms and overemphasizes biological (as opposed to social or psychological) information in reaching a diagnosis. Illness, however, is defined as an experience of disvalued changes in states of being and in social function (Kleinman et al., 1978, p. 251). According to Helman (1985, p. 923), illness is a wider and more diffuse concept that is patterned by social, psychological, and cultural factors.

Disease is objectively determined, while illness is determined subjectively. Thus, disease can exist in the absence of illness, for example, when a patient has a biological abnormality of which she is not aware. A woman could, for instance, have a malignant ovarian tumor in the absence of symptoms. Likewise, illness can occur in the absence of disease. Common complaints such as headache and gastrointestinal distress may be distressing for patients and cause disruption in social functioning, such as the ability to work or go to school, yet occur in the absence of any abnormality in the structure or function of body organs or systems.

Also, illness conditions that are specific to certain cultures, such as *susto* in Mexico (Rubel, 1977), *koro* in Malaysia, and *pibloktoq* or arctic hysteria among Eskimos (Foulks, 1972; see Table 9.2), fall under the rubric of illness rather than dis-

**Table 9.2**  
Culture-Specific Syndromes

Syndrome	Description	Cultural Origins
<i>Susto</i>	Illness arising from fright in which the soul is thought to leave the body	Mexico
<i>Koro</i>	An episode of sudden, intense anxiety in which the penis recedes into the body and which may cause death	Malaysia
<i>Pibloktoq</i> (Arctic hysteria)	Sudden onset bizarre behavior that is short-lived and thought to be induced by fright	Circum-polar regions

ease. Although considered real by the culture groups that recognize them, providers do not universally recognize these culture-specific syndromes. They are not included in the International Statistical Classification of Diseases and Related Health Problems (ICD), a compendium of internationally recognized diseases published by the World Health Organization (WHO). The ICD, now in its tenth revision (ICD-10; World Health Organization, 2003), is the international standard diagnostic classification used for (a) monitoring the incidence and prevalence of diseases worldwide and (b) allowing the compilation of mortality and morbidity statistics by member nations.

That illness and disease are not directly correlated with one another can be a source of miscommunication and lead to nonadherence to medical treatment recommendations. Conditions such as brain cancers are considered serious diseases by physicians, yet in their early stages may cause less distress and social disruption for patients than muscle spasms of the lower back. Also, patients with the same degree of organ or system pathology (i.e., disease) report different levels of well-being and social dysfunction (i.e., illness). In other words, some patients with rheumatoid arthritis might report adequate well-being and are able to perform their own activities of daily living (ADLs), while others at the same stage of the disease might report that their well-being is diminished markedly and that they require assistance to perform ADLs.

Clinical encounters in which providers focus on disease and patients focus on illness are likely to result in frustration, mistrust, and less favorable health outcomes, because providers may feel that their recommendations are not being given due consideration by patients and patients may perceive that their complaints are not being taken seriously. A poignant real-life example comes from a book entitled *The Spirit Catches You and You Fall Down* (Fadiman, 1997). In this book the non-English-speaking Hmong immigrant parents of a young girl with epilepsy viewed her illness through the eyes of their culture, namely as the flight of her soul from her body. They treated the condition according to their beliefs, with animal sacrifices and traditional remedies. The Merced County, California, physicians who were treating the child focused on her condition as a disease (epilepsy) requiring fine-tuned doses of prescribed anticonvulsant medications. Both sides were operating with the best of intentions and compassion, yet their inability to communicate with one another and subsequent mutual mistrust and blaming resulted in a situation in which the two sides could only watch impotently as the child's situation deteriorated to the point of serious disability.

Social workers who are aware of incongruent understandings between patients and providers can help to remedy the situation by pointing out the discrepancy, interpreting each side's frustration to the other, and helping to establish a clinical accord. Setha Low (1984, p. 13) wrote that "often the social worker is the only person who can see both sides of the cultural picture—the bureaucratic, mainstream and the ethnic or subcultural perspective—and from this vantage point may be the single most critical actor in the provision of care and information." This is congruent with Richard Cabot's notion of social workers as translators in health-care environments (see Chapter 1 in this *Handbook*).

A list of questions developed by Kleinman (1980) can serve as a valuable tool for social workers and other providers in their efforts to elicit patients' health beliefs. These questions include:



What do you think caused your problem?

How severe do you think the problem is?

Do you think that its course will be short or long?

What difficulties is the problem causing for you?

About what are you most concerned?

What treatment do you think is warranted for your problem?

What benefits do you expect to receive from the treatment?

A vivid example of what might occur if a provider is not aware of a patient's health beliefs comes from the work of Young and Flower (2001, p. 91). A young man named Pete who worked in a fast-food restaurant went to the emergency room after injuring his ankle. He assumed that his ankle was fractured, because he was in a great deal of pain and heard the same cracking sound that he had heard when he had fractured his ankle in the past. His greatest concern was that he would lose his job if he missed work. Pete lost trust in the physician when he was told that his ankle was sprained rather than fractured and that the only possible treatment was to stay off it for 5 days. He had framed the problem very differently from the physician and had given the situation different meaning. Because his cultural construction of reality weighted serious sprains and fractures differently, he assumed that he would not be granted sick leave if his ankle were sprained rather than broken. The clinical situation deteriorated rapidly, with the physician, who had given Pete no opportunity to tell his story, viewing Pete as uncooperative and wanting to get off from work for no reason. Pete left the encounter assuming that the physician had made a mistake. He promptly threw away the ace bandage that he had been given for his sprain and returned to work. This left his ankle prone to re-injury and his view of physicians compromised. The physician's view of patients as malingerers was reinforced.

#### SOCIAL WORKERS ON HEALTH-CARE TEAMS

Although written over 15 years ago, Cleora Roberts's (1989) observations on the strain inherent in the professional relationship between social workers and physicians still rings true today. Roberts suggested that an appreciation of this strain and the necessary tension that it produces could catalyze successful collaboration between social workers and physicians (p. 211). The five areas of major difference in perspectives are that: (1) a physician's goal is to save lives while the social worker's focus is more on quality than quantity of life; (2) physicians are more likely to base decisions on objective data, such as laboratory tests, while social workers consider patients' subjective interpretations of events; (3) physicians are likely to develop treatment plans based on the assumption that the goal of treatment is improved health and the longest possible life, while social workers are trained to encourage self-determined treatment goals; (4) social workers are more likely than physicians to feel comfortable in dealing with patients' emotional problems; and, (5) physicians are more likely to take charge on health-care teams, while social workers are accustomed to collaboration.

Turner (1990) describes social work in health care as a transcultural resource. He implicates three phenomena in Western medicine as particularly culture specific and value laden and thus potential obstacles to health communication. Each

of the three conflicts with the values of social work. The scientification of medicine is a trend toward addressing the somatic aspects of health at the expense of behavioral and social aspects. Turner describes the “recurrent, unofficial, and popular ‘anti-scientific’ theme” (p. 14) of social work as counter to the trend toward scientification. A second trend is toward increased specialization, which Turner says leads to decreased sensitivity to the whole person. Social work’s holistic perspective broadens the health-care team’s view to consider the individual as a whole. The third trend noted by Turner is medicine’s increasingly patient-only focus, to the exclusion of salient others, events, and issues in the environment. Again, social work’s emphasis on person in environment broadens the scope of the health-care team.

Because of an appreciation of the complex interplay of biological, social, and behavioral factors leading to instances of early death in the United States (see e.g., McGinnis, Williams-Russo, & Knickman, 2002), Harold Varmus, who directed the National Institutes of Health (NIH) during the Clinton administration, took a new approach to health research that emphasized broad collaboration. NIH is made up of 19 institutes, such as the National Cancer Institute (NCI) and the National Center for Child Health and Development (NICHD), which for decades had operated as separate entities, almost like a series of cottage industries. In 2003, Elias Zerhouni, who followed Varmus as the director of NIH, initiated the Roadmap for 21st Century Medical Research, which for the first time required NIH institutes to work together to address health problems. The NIH Roadmap likewise required professionals from different disciplines to work together in new ways and to include community members as active participants in scientific investigations. NIH personnel, scientists, and community members are all considered stakeholders in research.

New professional collaborations prescribed by the NIH Roadmap take research from the multidisciplinary and interdisciplinary to the new concept of transdisciplinary (see Table 9.3). In the latter, investigators from the biological, social, and behavioral sciences work so closely together in addressing major health issues that they must develop new shared languages that incorporate key words from their separate disciplines, pool the best of their disciplinary theories, and forge new methodologies and analytical approaches that allow factors at multiple levels to be included in the same analyses. Kahn and Prager (1994) point out that, for

**Table 9.3**  
Types and Descriptions of Health-Care Teams.

Type	Description
Multidisciplinary	Team members represent a variety of professional backgrounds. Although part of the same team, they exhibit separate bodies of professional knowledge and maintain different disciplinary languages.
Interdisciplinary	Team members from a variety of professional backgrounds share their bodies of knowledge and disciplinary languages.
Transdisciplinary	Team members from a variety of professional backgrounds develop a shared language, based on their separate disciplinary languages, pool bodies of knowledge and theories, and jointly develop new methods and analytical techniques.

true transdisciplinary teams to be successful, university structures, such as rewards for publishing frequently and on narrow topics, must be modified.

Social work education faces similar challenges, especially providing sufficient biological and genetic training to students interested in working in health care so that they are able to operate effectively on transdisciplinary teams. Toward that purpose, a guide to understanding medical terminology is located in the Appendix of this chapter.

Additional challenges presented by the transdisciplinary approach to health include preparing students to work with professionals from other disciplinary cultures and teaching them new ways to include community members in health-care decision making. The tradition of family support in social work education can provide guidance for the latter.

Although the NIH Roadmap addresses research directly, it has major implications for how health care is viewed and delivered in the United States. NIH is the largest funder of medical research in the world, and hospitals and other health-care facilities depend on research funding for their operations. This has been the case with teaching hospitals for some time, but is increasingly becoming the case for community clinics, other outpatient facilities, illness-specific consumer organizations (e.g., the American Heart Foundation), and advocacy groups. The broad view of health as a complex interplay of biological, social, and behavioral factors, and of community residents as important contributors presented by the NIH Roadmap is significant for how social work is viewed in health care for two major reasons. First, it forces a broader view of health that includes social and behavioral factors. Second, it places a premium on being able to establish and access community ties. Because social work is recognized by other health-care professionals as particularly expert in these two areas, the profile of the profession is likely to rise.

Group theory has traditionally been used by social workers in health care to understand patients as members of groups. It also serves them well in helping to understand the dynamics of the teams on which they serve, however. The often-used classification of group roles that include opinion giver, coordinator, gatekeeper, and special interest pleader (Benne & Sheets, 1948), work as well for health-care teams as they do for patient groups, for instance. Likewise, the phases of small groups (see e.g., Northouse & Northouse, 1985), namely orientation, conflict, cohesion, working, and termination, work equally well for patient and provider groups in health care, although health-care teams are often ongoing and not time limited.

Yalom (1998) provides a list of factors through which groups work to achieve therapeutic aims. Understanding factors such as: (a) catharsis, which occurs when team members are able to express openly or ventilate their frustrations; (b) the corrective recapitulation of the primary family group, in which group members experience interactions that mimic those they experienced with their parents and siblings, but in a more positive way; and (c) interpersonal learning, in which members learn from one another through observation, can be useful in understanding why members of a health-care team are behaving as they are. Many social workers report anecdotally that they have become team diagnosticians and that other professionals turn to them for advice on personal matters.

A number of articles published in the late 1980s and early 1990s examined the role of social workers on health-care teams. Sands, Stafford, and McClelland

(1990), for example, echoed the sources of conflict between social workers and physicians noted by Roberts (1989) and Turner (1980; also see Mizrahi & Abramson, 1985) and added others germane to social workers' relationships with other health-care team professionals. These include status differences between disciplines that interfere with democratic functioning and the competition that arises when professional roles and functions overlap.

As noted in Chapter 1, social workers in health care have been less likely than other professionals to have roles identified as uniquely their own. This phenomenon originally was noted in a 1980 study by Lister in which health professionals from 13 disciplines were surveyed on role expectations. No role was assigned uniquely to social work. This leads to confusion when psychologists, nurses, and therapists perform some of the same functions, such as taking social histories or helping patients prepare psychologically for medical procedures. Overlap of roles is more likely in some settings than others. Settings that rely more on technology, such as emergency departments or intensive care units, generally exhibit more role distinction and more hierarchical decision making. In settings less tied to technology, such as long-term care facilities or nursing homes, professionals' roles are less distinct and more likely to overlap. Decision making is more likely to be democratic.

Sands et al. (1990, p. 56) note that conflict has a function in health-care teams, namely to ensure that situations and issues facing the team are viewed from a variety of perspectives. Conflict can be a catalyst for growth and contribute to good decision making if team members are able to speak freely, negotiate effectively, and achieve resolution. Group think (Janus, 1972), which occurs when group members feel pressured to conform, has been implicated in some of the worst disasters in history, including the Bay of Pigs Invasion and the escalation of the War in Vietnam.

#### COMMUNICATION PATTERNS IN HEALTH-CARE SETTINGS

A landmark study of communication in outpatient settings noted a pattern of communication in which patients were cut off by physicians before they were able to express all of their health concerns. Beckman and Frankel (1984) recorded 74 outpatient return visits and measured physicians' questioning style and whether or not they interrupted patients during their opening statements of concern. In 8% of visits, physicians failed to solicit patients' concerns entirely and asked only closed-ended questions. In 69% of visits, physicians interrupted patient within 18 seconds of their beginning to talk and redirected interviews. In only one of 74 instances (< 1%) did a physician allow a patient to return to his initial statement of concerns. In the remaining 23% of visits, patients were allowed to complete their opening statement of concerns without interruption. The authors cautioned that the physician-directed style observed in their study would almost certainly result in the exclusion of information pertinent to diagnosis and treatment planning. In a subsequent interview, Frankel (Goleman, 1991) stated that physician interruptions are particularly troubling in light of the fact that patients rarely list their most troubling complaint first, but instead submerge it in a list of less troubling concerns. The third complaint listed by patients is, in general, the most troubling for them.

Clinical encounters are even more problematic when providers and patients are from different racial or ethnic groups or different socioeconomic statuses, especially when providers are White American and patients are low income or members of a minority group. A 2002 report issued by the Institute of Medicine went so far as to implicate physician behavior in health disparities in the United States. McGinnis et al. (2002), based on a review of the best available empirical studies, attributed 10% of early deaths in the United States to shortfalls in medical care, a portion of which was thought to be due to provider behavior.

Johnson, Roter, Powe, and Cooper (2004) conducted a study to determine the extent to which patient race and ethnicity affect communication between providers and patients. The outpatient clinic visits of 458 White American and African American patients and 61 physicians were rated by experts in terms of physician verbal dominance (measured by dividing the total number of physician statements by the total number of patient statements), patient-centeredness (measured by dividing the total amount of socioemotional talk by the total amount of biomedical talk), and emotional tone (affect) of the interviews. Physicians were 23% more verbally dominant and communication was 33% less patient-centered in physician visits with African American patients than with White American patients. Also, African American patients and their physicians were rated as exhibiting lower levels of positive affect than were White American patients and their physicians.

In attempting to tease out the sources of unintentional provider bias that might be impacting health disparities, Burgess, Fu, and von Ryn (2004) outlined a number of possible explanations. They suggest that White American providers may unknowingly convey negative affect toward African American patients, which triggers the patients' own negative affect, resulting in a situation that is suboptimal for communication. They suggest that majority providers hold conscious beliefs on equality that are inconsistent with their automatic, unconscious reactions to low-income and minority patients (p. 1155). The authors go on to say that in clinical situations in which the time allotted for information gathering is almost never sufficient, providers tend to fill in the gaps with information based on group stereotypes and behave in ways that confirm those stereotypes (p. 1156).

An example of this phenomenon comes from a study published in the *British Journal of Psychiatry* (Lewis, Croft-Jeffreys, & David, 1990). In this study, 139 psychiatrists completed a questionnaire after reading one of two versions of a case that varied only by whether the patient was Afro-Caribbean or White American. Another two versions of the vignette varied only in terms of the patient's gender. All vignettes described the behavior of a patient with psychosis. Respondents rated the Afro-Caribbean case as more violent and criminal and less likely to need narcoleptics than the White American case. Female cases were rated as less violent, less criminal, and less likely to need narcoleptic medications than male cases.

Two additional studies linked patient race to physicians' treatment recommendations. In the first, van Ryn and Burke (2000) gathered survey data from 618 patients visiting 193 physicians after an angiogram. Physicians tended to rate African American patients as lower in intelligence and less likely to be adherent to treatment recommendations and more likely to exhibit risk behaviors than White American patients. They attributed patients of lower and middle socioeconomic

status less favorably than upper socioeconomic status patients on measures of personality, ability, role demands, and behavioral tendencies. In a second study (Schulman et al., 1999), 720 primary-care physicians attending two national meetings viewed a taped interview with a patient and reviewed hypothetical data on the same patient. They were then surveyed about how they would manage the patient's chest pain. Women and African American patients were less likely than men and White American patients to be referred for cardiac catheterization. African American women were significantly less likely to be referred for the procedure than White American men.

Biases in communication by gender have been observed in the few studies that have addressed the topic. Although little is known about variation in communication by gender of patient, a number of studies have demonstrated differences in communication between male and female physicians. Roter, Hall, and Aoki (2002) reviewed available studies from 1967 to 2001 and found 26 that used a communication database that could be analyzed by raters. They found no gender differences in the quantity or quality of biomedical communication or social conversation between male and female physicians. Female physicians, however, exhibited significantly more patient-centered talk than their male colleagues, specifically emotionally focused talk, psychosocial counseling, psychosocial question asking, active partnership behaviors, and positive talk. Clinic visits to female physicians were on average 2 minutes longer (10%) than visits to male physicians.

The 2001 Institute of Medicine report and empirical studies by Roter et al. (2002) and Burgess, Fu, and von Ryn (2004) are aimed at physicians, despite the fact that the latter authors use the generic term *provider*. Yet, issues of cross-cultural communication are equally important to social workers in health care. Although the perspectives and values of social workers differ from those of physicians, as aptly pointed out by Roberts (1989) and Turner (1990), social workers are as vulnerable to stereotyping and heuristics as other professions and therefore have to grapple with the same issues and biases when attempting to communicate with persons with other cultural constructions of reality.

There is evidence that being ill-equipped to communicate with patients from different cultural backgrounds has consequences for providers as well as patients. Ulrey and Amason (2001) measured the cultural sensitivity, intercultural communication skills, and levels of state anxiety of 391 employees of two hospitals and four clinics in the U.S. South and found low levels of sensitivity and communication skills to be significantly correlated with high levels of anxiety. In other words, providers who were high in cultural sensitivity and better intercultural communicators experienced less anxiety than providers who were less sensitive and less adept at intercultural communication.

The idea that communication problems can be as problematic for providers as patients is supported by a recent Dutch study (Zandbelt, Smets, Oort, Godfried, & de Haes, 2004) in which the authors measured the same five visit-specific relationship phenomena in 30 physicians and 330 patients following outpatient clinic visits. They found physicians to be less satisfied in general with health encounters than patients. Patients were most satisfied with physicians whom they thought attended better to their health concerns and from whom they were able to obtain information. Physicians reported greater satisfaction after medical encounters with patients who were better educated, had better mental health, and preferred to receive fewer details about their care.



## PATIENT-PROVIDER COMMUNICATION AND HEALTH OUTCOMES

A number of empirical studies have linked improved provider and patient communication to positive changes in physiological and behavioral measures of health status. Besides helping to ensure an accurate exchange of information, enhanced provider communication skills are thought to improve health outcomes by motivating patients to engage actively in their treatment and increasing their confidence in their ability to influence their health. Maguire and Pitceathly (2002, p. 697) add that patients' propensity for anxiety and depression is lessened when communication is effective and providers' well-being is enhanced.

Several studies have linked better communication between patients and providers with improved adherence to treatment regimens and other favorable health-care outcomes. Schneider, Kaplan, Greenfield, Li, and Wilson (2004), for instance, linked better communication to improved adherence (measured on a four-point scale) to antiretroviral therapy in a sample of 554 patients treated at 22 outpatient HIV clinics. The study's seven independent variables were: (1 to 6) quality of physician-patient communication, measured using six available scales (general communication, HIV-specific information, egalitarian decision-making style, overall physician satisfaction, willingness to recommend physician, and physician trust) and (7) the extent to which patients thought their physicians understood and were able to solve problems with their antiretroviral regimens. Six of the seven physician-patient communication variables (all but egalitarian decision-making style) were significantly associated with adherence to antiretroviral therapy.

In another study (Stewart et al., 2000), the outpatient visits of 315 patients and their 39 family physicians were audiotaped and rated on patient-centered communication (measured as the extent to which the physicians explored patients' disease and illness experiences, understood patients as whole persons, and discussed and sought agreement with patients on treatment plans). Patients were asked to rate their encounters for patient-centered communication independently. Outcomes measured were patients' health and health care, specifically diagnostic tests taken, referrals made, and visits to the family physician in the 2 months following the audiotaped visit, all of which were extracted from patients' charts. Higher rates of patient-centered communication were significantly associated with better recovery from the complaint that brought the patient to the physician in the first place, fewer diagnostic tests, and fewer referrals. Additional empirical studies link better communication to reduced pain after surgery (Egbert, Battit, Welch, & Bartlett, 1964) and other physiological outcomes (Orth, Stiles, Scherwitz, Hennrikus, & Vallbona, 1987; Skipper & Leonard, 1968).

## METHODS FOR IMPROVING HEALTH COMMUNICATION

The body of literature on interventions that improve providers' and patients' communication skills has grown in recent years.

### CHANGING PROVIDERS' BEHAVIOR

Interventions range from prompting physicians to check patients' understanding of information to complex, comprehensive training programs that address a number of factors thought to improve communication.

Based on data obtained from observations of the clinical performance of 25 physicians, Sideris, Tsouna-Hadjis, Toumanidis, Vardas, and Moulopoulos (1986) developed a 4-hour training seminar for physicians on health communication. Physicians were taught how to: (a) explain diagnoses, treatment objectives, and prognoses; (b) provide oral and written instructions; (c) check patients' comprehension; and, (d) convey positive affect. Communication scores were obtained prior to and after the training seminar by asking dyads of participating and nonparticipating physicians and their patients a series of complementary questions about the medical encounter. Adherence was measured by comparing patients' behavior with instructions given. Both communication and adherence scores of the dyads of physicians who participated in training and their patients were statistically significantly higher than those of dyads in which the physicians did not participate in training.

Maiman, Becker, Liptak, Nazarian, and Rounds (1988) tested an intervention in which pediatricians were trained to use simple informational and motivational techniques for enhancing mothers' adherence to prescribed treatment recommendations. The intervention focused on how to: (a) express sincere concern and empathy; (b) provide information in a way that can be understood and remembered; (c) simplify treatment regimens; (d) elicit, assess, and modify health beliefs; (e) elicit and meet mothers' expectations for treatment; and, (f) monitor adherence to prescribed treatment recommendations. Mothers whose physicians were in the intervention group were significantly more likely to adhere to medication recommendations and to keep follow-up appointments than mothers whose physicians were in the control condition.

Kinmonth, Woodcock, Griffin, Spiegel, and Campbell (1998) tested a 1.5-day training program for nurses and physicians aimed at increasing levels of patient-centered communication. Teams of physicians and nurses from 41 practices were randomly assigned to an experimental or a control condition. Nurses in the experimental condition were offered a half-day's training to review evidence for patient-centered interviewing and a full day of facilitated practice in implementing patient-centered interviewing skills. Physicians in the experimental group received a half-day's training in active listening and negotiation of behavioral change. Nurses received two additional support sessions with the facilitator. Nurse/physician dyads in the control condition received no training. The quality of life, well-being, hemoglobin A1c and lipid concentrations, blood pressure, and body mass index (BMI) of 250 patients with type 2 diabetes from the same practices as the nurse-physician dyads were measured 1 year after training. Patients were also asked to rate the quality of communication of their nurses and physicians and their satisfaction with care. Patients of dyads in the experimental condition reported better communication, greater satisfaction with care, and greater well-being than did patients of dyads in the control condition. Patients whose nurses and physicians were in the experimental group did not, however, exhibit more favorable hemoglobin A1c or lipid concentrations, blood pressure readings, or BMI than the control group.

A second study (Brown, Boles, Mullooly, & Levinson, 1999) failed to find gains in patient satisfaction after a communication skills training program entitled "Thriving in a Busy Practice: Physician-Patient Communications." Sixty-nine primary-care physicians, surgeons, medical subspecialists, physician-assistants, and nurse practitioners participated in a 4-hour interactive workshop focused on skills for building effective relationships with patients (active listening, express-

ing concern, understanding, and respect, and responding to feelings) followed by 2 hours of homework in which they were asked to audiotape at least two patient interviews and listen to the recordings. A 4-hour follow-up session focused on teaching skills for effective negotiation with patients was conducted 1 month after the first 4-hour session. Patients of the providers who received training were asked to complete the Art of Medicine survey, which measures both satisfaction with providers' communication abilities and global visit satisfaction. No difference was seen in the Art of Medicine survey scores of patients whose providers had or had not participated in the communication skills training program.

#### CHANGING PATIENT BEHAVIOR

A number of studies have focused on modifying patient behavior during interviews with physicians to improve health-care communication and outcomes. Most focus on increasing patients' participation in treatment.

Roter (1977) developed a 10-minute intervention in which a health educator assisted patients in formulating questions for their physicians and asking the questions early in clinic visits. Patients in a control condition were only provided with information on services. Interestingly, patients in the experimental condition reported more anxiety than did control patients, but were significantly more likely to keep appointments during the 4-month follow-up period of the study. Although patients in the experimental group asked significantly more direct questions of their physicians than did control patients, their visits were no longer than those of patients in the control condition. In other words, the intervention changed the nature of the clinic visit without increasing its length.

In another early study of patient and physician communication, Greenfield, Kaplan, and Ware (1985) developed and tested an intervention in which patients were helped to read the medical records from their last clinic visit. In a 20-minute session, patients were taught to identify relevant medical issues and decisions from their records, devise ways to negotiate these decisions with their physicians, and ask questions. The audiotaped interviews of patients who participated in the intervention were compared to those who did not. No significant difference in length of visits was found between the two groups. Patients who received training, however, were found to be significantly more assertive in their interactions with physician. They exhibited a 48% higher ratio of patient to physician utterances than the control group and elicited around two times the number of factual statements from their physicians.

Kaplan, Greenfield, and Ware (1989) report the results of an intervention study in which patients with ulcer disease, hypertension, breast cancer, and diabetes were given copies of their medical records and an algorithm for interpreting the information and coached in behavioral strategies for increasing their participation in clinical interviews with their physicians. The interviews prior to and after the intervention were audiotaped and coded by experts. More patient control and more affect, especially negative affect on the part of both the patient and physician, and more information provided by physicians in response to patients' seeking of information were associated with better health status, including better control of diabetes and hypertension. The authors interpreted negative physician affect, such as tension, nervous laughter, frustration, and anxiety, as beneficial because it conveyed caring on the part of the physician.

Thompson, Nanni, and Schwankovsky (1990) tested a simple intervention to improve patients' participation in communication during outpatient clinic visits. Sixty-six women were randomly assigned to a control group or a group that was asked to prepare three written questions for their physician. The group that prepared questions asked significantly more questions during their clinic visits and reported less anxiety after the visits than did women in the control group.

McCann and Weinman (1996) prepared a pamphlet explaining how patients could increase their participation in interviews with their primary-care physicians. The pamphlet encouraged patients to take a more active part in their interactions with their physicians. The pamphlet first asked patients to describe the nature of their problems and to consider the problems' possible causes and treatments and likely impacts. The pamphlet then outlined how to voice concerns during visits as well as how to ask questions about diagnosis and treatment and check understanding. The 59 patients who received the intervention materials prior to their visits asked significantly more questions of their physicians than did the 61 individuals in the control condition who received an educational pamphlet.

In another study (Davison & Degner, 1997), 60 men newly diagnosed with prostate cancer in a community urology clinic were randomly assigned to either an experimental group that received written information about prostate cancer, a list of questions to ask their physicians, and an audiotape of the medical consultation or a control group that received only information on prostate cancer. Although the two groups did not differ significantly in levels of depression, the men in the intervention group took a more active role in treatment decision making and reported significantly lower levels of anxiety 6 weeks after the intervention than did men in the control condition.

Two hundred and five patients with chronic health conditions were randomly assigned to experimental and control conditions. Those in the experimental condition were given copies of their medical record progress notes and asked to prepare two questions about their conditions that would be attached to the front of their charts. Patients in the control conditions received educational materials and completed suggestion lists for improving clinic care. Those in the experimental group reported significantly better overall physical functioning and satisfaction with their physicians' care and were significantly more interested in seeing their medical records than those in the control group. In addition, patients in the experimental group reported a significantly better overall health status than they had prior to the intervention (Maly, Bourque, & Engelhardt, 1999).

#### ADDITIONAL TECHNIQUES FOR IMPROVING HEALTH COMMUNICATION

Several techniques have been suggested for improving health-care communication. They can be divided roughly into individual-level techniques that address building empathy and elicit patients' thoughts and feelings and group- or community-level techniques.

Coulehan et al. (2001) devised a method for improving empathy, which they defined as "the ability to understand the patient's situation, perspective, and feelings and to communicate that understanding to the patient" (p. 221). Their method involved active listening, framing or sign posting, reflecting the content, identifying and calibrating the emotion, and accepting and requesting correction. Active listening involves verbal and nonverbal techniques, such as the mir-

roring of facial expression, making direct eye contact, assuming a posture indicating attention, and exhibiting facilitative responses, such as nods of understanding. Framing or sign posting is analogous to the empathic responding advocated by social work clinicians (see e.g., Hepworth, Rooney, & Larsen, 2002), and may take forms such as "Sounds like you are saying . . ." Reflecting the content is another term for paraphrasing. Identifying and calibrating the emotion is a means of eliciting the nature of emotion through the use of statements such as "I have the sense that you feel strongly, but I'm not sure I understand exactly what the feeling is. Can you tell me?" (p. 222). Requesting and accepting correction comes after statements of providers' understanding of what patients have said through phases such as "Did I get that right?" The sequence (patients' narrative, provider's statement of understanding, and request for correction) is repeated until the provider's understanding is validated by the patient.

DuPre (2001) outlines four additional techniques to elicit patients' feelings and thoughts which she gleaned from a review of interviews conducted by a physician well-known for her communication skills. These are: (1) involving patients in decision making, (2) talking openly about patients' fears, (3) asking open-ended questions, and, (4) self-disclosing. The latter is appreciated more by some patients than others, based on their personal preferences and cultural expectations. Whether or not to self-disclose always should be based on cues and responses from patients.

A category of techniques in which providers partner with groups or communities to achieve health-care goals have gained popularity. These techniques are variously referred to as community-based participatory research, participatory research, participatory action research, and other terms. Their hallmark is the active involvement of community members at every stage of the research process. They share an aim to "enhance understanding of a given phenomenon and the social and cultural dynamics of the community, and integrate the knowledge gained with action to improve the health and well-being of community members" (Israel, Schulz, Parker, Becker, Allen, & Guzman, 2003, p. 54). Community-based approaches have been used with a variety of culture groups and illness conditions.

A novel approach was developed in the Wai'anae Cancer Research Project (Matsunga et al., 1996) to test the effectiveness of a culturally appropriate intervention for increasing the participation of Native Hawaiian women in cervical and breast cancer screening. The impetus for the intervention was that Native Hawaiians had the second highest cancer rates in Hawaii, second only to those of White American women. An advisory committee made up of community residents was selected to work collaboratively with project scientific investigators to devise and test an intervention over a period of years. The intervention was a series of health-focused support groups using existing social networks, based on the traditional Hawaiian values of a mutual willingness to help others without expectation of reciprocity and without having to be asked. Native Hawaiian paraprofessionals recruited women to host groups, presented information to the groups, and facilitated discussion about breast and cervical cancer screening. Peer group leaders, who volunteered to host groups, helped investigators to access community groups. Group discussion took traditional "talk story" form, which was familiar to the women and thus more acceptable. Vouchers for free mammograms, breast examinations, and Pap smears were provided to participants and one of their friends who was unable to participate. An evaluation of the program indicated that it had a positive



impact on community knowledge, attitudes, and behaviors about breast and cervical cancer screening. In addition, investigators learned a great deal about traditional Hawaiian health beliefs and forged positive relationship with community members and groups.

### WORKING WITH PATIENTS WITH LIMITED OR NO ENGLISH PROFICIENCY

Perhaps the greatest challenge to health communication comes when patients and families have very limited or no English skills. This is an issue in health care today, because according to data from the 2000 census, 19 million people in the United States have limited proficiency in English (Marcus, 2003).

The optimal approach to a patient and family who have limited or no English skills is to work with a professional medical interpreter. Federal law in fact mandates that health-care facilities that receive Department of Health and Human Services funding provide interpreter services to all persons seeking or receiving medical care. The mandate is enforced by the federal Office for Human Rights. Some states also require the use of interpreters. Illinois, for example, passed the Language Assistance Services Act, which requires that nursing homes and hospitals make interpreter services available in person or by telephone 24 hours a day.

Professional medical interpreters are specially trained individuals who can take a spoken message in one language and render it into another language (Luckman, 2000, p. 152). Their task is not merely to change a word in one language to that in another, but to reflect accurately differences in culture that influence communication. For this reason, Luckman refers to professional medical interpreters as *culture brokers*. Interpretation differs from translation in that it deals with spoken language and translation deals with written language.

Several points are known to enhance the accuracy of interpretation. It is important for the provider to face and speak directly to the patient, instead of to the interpreter. This helps to ensure that some measure of relationship and rapport is established between patient and provider. Providers should make eye contact with patients when they are speaking or listening unless it is inappropriate for the patient's culture group. Appropriateness of eye contact can be determined from the professional interpreter or from family members. Questions and comments should be interpreted exactly as they are stated by the provider and in the same voice (i.e., in first person). If the provider said, for example, "I would like to know why you came in today," the interpreter should interpret the statement in the first person, rather than saying "The doctor would like to know why you came in today." The provider should avoid asking more than one question at a time (e.g., "How are you feeling and why did you come in today?") and avoid using acronyms or colloquialisms (e.g., "Did you hurt your noggin?"), which might be difficult to interpret.

The interpreter should be positioned behind and to the side of the patient and between the patient and the provider, so that the three form a triangle. If the interpreter has questions for the provider, they should be spoken directly to the provider in English after informing the patient that this will occur. Similarly, questions or requests for clarification from patients should be made directly to the patients, after informing the provider that this is to occur.



Because interpreting from one language to another entails more than merely rendering a word from one language into a second language, some interpretation may entail additional explanation. This might occur when a phenomena does not take the same form in one culture as it does in another. If a patient refers to a culture-specific condition, such as *evil eye*, for instance, a direct word-for-word interpretation would not be sufficient to convey the patient's meaning to the provider. In these situations, after interpreting word for word, the interpreter should tell the provider that the words do not have the same meaning in English as in the patient's language and provide an explanation (e.g., "*mal ojo* or evil eye is a condition in Mr. Garcia's culture in which illness is thought to occur suddenly when one person casts his gaze on another"). The patient should also be informed that the interpreter is explaining a condition that does not occur in the same way in the two cultures. Otherwise, the patient may wonder why the length of the interpreter's statement to the provider in English took twice or three times as long his response in his own language.

Some facilities contract with telephone interpretation services, especially for unusual languages. An example is the *AT&T Language Line*, a 24-hour service available in all parts of the country that employs interpreters in 140 languages. In some states, Medicaid covers the cost of this service. The interview is usually done using the telephone's speaker feature. The disadvantage of using telephone interpretation services is that they don't provide the interpreter with valuable nonverbal cues. Also, telephone interpretation services are often not familiar with medical terminology.

A key advantage to using in-person professional medical interpreters is that they have no stake in patients' answers to physicians, since they presumably are strangers. When no interpreter is available, such as in community health centers, it may be necessary to use a family member of the patient or someone working in the facility who is bilingual. Using family members as interpreters poses problems with objectivity, and patients may be reluctant to discuss sensitive information in front of their relatives. Families might also want to make a patient look good to providers and thus minimize problems they think are socially less acceptable, such as hallucinations (Slomski, 1993). A family member's English skills may be only slightly better than those of the patient.

Using nonfamily members who speak the patient's language, such as workers in other units of the hospital, may be expeditious, but yield poor results, because they may be unfamiliar with medical terminology and not understand how to interpret precisely and objectively (Luckman, 2000). Regional differences in word use between different countries or cultures that speak the same language may also present problems. In a review of audiotaped transcripts of interviews with six Spanish-speaking patients in which a nonprofessional interpreter was used (either a bilingual employee or family member), 165 errors were noted, 77% of which had the potential to cause serious clinical problems (Flores et al., 2003). These included telling a mother to put antibiotics in a child's ears instead of his mouth and failing to translate questions about drug allergies.

While it may be necessary to use bilingual relatives or employees to interpret in situations in which a patient has no or very limited English skills, it is preferable to use a professional medical interpreter who is familiar with medical terminology. Telephone interpreting services, with the interpreter participating via telephone, are viable options, especially if they employ interpreters with

expertise in medical terminology. In situations involving bilingual family members or employees or telephone interpreters who have not been trained in medical terminology, the provider should: (a) take time to explain the importance of interpreting objectively and without editing what the provider says and (b) use less technical terms that are more likely to be understood by the person interpreting and the patient (e.g., "Have you been running a temperature?" rather than "Have you been febrile?" or "Have you gone to the bathroom today?" instead of "Have you voided today?"). The more technical the language, the less likely it is that it will be understood in the same way by provider, interpreter, and patient.

## CONCLUSION

Clinical encounters in health care are problematic and require negotiation when patient and provider come with markedly different cultural constructions of reality and hold divergent health beliefs. Good communication between patient and provider can help to overcome divergent beliefs and smooth the path toward a negotiated clinical reality that optimizes the flow of information, motivates patients to engage actively in their treatment, increases patients' confidence in their ability to influence their own health, and enhances the well-being of both patient and provider.

A number of techniques for promoting effective communication were outlined and discussed. A number of techniques for increasing patients' participation in treatment have demonstrated empirical support and show promise for use in clinical settings. Techniques for improving providers' communication skills, by attending more to the nonsomatic aspects of patients' health and making interviews more patient-centered, have stood up less well in empirical testing.

The input of social work in the development and testing of interventions to improve communication in health care is needed. Although the majority of studies reviewed in this chapter had strong research designs, they were almost exclusively atheoretical. Interventions based on strong social science theory constructed by social workers with experience in health care would likely fare better. Similarly, techniques for maximizing the accuracy of communication with persons with no or limited English skills need empirical testing.

More challenging for social work and other disciplines is how to acknowledge and minimize often-subtle provider bias toward patients from sociodemographic groups who are very different from their own. This is as much a challenge for social workers as for any other professional group. Empirical evidence of the outcomes of health encounters between majority providers and patients from minority and lower and middle socioeconomic status groups is sobering, especially in terms of its potential negative impact on health outcomes. A great deal more work is needed to develop interventions for providers to sensitize them to the dangers of unacknowledged bias and provide guidance for overcoming that bias. Social workers clearly have a role in developing and testing these interventions and in serving as models of good practice through their positions on transdisciplinary health-care teams. The success of these efforts could profoundly diminish the contribution of the shortfalls in health care noted by McGinnis and colleagues (2002) to health disparities in the United States and other parts of the world.

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## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 9.1

Interview a clinician in the community who treats patients using nontraditional health-care practices, such as homeopathy, acupuncture, herbalism, *espiritismo*, or *curanderismo*. They may be found by looking at newsletters, neighborhood newspapers, the Yellow Pages of the telephone book, or through advertisements in health food stores. The following information should be obtained and included in the paper: (1) the history of use of the nontraditional health-care practice over time, emphasizing its cultural origins; (2) how the technique works; (3) indications (i.e., for what ages, health conditions, and so on, should it be used) and contraindications for its use (i.e., for what ages, health conditions, and so on, should it not be used); (4) your reactions to its effectiveness. Interviews with practitioners can be supplemented with written materials, academically published or otherwise, but students should be careful to distinguish and attribute their sources of information throughout their papers.

### LEARNING EXERCISE 9.2

Using the procedure for understanding medical terminology that is outlined in the Appendix that follows, determine the meanings of the following terms:

1. Epigastric
2. Metaplasia
3. Hypotrophy
4. Paralysis
5. Craniomegaly
6. Arrhythmia
7. Scleroderma
8. Polyneuritis
9. Ptosis of the eyelid
10. Hepatomegaly
11. Prostatic hyperplasia
12. Pubic symphysis
13. Hemostasis
14. Perinatal
15. Rhinoplasty
16. Metastatic carcinoma
17. Endocarditis
18. Pancreatitis
19. Cardiopathy
20. Tachypnea

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## APPENDIX: MEDICAL TERMINOLOGY

The following section describes how medical terms can be understood by breaking them into their component parts and following a few decision rules. Breaking

down medical words into their components and learning the meaning of those components allows a person to understand the meaning of a wide range of terms. This is especially important in preparing social workers to work in transdisciplinary environments, in which they must communicate with team members from a variety of disciplines.

In analyzing medical terms, begin with the end of the word, with the suffix. For example, the word neurology ends in *-LOGY*, which means “the study of.” Next, go to the beginning of the word. *NEUR-* is the word root, or the component of the word that provides its essential meaning. The root *NEUR-* means “nerve.” The third part of the word, the letter *O*, has no meaning of its own but is a connector of the suffix and the root. It is called a combining vowel. Putting it all together, we get “the study of nerves.”

Another word is gastroenteritis. The suffix *-ITIS* means “inflammation.” The root is *GASTR-*, which means “stomach.” The word has a second root, *ENTR-*, which means “intestines.” The connector is *O*. The word is read from the suffix, back to the beginning, and then across, from left to right. Gastroenteritis thus means “inflammation of the stomach and intestines.” It helps to look for the connector in dividing the word into its component parts. The combining vowel and root together are referred to as the combining form. Some words have two combining forms. In this case, the rule is to drop the combining vowel before a suffix that starts with a vowel. In *GASTROENTERITIS*, for example, the root *ENTER-* does not have a combining vowel before it joins with *-ITIS*, because *-ITIS* begins with a vowel. The combining vowel between root components is kept (as in *GASTR-O-ENTER*), even if the root begins with a vowel. Another example of a word with two combining forms is *ELECTROENCEPHALOGRAM*. The suffix *-GRAM* means “record of.” The combining form *ELECTRO-* means “electricity.” The combining form *ENCEPHALO-* means “brain.” So the word *ELECTROENCEPHALOGRAM* means “record of the electricity in the brain.”

In addition to suffixes, roots, combining vowels, and combining forms, some words have components attached to their beginnings, which are called prefixes. They can change the meanings of words to which they are attached. An example is the word *PERICARDIAL*. The suffix *-AL* means “pertaining to.” *CARDI-* is a root that means “heart.” *PERI-* is a prefix that means “surrounding.” So, *PERICARDIAL* means “pertaining to the area that surrounds the heart.” *RETRO-* is a prefix means “behind.” Thus, *RETROCARDIAL* means “pertaining to the area behind the heart.” Because the prefix *EPI-* means “above,” *EPICARDIAL* means “pertaining to the area above the heart.”

Tables 9.4 through 9.6 provide a number of common medical suffixes, prefixes, and roots. The information provided is general, due to space considerations, and should be seen as a resource for learning rather than a complete list of medical terms. A number of excellent manuals are available which can supplement the information in this text and provide medical terms germane to specialty areas. A selection of these manuals is listed at the end of this section of the appendix.

Using the information in these three tables should allow social workers in health care to deconstruct and understand medical terms that they encounter. Remember the following steps in identifying medical terms:

1. Identify the suffix and determine its meaning.
2. Identify any prefix that may occur and determine its meaning.

**Table 9.4**  
Common Medical Prefixes, Their Meanings, and Examples of Their Use

Prefix	Definition	Example
a-, an-	not, without	apnea
ante-	before, forward	antepartum
anti-	against	antibiotic, antiseptic
auto-	self, own	autoimmune
bi-	two	bilateral, bifurcation
brady-	slow	bradycardia
cata-	down	catabolism
con-	with, together	congenital
contra-	against, opposite	contralateral
de-	down, lack of	dehydration
dia-	through, apart, complete	dialysis, diarrhea
dys-	bad, painful, difficult	dyspnea
ec-, ecto-	out, outside	ectopic
en-, endo-	in, within	endoscope
epi-	upon, on, above	epithelium
eu-	good, well	euphoria
ex-	out, away from	exophthalmia
hemi-	half	hemiplegia
hyper-	excessive, above	hyperplasia
hypo-	below	hypothermia
in-	not, in	insomnia, incision
infra-	beneath	infracostal
macro-	large	macrocephalia
mal-	bad	malignant
meta-	change, beyond	metastasis
micro-	small	microscope
neo-	new	neoplasm
pan-	all	pancytopenia
para-	along side of, near, beside, beyond	parathyroid, paralysis
peri-	surrounding	pericardial
poly-	many, much	polyneuritis
post-	after, behind	post mortem, postnatal
pre-	before, in front of	prenatal, precancerous
pro-	before, beyond	prodrome, prolapse
pseudo-	false	pseudocyesis
re-	back, again	relapse
retro-	behind, backward	retroperitoneal
sub-	below, under	subcutaneous
supra-	above, upper	supracutaneous
syn-, sym-	together, with	synthesis, symphysis
tachy-	fast	tachycardia
trans-	across, through	transfusion
uni-	one	unilateral

**Table 9.5**  
Common Medical Roots and Connecting  
Vowels and Their Definitions

Root	Definition
abdomin/o	abdomen
aden/o	gland
angi/o	vessel
arthr/o	joint
carcin/o	cancer
cardi/o	heart
cerebr/o	cerebrum (largest part of the brain)
chondr/o	cartilage
cutane/o	skin
encephal/o	brain
enter/o	intestines
gastr/o	stomach
gynec/o	women, female
hepat/o	liver
hemat/o	blood
lapar/o	abdomenal wall
mamm/o	breast
mast/o	breast
nephr/o	kidney
neur/o	nerve
onc/o	tumor
ophthal/o	eye
orch/o	testes
oste/o	bone
ovari/o	ovary
ped/o	child
psych/o	mind
pulmon/o	lung
rhin/o	nose
sarc/o	flesh
thel/o	nipple
thorac/o	thorax
thyr/o	thyroid
trache/o	trachea
urethr/o	urethra



**Table 9.6**  
Common Medical Suffixes, Their Meanings, and Examples of Their Use

Suffix	Meaning	Example of use
-algia	pain	neuralgia
-centesis	surgical puncture to remove fluid for analysis	amniocentesis
-coccus	berry-shaped bacterium	streptococcus
-cyte	cell	lymphocyte
-dynia	pain	mastodynia
-ectomy	removal of, excision	tonsillectomy
-genesis	producing, forming	carcinogenesis
-genic	producing, produced	carcinogenic
-gram	record	mammogram
-itis	inflammation	tonsillitis
-logy	study of	morphology
-lysis	breakdown, separation	paralysis
-malacia	softening	osteomalacia
-megaly	enlargement	splenomegaly
-oma	tumor, collection	myoma
-osis	condition, usually abnormal	necrosis
-pathy	disease condition	cardiopathy
-penia	deficiency	leucopenia
-plasia	development, growth	achondroplasia
-plasty	surgical repair	angioplasty
-ptosis	sagging, drooping	visceroptosis
-sclerosis	hardening	arteriosclerosis
-stasis	stopping, control	metastasis

3. Identify the first root and combining vowel, which make up the combining form, that occur after a prefix or in the absence of a prefix. Determine its meaning.
4. Identify additional combining forms that may occur after the first combining form that was identified. Determine their meanings. Recall that the last root before a suffix that begins with a vowel will not have a combining vowel.
5. Read the word from its suffix to its prefix to its combining forms or roots.

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## CHAPTER 10

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# Religion, Spirituality, and Health

KEVIN BURKE

**T**HIS CHAPTER REVIEWS correlations between religion, spirituality, and health. Relevant definitions and historical perspectives are offered. Issues in social work research and practice are discussed as well as cultural considerations and emerging ethical issues.

### CHAPTER OBJECTIVES

- Discuss general themes and common understandings of how religion and spirituality are related to health.
- Explore historical perspectives on religion and healing.
- Discuss the difference between religion and spirituality.
- Explore how religion and spirituality are correlated with health.
- Discuss how cultural and diversity issues are related to religion, spirituality, and health.
- Define challenges and obstacles for health social workers related to religion, spirituality, and health.

### AN OVERVIEW OF RELIGION AND SPIRITUALITY

When we speak of religion and spirituality, each individual has a unique understanding of and personal meaning for these terms. Individuals may have common definitions, but for many people, *religion* and *spirituality* are difficult to define. Generally, religion is thought of as the institutions, and participation in those institutions, in which the members have shared ideology of the divine or sacred. Typically, researchers measure aspects of religion by participation in these institutions, by frequency and type of prayer associated with them, or by self-identification of the respondent. Moberg (1971) defines religion as a set of ideological beliefs, practices, and rituals associated with a specific creed.

Spirituality is a bit more difficult to define. In the vast majority of cultures, “spirit” embodies what is “sacred” or “divine.” While in many cultures the sacred is perceived as a godhead, a divine, or all-powerful being, in other cultures, the sacred is seen more as the embodiment of life force in nature, people, or certain phenom-



ena. There is no common definition among researchers regarding spirit or spirituality (Wulff, 1991). "Closeness to God," "satisfaction/efficacy of prayer," and "satisfaction with religious practice" are constructs that researchers sometimes use to measure spirituality (Pargament, 1997). Measuring spirituality by proxy, that is, satisfaction with religious practice illustrates one of the basic problems in defining and measuring it. Spirituality has most commonly been defined by social scientists as "a sense of inner-connectedness with a feeling of purpose and meaning in life, which enables transcendence over immediate circumstances" (Pargament, 1997).

Perhaps the most important distinction to be made is that religious persons may or may not be spiritual persons, and likewise persons who claim to be spiritual may or may not be religious. A number of researchers have gathered data that suggest that spirituality and religion are not highly correlated (Poloma & Gallup, 1991). It might be said that a religious person is considered to be more concerned with social role, religious institutions, and the understanding of dogma, while the spiritual person might be considered to have more concern with understanding the relationship of the self to the divine, transformation, and observance of phenomena with or without institutional mediation. Both religious and spiritual persons acknowledge the divine or sacred, but religious persons have an added "layer," namely religious institutions that give form and substance to their meanings and understandings of the sacred.

While the values of many cultures are manifest in health-care settings, and all are equally valid for those patients attempting to make personal sense out of medical diagnosis and health phenomena, there are overriding social constructs of dominant culture in America that are hegemonic. Because of this, an understanding of some basic themes of American religious practice is extremely useful for social workers in helping clients navigate health-care systems.

Some data specific to America's religious and spiritual practice are helpful in framing the historical perspective of national religious values: 96% of Americans believe in God; 42% claim to attend worship services weekly; 67% are members of a local religious body; 82% believe in the healing power of personal prayer, and 60% would like to discuss spiritual issues with their doctors (Poloma & Gallup, 1991). These percentages are among the highest in the world. However, most studies suggest that medical providers, especially physicians, hold religion and spirituality in a much less esteemed position. In most scientific quarters, atheism, far from being rare, may be the norm. A recent poll of those listed in the *American Men and Women of Science* found that only 40% believed in a "personal God" who would listen to their prayers (Canda, 1988). But when researchers looked at the members of the National Academy of Sciences, belief in a personal God was held by 7%. A study done at the University of California at San Francisco found that while over 70% of patients with life-threatening illnesses wanted to talk to their physicians about spiritual concerns, an even greater percentage of physicians thought such discussions incompatible with their professional roles (Cooke, 1986). There seems to be a basic disconnect between those seeking medical services and those providing them in the sphere of religion and spirituality (Pargament, 1997).

#### EMERGING DEFINITIONS OF RELIGION AND SPIRITUALITY

An enduring problem for both social science researchers and practitioners is that there are no common definitions or understandings of the words religion and

spirituality. During a series of meetings sponsored by the Fetzer Foundation (1999), at which common understandings of these terms were addressed, leading researchers in medicine, psychology, substance abuse, and the neurosciences found that it was difficult to find definitions that were acceptable to everyone (Larson, Swyers, & McCullough, 1997). Those in attendance agreed that both religion and spirituality have a “sacred core” that consists of “feelings, thoughts, experiences, and behaviors that arise from a search for the sacred.” For their purposes, “sacred” was defined as “a divine being or ultimate reality or ultimate truth as perceived by the individual.”

“Religion” was distinguished from “spirituality” by the addition of two criteria: extrinsic religiosity and utilization of ritual. Some religious behavior might involve seeking nonsacred goals either in or outside of a religious context. This phenomenon, also known as extrinsic religiosity, involves using religion to pursue nonsacred goals such as an enhanced social role. A person might attend church services to build a social network, make business contacts, meet a prospective spouse, or attain some other benefit not associated with the sacred. Religion must also necessarily involve the use of ritual, or specified behaviors associated with the sacred or divine, that are sanctioned by a specific population or group of people. Ritual has the power to prompt transformation through regeneration and symbolic use of time (Eliade, 1971), thus allowing individuals to reinterpret personal experience in terms of group norms.

Building on the consensus of the 1997 Fetzer Foundation working group, Koenig, McCullough, and Larson (2001) give us the following definitions and characteristics of religion and spirituality that are helpful for clinical research and social work practice (see Table 10.1):

- *Religion*: An organized system of beliefs, practices, and rituals, and symbols designed to (a) facilitate closeness to the sacred or transcendent (God, higher power, or ultimate truth/reality) and (b) to foster an understanding of one’s relationship and responsibility to others in living together in a community.
- *Spirituality*: The personal quest for understanding answers to ultimate questions about life, meaning, and relationship to the sacred or transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formation of community.

Koenig et al. (2001) summarize 12 dimensions of religion that they find present in the work of a number of theological researchers and philosophers. These

**Table 10.1**  
Characteristics Distinguishing Religion and Spirituality

Religion	Spirituality
Community focused	Individualistic
Observable, measurable, objective	Less visible and measurable, more subjective
Formal, orthodox, organized	Less formal, less orthodox, less systematic
Behavior oriented, outward practices	Emotionally oriented, inward directed
Authoritarian in terms of behaviors	Not authoritarian, little accountability
Doctrine separating good from evil	Unifying, not doctrine oriented

can be useful to health social workers to determine the religious involvement of patients that can impact their response to illness and that of their families and others in their social environments. They include:

1. Religious belief, or adherence to a common ideology with a sacred core.
2. Religious affiliation or denomination, or identification with others in a particular group.
3. Organizational religiosity, or participation in the religious institution.
4. Nonorganizational religiosity, or private prayer. (Prayer may be further subdivided into six types: petitionary, intercessory, contemplative, meditative, prayers of adoration, and prayers of confession.)
5. Subjective religiosity, or individual salience of specific religious themes to daily life.
6. Religious commitment or motivation, or the degree of religious commitment.
7. Religious quest, or the process of reconciling one's self to the larger whole.
8. Religious experience, or the mystical, dramatic, or unexplainable that are nevertheless experienced.
9. Religious well-being, or having a meaningful relationship with the sacred.
10. Religious coping, or cognitive constructions or behaviors based on religious themes that allow one to cope or adapt to stress.
11. Religious knowledge, or the amount of information an individual has about major aspects or doctrines of professed religious faith.
12. Religious consequences, or the manner in which religious ideology translates into daily living.

Spirituality is much more difficult to parse, delineate, or deconstruct. In the *Christian Century*, Martin Marty talks of "moored" spirituality in the United States, describing five types (from Koenig et al., 2001, p. 19):

1. Humanistic spirituality, focusing on the human spirit.
2. Unmoored spirituality, borrowing from many traditions, focusing on the self and not institutions.
3. Moored Eastern spirituality, as in traditional Eastern religions such as Buddhism and Taoism.
4. Moored Western spirituality, type I, focusing on a traditional God who intervenes.
5. Moored Western spirituality, type II, focusing on a benevolent unspecific God.

## RELIGION AND THE HISTORY OF HEALING

Religion and healing have been intertwined from the beginning of recorded history. From the earliest of times, the roles of priest and physician have been difficult to separate. In many cultures, their roles were the same. Writings in the Bible and the medical literature of ancient Egypt and Babylonia describe healing roles for priests. In classical Greece, Plato wrote at length of *epode* or charm—a magical force capable of healing. Plato's ideas evolved in his writings about charm, focusing finally on the exponential power that *epode* seems to have had when coupled

with more commonly accepted "bodily medicines." In Plato's view, it was a very poor physician who treated only the body without attention to the *epode*, the charm that ministered to the soul. In his beautiful verse, Plato addresses diseases of the body that may be healed by skilled use of charm. The body may deteriorate, but as a result of the medical/priestly intervention, the soul grows stronger, sustaining the body's spirit for whatever is to come.

In the Roman Empire, Asclepius was the god most widely associated with healing. He is variously described as a mortal, the son of Apollo, or the ward of the centaur Cheiron. He is said to have learned to cure disease and was paid for his services. Treatment always involved sleeping in one of his temples. The followers of Asclepius existed side by side with those of Hippocrates. Healing in the ancient world took place in the context of religion. While Hippocratic medicine focused on the naturalistic interpretation of disease, it existed side by side with religious interpretations, and the two were not mutually exclusive. Early Christians increasingly rejected Asclepius as a false god, finding Hippocratic medicine more compatible with Christian thought. A dichotomy for healing was emerging that separated the care of the body from the care of the soul (Temkin, 1991).

Through medieval times into the Renaissance, medical literature increasingly focused on naturalistic understandings and treatments of illness. Complimenting this emerging paradigm was the notion that sin was often, if not always, a causative factor of illness. In a very telling passage from *Dark Night of the Soul*, John of the Cross observes that there are two types of physical distress. One type of distress is of an organic nature: an "imperfection" that responds to "sense." Another type of distress, "the dark night of the soul," responds to spiritual interventions. He cautions religious persons to distinguish between the two (John of the Cross, 1578/1962).

As the Renaissance developed, the roles of priest and healer became unique. Rapid progress in discovering the nonphenomenological causes of illness in the nineteenth century allowed these roles to be further delineated. At the end of the nineteenth century, William James (considered to be one of America's foremost psychologists), wrote *The Varieties of Religious Experience* (1902). In it, he argues against "medical materialism," the assumption that religious phenomena related to health are less important than identifying the psychological and physiological correlates of health. He points out that mental states are dependent on physical states and do not happen in a vacuum. He argues that scientific theories as well as atheistic convictions are conditioned by organic causes. An idea or an experience must then finally be evaluated in light of the efficacy it has for a unique life.

Sigmund Freud, a contemporary of James, took quite a different view of religion. In *The Future of an Illusion* (1927/1962), he describes religion as a pathological cultural variant, in effect, a failed social phenomenon. He thought religion had failed throughout history to ameliorate suffering and anxiety. He saw religion as a "crutch" that kept individuals from functioning at their whole psychic potential. His views held sway in most of the scientific community throughout the twentieth century, and continue to hold sway in much of the established scientific community.

On the cusp of the last millennium, renewed debate about the role of religion in both health and mental health began to surface. In its 1968 report, *The Psychic Function of Religion in Mental Illness and Health*, the Group for the Advancement of

Psychiatry noted that religious themes often surface in the treatment of illness, and that religion can positively as well as negatively impact health status. Since 1980, another transformation has taken place as the knowledge base in the neurosciences and psychopharmacology that has called into question traditional assumptions about psychiatry. The evolution of criteria used for diagnosis and case examples cited in the *Diagnostic and Statistical Manual of the American Psychiatric Association (DSM)*, parallels new ways of thinking about religion. A residue of a nineteenth-century paradigm, "religious insanity," could be found in the *DSM* until 1995. Although terms that implied a religious origin of mental illnesses were absent, the glossary frequently used examples of psychopathology that had religious content, suggesting that mental illness was often characterized by religious themes.

Currently, patient religion and spirituality are largely accepted as important predictors of health outcomes. Small community-driven health projects, as well as entire countries such as Scotland, have incorporated religious and spiritual concerns into their care and treatment plans. Social science research in the field that was considered inappropriate a few decades ago is now commonplace.

#### THE SACRED AND THE PROFANE

Health social workers should be familiar with the concepts of the "sacred" and the "profane" (and the boundaries between them) because they are basic tenets of religion and spirituality. Without a basic understanding of this dichotomy, interventions run great risk of being insensitive, ill-informed, or counterproductive. If an intervention incorporates elements of the sacred when none is present, or the reverse, ignores the sacred when it is of great importance to the client, trust is lost.

Perhaps there is no better discussion of how the lack of such understanding leads to a muddle of meanings as in the book *Habits of the Heart* (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1985). A young professional woman, Sheila, describes her faith as "Sheilism." Essentially it is a belief in herself, her well-being, and her well-intentioned actions—it fills a gap, but not much else. She clings to it, yet its profanity seems to overwhelm her. It is hollow for her, in that it provides none of the resources associated with both religion and spirituality.

Health social workers can discuss concepts such as the sacred and the profane with patients to better understand the individual influence of religion and spirituality. The sacred is central to any discussion of religion or spirituality. Sociologists, anthropologists, and philosophers of the early twentieth century speculated at length on the nature and form of spirit as manifest in the "sacred." Sociologist Emile Durkheim's general theory of religion (1965), still an enduring paradigm in looking at the function of religion, contains only two key concepts, the idea of the sacred and the concept of the moral community. His theory is based on the distinction between the sacred and the profane. By sacred, he meant not only those things worthy of worship, but also everything that is not commonplace or ordinary. The sacred embodies ultimate truth and ultimate reality to individuals. Building on Durkheim's work, the theological scholar Mircea Eliade in *The Sacred and the Profane* (1959) further delineates function of the sacred: "When the sacred manifests itself in any hierophany, there is not only a break in the homogeneity of space; there is also revelation of an absolute reality, opposed to the nonreality of the vast surrounding expanse. The manifestation of the sacred ontologically

finds the world, . . . If the world is to be lived in, it must be founded—and no world can come to birth in the chaos and the homogeneity and relativity of profane space. The discovery or projection of a fixed point—the center—is equivalent to the creation of the world” (p. 21–22).

In other words, when the sacred manifests in any (religious) system, the believer in that system grounds himself in what is essentially two parallel worlds: the profane (day-to-day world of eating, sleeping, and other bodily functions), and the sacred world of giving meaning to those bodily functions—seeing those activities of daily living as part of a larger whole that has some greater meaning or purpose. From earlier times, we can see gods as transitional objects that help persons realize and operationalize the parallel universes of the sacred and the profane, a function now more attributable to religious ritual. The personal gods of the Greeks were capable of thieving, adultery, and fraud, yet these character flaws seem to have been the mechanism that allowed persons to travel a bridge from human to divine or sacred nature. The gods did not emphasize moral ideals and were interested in and favored the common person. They are shrewd and cunning. Individual gods and goddesses had favorites who were appreciated, loved, and favored not on the grounds of personal attributes, but rather by a type of mental relationship that connects the god and the person. Morals were outside of the relationship. It is the moral cohesiveness of the religious community that gives form and structure to the sacred space.

Looking at the research that correlates religious and spiritual factors to health states and healing, it is important to remember the structure of the sacred in meeting parallel needs in parallel systems with differing values. It is in this duality of meanings that healing, cure, and care may happen for one person but not another, even though their objective diagnoses and medical charts may look almost identical. If one client is coping extremely well with adverse circumstances, while another is having great difficulty with relatively minor annoyances, a social worker might want to ask what spiritual or religious resources might be available to support or challenge coping. If a client can use her understanding of the sacred to transform an otherwise negative phenomenon into something more positive, that should be incorporated and supported in the intervention. It is much more difficult to interject a spiritual element into an intervention when a client has limited understanding or is opposed to religious or spiritual understandings.

## THE RELATIONSHIP OF RELIGION AND HEALTH

The great majority of research that attempts to correlate religion with health states focuses on measurable behaviors specific to organized religious institutions. Thus, the research omits a large segment of the population who describe themselves as spiritual but not religious. The omitted group is distinctive in that it is composed disproportionately of persons with a high level of socioeconomic privilege. Within each domain, the limited research is somewhat equivocal, with few robust findings or themes.

The National Institute of Health (NIH) has identified 10 key domains of religion and/or spirituality for which there is evidence of links to health outcomes. They are:



1. *Religious/spiritual preference or affiliation*: Membership or affiliation with a specific religious or spiritual group.
2. *Religious/spiritual history*: Religious upbringing, duration of participation in religious or spiritual groups, life-changing religious or spiritual experiences, and “turning points” in religious or spiritual participation or belief.
3. *Religious/spiritual participation*: Amount of participation in formal religious or spiritual groups or activities.
4. *Religious/spiritual private practices*: Private behaviors or activities, including but not limited to prayer, meditation, reading sacred literature, and watching or listening to religious or spiritual radio or television programs.
5. *Religious/spiritual support*: Tangible and intangible forms of social support offered by members of one’s religious or spiritual group.
6. *Religious/spiritual coping*: The extent to which and ways in which religious or spiritual practices are used to cope with stressful experiences.
7. *Religious/spiritual beliefs and values*: Specific religious or spiritual beliefs and values.
8. *Religious/spiritual commitment*: The importance of religion/spirituality relative to other areas of life and the extent to which religious or spiritual beliefs and practices serve to affect personal values and behavior.
9. *Religious/spiritual motivation for regulating and reconciling relationships*: Most measures in this domain focus on forgiveness, but other issues may be relevant as well (e.g., confession, atonement).
10. *Religious/spiritual experience*: Personal experience with the divine or sacred, as reflected in emotions and sensations (George, Larson, Koenig, & McCullough, 2000).

These 10 domains provide the framework for looking at correlates of religiosity and health states, and an attempt to codify research categories within the study of health and religion. Most extant studies can be grouped generally into those that look at onset, outcome, and mortality from disease. These correlations are generally explained in terms of behavior, social support, and coherence or meaning that are fostered by religion.

Studies that look at the onset of symptoms of disease generally focus on health behaviors. Persons who attend to health matters and live “healthy” lifestyles experience less disease and that which they do experience occurs later than those who have less healthy lifestyles. Particularly convincing in this regard are the studies of religious orders (De Gouw, Westendorp, Kunst, Mackenbach, & Vandenboucke, 1995) that show less morbidity, decreased mortality, and later onset of symptoms and disease among monks.

Medical outcome studies focus on a variety of acute and chronic conditions including heart disease (Oxman, Freeman, & Manheimer, 1995), hypertension (Koenig et al., 1998), immune system dysfunction (Woods, Antoni, Ironson, & Kling, 1999), and cancer (Creagan, 1997). A large majority of these studies show a correlation between better medical outcomes and active religiosity. The mechanisms that may help explain this relationship are myriad and range from increased social support to the effect of health behaviors. An underlying theme of the positive benefits shown in these studies has to do with the resources that a social network (that religious activity can provide) brings to an individual

experiencing stress, adversity, or merely a decision-making process. Many of the resources may be practical, such as provision of material goods and transportation. However, some are much more ambiguous, running the spectrum from psychological support to friendship networks. The studies suggest that medical outcomes are dependent on complex processes, including religiosity.

In a study of religion and cognitive dysfunction among the elderly, Van Ness and Kasl (2003) found a strongly inverse association between religious attendance and mortality. While the researchers acknowledge that any type of social engagement is correlated with lower mortality rates, they and other researchers (see Bassuk, Glass, & Berkman, 1999) found that church attendance has an independent predictive value for lower mortality and increased cognitive function among elderly cohorts. In a meta-analysis of religious involvement and mortality, McCullough, Hoyt, Larson, Koenig, and Thoresen (2000) found that religious involvement was significantly associated with lower mortality. While they found that the strength of the religion-mortality association varied as a function of several moderator variables, the association of religious involvement and mortality was strong and on the order of magnitude that one would expect for psychosocial factors.

Health behaviors vary from spiritual practices that see the human body as a manifestation of the sacred to prohibitions of certain behaviors, and encouragement of others. Today, many religions have very strict dietary laws that promote healthy living. Kosher dietary laws can be seen as an early effort to promote health. Religious ideology also plays a role in that it often proscribes risky behaviors. Persons who attend religious services frequently participate in far fewer risky health behaviors than those who do not attend services (Kark, Shemi, & Friedlander, 1996). Persons who are monogamous have far fewer sexually transmitted diseases than those who are not. Alcohol and recreational drug use are regulated by many religions. However, when looked at as a whole, the amount of variance explained by health behaviors is relatively small, approximately 10% (George et al., 2000). In their meta-analysis of these studies, George and her co-investigators also found that the terms religion and spirituality were sometimes used interchangeably.

Social support is another possible mechanism that helps to explain the correlation between health and religion. By participating in a religious institution, individuals develop social bonds outside of the nuclear and extended family that can ameliorate stressors and provide positive and alternative pathways of addressing trauma and misfortune. Members who share a religious ideology have perhaps even stronger bonds in addressing adversity. Research has suggested that persons who report high levels of public religious participation also report larger social networks, more interaction within those networks, receiving greater assistance from others, and higher levels of satisfaction from those interactions (Ellison & George, 1992; Zuckerman, Kasl, & Ostfeld, 1984).

By providing and fostering meaning, religion and religious ideology assist individuals in creating a narrative structure that "strings together" isolated phenomena into a coherent whole. Thus, religion may benefit health by providing a global understanding, allowing individuals to better understand their roles in the cosmos, the purpose of their lives and those of others, and perhaps most important, the mystery of pain and suffering. Incoherence, religiosity, and spirituality often become blurred. The religious function of coherence seemingly has more to do with the sociology of meaning, the ways of which banishing anomie,

or normlessness, than promoting personal well-being. When persons become ill, many rely on religious beliefs and practices to relieve stress, retain a sense of control, and maintain hope in their sense of meaning and purpose in life. Religious involvement seems to allow those with disabling physical illness to cope better and grow psychologically from the health experiences, rather than being overwhelmed by them (Cole, 1992).

#### RELIGIOUS ISSUES OVER THE LIFE COURSE

Only recently have researchers and clinicians addressed the issues of evolving religious concerns over the life span. This is extremely important for social workers to realize because interventions may have efficacy at one particular developmental stage, yet limited efficacy at other points. Generally, religious issues gain more prominence as a person ages and experiences life stressors. Many studies demonstrate that individuals tend to become more religious as they grow older. Ehmann (1999) found that when compared to persons less than 30 years of age, many more persons over the age of 75 say that religion is very important to them (77% versus 45%). Levin and Taylor (1997) found that the frequency of private prayer increases as people age.

Empirical research seems to validate a theoretical perspective developed by Fowler (1981), who outlined a series of stages that people go through in their development of faith. He observed that as individuals progress through developmental stages, the intensity and nature of faith tends to become deeper and more complex. In his staging system, the final periods are characterized as a time of deep critical introspection during which spiritual commitment broadens and deepens. Koenig (1994) identified qualitative changes that take place in religious orientation as people age. He maintains that a "mature religious faith involves a deep, intimate, stable, and exclusive relationship with God" (p. 124). Koenig's hypothesis remains largely in the realm of intuitive speculation, in that virtually no scientific research exists that looks at those factors that promote, much less cause, a deep personal relationship with God.

Children and adolescents' religious life concentrates on the development of morals and moral values that will serve as a framework for later life (Erikson, 1959; Fowler, 1981). From a health standpoint, the socialization that parents provide during early years provides the basis of how the child comes to view the world. The basis for hope is instilled during the early years. The health behavior literature, provides ample support for the notion that adequate parenting, which is often nurtured and augmented by religious institutions, sets a framework in place that allows the child to master developmental milestones that will serve as the basis for sound decision making in later life (Wulff, 1991). Religion has much more to do with socializing and learning social roles than matters directly related to health.

In middle age, religion plays an important role in what Erik Erikson (1959) characterized as the generativity versus stagnation milestone. Aside from providing enhanced and more varied coping skills and strategies, religious institutions and religious ideologies also can provide greater insight into common themes of this period, such as valuing wisdom versus valuing physical power, socializing versus sexualizing in human relationships, "cathectic flexibility" versus "cathectic impoverishment," and mental flexibility versus mental rigidity. When health

issues disrupt negotiation of these milestones, religion often plays a role in allowing the individual to make sense out of adversity (Blanchard-Fields & Norris, 1995). Social workers support and develop these coping abilities and resources, enhance trust with their clients, and help them mitigate adversity by assessing the role of religion for a patient.

In later adulthood, religion plays an increasingly prominent role in individuals' lives. In this last developmental stage, which Erikson characterized as integrity versus despair, religious ideology can be particularly important in addressing common themes of this period, such as ego differentiation versus work role preoccupation, body transcendence versus body preoccupation, and ego transcendence versus ego preoccupation. Persons in the end stages of life often feel the need to "tie up loose ends," to make sense out of their lives. In making sense out of chronic health states that can often lead to disability and disease, coherent narratives have been shown to improve both persons' self described health states and perceived well-being (Cohler, 1992). This coupled with the practical support that religious social networks foster are seen by many to be a basic mechanism that positively impacts health. Physical, as well as mental health may also respond positively to faith-based interventions. Pastoral counseling is a rapidly expanding field that seeks not only to impact spiritual well-being, but to also address activities of daily living and social role enhancement (Kimble, 1995). Pastoral care involves religious or laypersons reaching out to members of a faith-based community in an effort to support physical, emotional, and spiritual well-being. Pastoral care projects provide many of the resources and links in an otherwise frayed social network that allow older individuals to maintain both autonomy and a sense of well-being.

#### SPIRITUALITY AND HEALTH

Markedly less research has sought to correlate spirituality and health, and much less is understood about this relationship than about religion and health. This is partially due to a lack of a common definition for spirituality. Since definitions of spirituality are much more subjective and less easily measured than those for religion, scientific research in the field is less well developed. What seems to be emerging is a more standardized definition of spirituality that emphasizes the individual's closeness to or the importance of the sacred or the divine in everyday life. In looking at the correlations between spirituality and health, three main areas emerge: coherence and life satisfaction as related to spirituality; spirituality as a motivating force in the construction of well-being; and the importance of spiritual narrative in the formation of meaning.

Antonovsky first presented the concept of coherence in 1979. He further developed his ideas in what he called the *salutogenic model*, which explains successful coping with life stressors. Over time, a person with positive life experiences and social resources comes to see the world as one that "makes sense." This worldview, the sense of coherence, is defined formally as: "a global orientation, that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement" (Antonovsky, 1979, p. 19).

There are three related and intertwined components of coherence:

1. Comprehensibility (a tendency to expect the world to be ordered or orderable) facilitates cognitive clarification of the nature the stressors pose;
2. Manageability (a tendency to expect the demands posed by problems to be manageable) leads one to seek out appropriate resources; and
3. Meaningfulness (the tendency to see life as meaningful) provides the motivational drive to engage in confronting problems.

Coherence is well formed by early adulthood. Absent any major life-altering changes, it is thought to be relatively constant for the remainder of life (Sagy, Antonovsky, & Adler, 1990). Health social workers can increase the likelihood of positive outcomes by helping patients foster or promote coherence in order to optimize meaning, manageability, and comprehension and increase salience.

Spirituality fosters a sense of coherence, in that religious ideology filtered through what the individual holds to be sacred or divine has the potential to form meaning out of otherwise meaningless situations and phenomena. When individuals understand their places in the universe vis-à-vis the sacred, the possibility for transcendent meaning greatly increases. Patients may experience great suffering or pain, yet minimize the risks of that suffering for health and well-being if they find meaning in the suffering. Coherence may allow one to reinterpret what might be unpleasant or painful to some other state, if sufficient resources are currently available to allow that transcendence to take place. Health social workers can play a critical role in allowing this transcendence to take place by recognizing and supporting these spiritual resources in their intervention strategies. One need not “agree” with an ideology or understand a phenomenon when asking prompts and questions about it that allow the client to flesh out meaning. The meaning may be important for the patient but not the social worker.

Closely related to coherence is the concept of narrative in allowing meaning to be constructed. Retrospectively creating narratives allows the individual to begin making sense of disparate events and phenomena that could easily cause demoralization, distress, and stress in the absence of a unifying theme or “story.” Narrative can readily be shown to distort the actual happenings (the history) of an experience, since its reason for being is not fidelity to historical circumstances, but rather significance and validity in the creation of a coherent life story. Creating narratives is also frequent in situations where an illness may lead to a catastrophic end, or when such an end has been narrowly avoided. In these instances, the narrative may hold a moral purpose: It acts something like a recitation of myth in a ritual that reaffirms core values under siege and reintegrates social relations whose structural tensions have been intensified. The narrative, like the ritual use of myth, gives shape and finality to an experience. This is especially true when that experience is a loss or leads to a loss or transition (Kleinman, 1988). In practical terms, patient narrative can be elicited by simple social work questions such as, “Is there something important that I should know about your life?” or “What has allowed you to do so well in the face of adversity?” Often having a dedicated space in the patient interview for life stories helps promote an atmosphere of trust and openness with the social worker. Most persons love to tell stories, yet are rarely given the time in professional space to do so.



In looking at how spirituality may prompt an individual to cope and adapt, narrative theory provides many possible insights (Taylor, 1989). Whether or not a narrative impacts or explains experience is a function of how “good” the story is and can be a measurement of the fit of the structure of explanatory variables. “Good stories” have powerful central figures that behave in accord with values shared by the teller and the listener. They have, in other words, actors who act well. When one of the actors is sacred, the possibility of transcendence or transformation increases greatly. The stories also have linearity (at least in Western cultures), and list or allude to a set of normative values.

“Good stories” have generative potential for several reasons. Perhaps primary is the fact that they are memorable. That is, they are aligned with the distortions that memory normally makes in creating personal history (Kotre, 1984). Greenwald (1980) has shown that when individuals remember past events, the basis of *egocentricity* and *benefectance* are present. He defines egocentricity as the tendency to distort personal history to make oneself more a cause (and also a target) of events than is realistic. Benefectance is the tendency to recall successes and take credit for them while forgetting or denying responsibility for failures. Without these biases, the ego would not survive, and personal history would not exist. Neisser (1982) further elaborates on memory by suggesting that its function is to look for events in which egocentricity and benefectance can be predicated, of which it can be said that there were actors who acted well. In simple terms, the ego seems to look out for the self, constantly processing and reinterpreting social fact and phenomena in an effort to construct a coherent whole biased to the “self” coming out on top. Narrative is a primary mechanism that allows this to happen.

The specific functions of narrative are a component of the more general “life review.” Often used interchangeably with “narrative,” the act of life review allows the person to discover that her individual life can have meaning even if life in general is meaningless (Moody, 1986). Baier (1981) suggested that upon successful life review, the individual will realize that (1) life is intelligible; (2) life has purpose; and (3) hopes and desires ultimately can be satisfied. Baier’s three conditions for meaning can be transposed from the objective to the cosmic level to the level of individual autobiography. Instead of asking about the meaning of life as a whole, the question becomes the meaning of the individual life being questioned.

Religious institutions provide an ideal setting for fostering the use of narrative or life review. Private prayer is often the mechanism by which spiritual concerns are integrated into a life narrative. Prayer is used by more than 80% of Americans as a coping mechanism. Among multiple-choice responses to a question concerning seeking help in the face of crisis, prayer (80%) was second only to family support (87%; Gallup & Jones, 1989).

Berger repeatedly suggested that spiritual meaning might influence subjective well-being in *The sacred canopy: Elements of a sociological theory of religion* (1990). He maintains that when persons are confronted with a series of painful and inconsistent situations in life that are not amenable to change, they must make sense or attempt to make sense of them, or face increased distress. Included among these are difficulties such as the presence of evil and suffering, the loss of physical functioning, and the unavoidable prospect of death. He argued that spirituality, or a spiritual ideology, helps people deal with these by providing *theodices*—religiously based worldviews with spiritual content, that explain phenomena such



as death and suffering, and show individuals how they fit into a larger whole or purpose. He thought that persons who internalized these theodices would derive a deeper sense of meaning and purpose in life. In contrast, he argues that persons with no spiritual framework are more likely to experience a state of anomie, or normlessness, which prompts painful separation from the wider social order that can cast the individual into a deep sense of meaninglessness and turmoil. There are relatively few empirical studies that assess this theory. In one noteworthy exception, Musick (2000) found that religiously based worldviews that were more positive were correlated with increased levels of life satisfaction.

Subjective well-being is often assessed by three measures: life satisfaction, self-esteem, and optimism. One of the key functions of spiritual meaning is to provide a better understanding of adversity and the challenges that arise in life. Perhaps more important, spiritual meaning helps persons see the larger reasons for difficult situations that lie beyond their own immediate concerns and abilities. Gaining these insights, and believing that they fit into a larger plan or purpose, may be the source of significant personal growth. Realizing that one has grown in the face of adversity may then be an important source for both efficacy and life satisfaction. The relation of spiritual meaning to self-esteem is straightforward. If people believe that God has a purpose or a plan for their lives, then it must mean that God loves and cares for them. Since feelings of self-esteem arise at least in part from the views of the self that are held by significant others, believing that God values, loves, and cares for them should positively impact self-esteem. It seems reasonable that if persons believe a spiritually based set of beliefs provides a sense of direction and purpose in life, they will then feel more optimistic about the future. They do not feel they are in the world alone. Seligman (1990) found that spiritual meaning enhances feelings of optimism by helping people see their lives will follow a specific and beneficial plan that has been devised by God. Health social workers can utilize this information to assist patients in coping with illness and its consequences.

#### CULTURAL CONSIDERATIONS

Two issues immediately present themselves when talking about religion, spirituality, and health in the context of culture. The first is the various cultural traditions and identities of persons seeking health care in a pluralistic society. The second is the cultural biases that health-care providers may bring into their professional settings. Many studies document the greater importance that religion and spirituality have in the lives of disadvantaged populations (Levin, Taylor, & Chatters, 1994). Persons of color, the elderly, the less educated, and those in poverty all claim that religion and spirituality are more important in their lives than do members of the general population. Disadvantaged populations, especially racial minorities, have lower life expectancies, are less likely to have health insurance, make fewer primary care medical visits, and have lower birth weights and higher infant mortality (Sutherland, Hale, & Harris, 1995).

Although we know that members of disadvantaged populations attach greater importance to religion and spirituality, the mechanisms by which this importance plays out in health and health care are a bit murky. It would seem that the health of these populations might be even worse if individuals did not positively invoke religious-based resources in promoting healthy behaviors. Krause (2002) sets out

to provide some answers through a meta-analysis of studies that look at a variety of demographic variables of church-based social support for older persons, focusing on social relationships in the church. He found empirical support for several theoretical linkages including, "older people who attend church often feel their congregations are more cohesive; older people in highly cohesive congregations receive more spiritual and emotional support from their fellow parishioners; older respondents who receive more church-based support have a more personal relationship with God; older people who feel more closely connected with God are more optimistic; and older people who are more optimistic enjoy better health." This series of findings expresses the basic mechanisms of the positive influences of religion on health.

Church attendance and congregational or group cohesiveness seem to be especially important variables for promoting support among any group, and perhaps take on a greater importance among disadvantaged groups (Pargament, Silverman, Johnson, Echemendia, & Snyder, 1983). Aside from the direct and practical support that individuals receive, group members also receive support for a shared experience that is often based on a history of oppression and a collective or cultural response to that oppression. In the context of health, this shared response to collective misfortune often transforms into individual responses to individual problems. The presence of a shared religious ideology gives additional support to individual synthesis of the problem system at hand.

Almost a century ago, Simmel (1905) held that a religious person "feels himself bound to a universal, to something higher, from which he came and into which he will return, from which he differs and to which he is nonetheless identical. All of these emotions, which meet as a focal point in the idea of God, can be traced back to the relationship that the individual sustains with the species . . ." (p. 372). In other words, all close ties with others are capable of generating those feelings toward God. These phenomena may help in explaining why institutional religion appears to be more important to members of socially marginal populations. Because of the relative lack of support from dominant cultural institutions, those institutions indigenous to specific demographic populations serve multiple functions. In the case of the religious institution, they not only provide support, but also translate and transform meaning in the context of a shared ideology incorporating the sacred.

Individuals with minority identities often look at health and health care differently than do those who provide their care. In spite of wide variability, persons with Hispanic origins view health and disease or illness as holistic, including spiritual, moral, somatic, psychological, social, and metaphysical dimensions. Both health and illness are seen as coming from God as a gift or punishment. For Hispanic American women, in particular, mind, body, and spirit are inseparable. Healing is very closely associated with religious practice (Musgrave, Allen, & Allen, 2002). African Americans are much more likely than White Americans to pray privately, practice religious rituals, attend religious services, and believe that the Bible is the word of God (Jacobson, Heaton, & Dennis, 1990). Elderly African Americans are more likely than elderly White Americans to derive comfort from religion during stress (Johnson, Matre, & Armbrrecht, 1991). African American caregivers see God as a source of help and score higher than White American caregivers on measures of prayer and comfort from religion (Picot, Debanne, Mamazi, & Wykle, 1997). Many studies seem to

conflate immigrant status with minority status, stigma status, and religious identity.

The biases of Western medicine and American Christianity often combine with other dominant culture values to produce an ethic within established medical practice that seeks to minimize difference among patients in an effort to promote scientific analysis and increased economy and productivity. These well-intentioned efforts often dismiss or denigrate the cultural conceptions of health, treatment, and spirituality among those seeking help. What a member of the medical establishment provides as an example of the best that science has to offer can often be dismissed by the consumer as the best that scientism has to offer, or something inauthentic. Until there is a respectful dialogue among persons with opposing, but perhaps not antagonistic world-views, many skilled medical interventions will be misapplied, ignored, or otherwise abandoned for cultural considerations that hold meaning to the person in need of healing. Health social workers are in an excellent position to mediate these situations. Often medical providers become extremely frustrated with what they see as a lack of compliance or follow-through by patients. At the same time, many patients feel disrespected, patronized, and marginalized by medical providers. The social worker often functions as a translator of medical culture to patients and of the culture of the patients to medical providers.

#### OBSTACLES AND CHALLENGES

Perhaps the greatest challenge facing those who would like to integrate religious and spiritual issues into health care is the perceived necessity of doing so. Policymakers continue to debate the role of religion and spirituality in health-care settings, with no consensus emerging as to whether it is even appropriate for inclusion. This is especially true in public health-care settings. Only recently have health-care maintenance organizations (HMOs) fielded studies that suggest that addressing spiritual concerns in health care is cost-effective (Naik, 2004). Whether cost consideration determines their perceived utility remains to be seen. Policy and ethical considerations also are coming to the fore, as the present administration in Washington calls for social and medical services to be provided by church-based and religious organizations. Finally, there are issues concerning the efficacy of spiritual and religious interventions, as well as the potential harm that either may cause.

For those medical providers who would like to address the religious and spiritual concerns of their patients, there are few formal instruments developed to allow them to do this. Those that do exist are largely untested and not yet normed. With support from the Fetzer Foundation, a pioneer in addressing religious and spiritual issues in health care, Hays, Meador, Branch, and George (2001) have developed a spiritual history scale that may be a valid, reliable measure of lifetime religious and spiritual experience. After considerable pretesting and statistical analysis, the members of this working group found that four variable domains tend to explain much of the relationship between religion and health. These domains are the degree to which God helped individuals in past help-seeking behaviors, a family history of religiousness, lifetime religious social support, and the cost of religiousness or the measure

of the presence or absence of physical, emotional, and interpersonal losses associated with one's past religious life. In essence these domains look at the efficacy of religion in personal life, the role and importance of religion in family life, the salience of religiosity over time, and the positive and negative aspects of religiosity.

Professional competency, boundaries, and ethics are also new grounds for exploration. While some health-care consumers would like their medical providers to pray with them, a large proportion of providers reject this behavior as either unethical or unprofessional (Koenig et al., 2001). Deciding how to respond to patients' spiritual and religious issues can raise complex ethical issues for providers. Should physicians discuss spiritual issues with patients though not invited to do so? Should a nurse offer a prayer for a comatose patient in the ICU? Is it ever appropriate to try to encourage or discourage religious beliefs for the "benefit" of the patient? What should be the professional boundaries between physicians and chaplains? Social workers have traditionally mediated discussions of issues such as these while imposing professional boundaries on the discussion (see the appendix to this chapter for a suggested set of guidelines for social workers).

The negative power of religion and spirituality is also emerging as dialogue evolves. When patients feel that their spiritual needs are neglected in standard clinical environments, they are often driven away from effective clinical treatment. This phenomenon is observed in a review of the medical records of 172 children who died after their parents relied on faith healing instead of standard medicine. The researchers found that most of the children would have survived if they had received medical care (Asser & Swan, 1998). Health social workers are in an excellent position to advocate for client needs, translate client perceptions, and focus on inherent issues of social justice related to these issues.

Although integrating religion and spirituality into health-care treatment is important in its own right, the fundamental issue remains of the effect of religion and spirituality on health. Patients usually have no trouble making these connections, yet their providers often have difficulty with it. Social workers have long been bridges between worlds, cultures, families and individuals. Religion and spirituality in health care is but another domain where the expertise of the social work profession is uniquely suited to addressing concerns of persons who would otherwise not be heard.

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### SUGGESTED LEARNING EXERCISES

The following case studies are based on actual issues encountered in social service agencies. The class or seminar should be divided into small groups of 4 to 6 persons. Each small group should discuss the case, with a recorder to report back to the larger group. Questions to be discussed can include the following: What could a social worker do in response to such a case situation? What are the social work ethics involved? What are the social work boundary issues? How might the helping professional actually cause harm to the client?

### **Case Example 10.1**

Mrs. Smith, a cheerful, bedridden widow of 89, is experiencing a rapid decline due to a number of chronic health conditions. She tells her care management team (a social worker, a nurse, and a physical therapist) that she would like to talk to them about end-of-life issues and her spirituality. The team offers her a pastoral referral. She says that she has no interest in talking to a religious person because, "I might not get it right." The physical therapist says that her church has a "friendly visitor" program. As a devout Catholic, Mrs. Smith says that she has even less interest in having a "proselytizing Pentecostal 'friendly visitor'" in her home. Mrs. Smith becomes incensed and asks everyone to leave her home.

The following week, Mrs. Smith calls the director of the care management agency, again asking if any of the social workers, nurses, or anyone else there who has seen her over the past 25 years, could be sent out to talk to her about what she calls "my religion." She again firmly states that she does not want to talk to her parish priest or any other religious person. Sensing some urgency, Ms. Greene, the executive director of the agency, thought it appropriate to visit Mrs. Smith and assess the nature of her concern.

Thinking that Ms. Greene is a social worker, Mrs. Smith first thanks her profusely for coming. She then says that she needs some very basic questions answered; questions that have kept her up at night and which cause her great emotional pain. Mrs. Smith says that she knows she is dying and has no doubt that she is going straight to heaven. She has strictly adhered to the Ten Commandments and always obeyed the Golden Rule, she tells Ms. Greene. What she can't figure out, the source of her agony, is whether or not she will have the beautiful face and body she had as a girl, or her current paralyzed morbidly obese body, sagging face, and eyes that cannot really see anymore. She sobs uncontrollably.

### **Case Example 10.2**

Mr. Brown, a spry widower of 86, reports to his social worker from the senior center that since joining the Everlasting Love and Joy in Christ Jesus Church, Inc., he has experienced a vastly increased sense of well-being, in spite of discontinuing use of all of his medications, including those for chronic back pain, high blood pressure, high cholesterol, and rheumatoid arthritis. Mr. Brown reports that he also signs over his monthly social security check to the church in return for a place to live and his meals.

Mr. Brown's medical doctor reports that she does not understand her patient's newfound mobility, reported lack of pain, and lowered cholesterol levels, given that he has discarded his medications and now claims to only "pray for health." She does state that she is very concerned about Mr. Brown's dangerously high blood pressure, which seems to be exacerbated by rounds of ecstatic dancing during church revival meetings.

Mr. Brown's case management team asks him about his new health regimen. He states, "It's an all or nothing deal. I'm not taking no more drugs. I've put myself in the hands of the Lord, and I feel 1000% better. Whatever the Lord wants to do with me now is fine with me."

### Case Example 10.3

Mrs. Jones, a widow of 76, lives in a mobile home in an isolated area outside of a rural town. She has multiple chronic health conditions that include lung disease, hypertension, and diabetes. At the monthly medical rounds, her case manager reports her to be increasingly despondent, with unmistakable signs and symptoms of clinical depression. A mental health consult is ordered from the local mental health center.

In the consult, it emerges that Mrs. Jones has lost her husband within the past year to lung cancer, her son to a gunshot wound 3 years ago, and her daughter, son-in-law, and their four children to the People's Temple mass suicide/murder in Jonestown, Guyana, in 1977.

Mrs. Jones reports that throughout her life, religion and spirituality have been very important. Her entire family were members of the People's Temple until 1977. In addition to her daughter's family perishing, many of her friends were also lost. Her church ceased to be an institution. She reports now that she has no use for any organized religion. Upon being asked about her spirituality, she breaks down and asks why she has to live anymore when everyone and everything she once held dear is now gone.

### SUGGESTED RESOURCES

Canda, E., Nakashima, M., Burgess, V., & Russel, R. (1999). *Spiritual diversity and social work: A comprehensive bibliography with annotations*. Alexandria, VA: Council on Social Work Education.

### APPENDIX: RELIGION THAT HURTS OR HEALS—SOME TESTS FOR MENTALLY HEALTHY RELIGION

Within social work, the Council on Social Work Education's (CSWE; 2002) working group on religion and spirituality has issued the following guide for practitioners using Clinebell's "Tests for Mentally Healthy Religion" (1965). While individual practitioners may agree or disagree with some of the following guidelines, they do serve as a stepping off point for a discussion of the issues within health social work. While these guidelines are geared toward mental health clinicians, the basic tenets apply to all types of healing and the under girding of a sense of personal well-being that is so crucial in the health-religion-spirituality matrix.

- Does a particular form of religious thought and practice build bridges or barriers between people?
- Does a particular form of religious thought and practice strengthen or weaken a basic sense of trust and relatedness to the universe?
- Does a particular form of religious thought and practice stimulate or hamper the growth of inner freedom and personal responsibility? Does it encourage healthy or unhealthy dependency relationships, mature or immature relationships with authority? Does it encourage growth of mature or immature consciences?
- Does a particular form of religious thought and practice provide effective or faulty means of helping persons move from a sense of guilt to forgiveness? Does it provide well-defined, significant, ethical guidelines, or does it em-



phasize ethical trivia? Is its primary concern for surface behavior or for the underlying health of the personality?

- Does a particular form of religious thought and practice increase or lessen the enjoyment of life? Does it encourage a person to appreciate or depreciate the feeling dimension of life?
- Does a particular form of religious thought and practice handle the vital energies of sex and aggressiveness in constructive or repressive ways?
- Does a particular form of religious thought and practice encourage the acceptance or denial of reality? Does it foster magical or mature religious beliefs? Does it encourage intellectual honesty with respect to doubts? Does it oversimplify the human situation or factor its tangled complexity?
- Does a particular form of religious thought and practice emphasize love or fear?
- Does a particular form of religious thought and practice give its adherents a "frame of orientation and object devotion" that is adequate in handling existential anxiety constructively?
- Does a particular form of religious thought and practice encourage the individual to relate to his unconscious through living symbols?
- Does a particular form of religious thought and practice accommodate itself to the neurotic patterns of the society or endeavor to change them?
- Does a particular form of religious thought and practice strengthen or weaken self-esteem?

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## CHAPTER 11

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# Families, Health, and Illness

JOHN S. ROLLAND and ALLISON WERNER-LIN

**I**LLNESS, DISABILITY, AND death are universal experiences in families. The real question is not if we will face these issues, but when in our lives they will occur, under what kinds of conditions, how long they will last, and how serious they will be. With major advances in medical technology, people are living much longer with conditions that in the past have been fatal. This means that ever-growing numbers of families are living with chronic disorders over an increasingly long time span. Families are also simultaneously coping with a greater number of chronic conditions. This chapter provides a normative, preventive model for assessment, psychoeducation, and intervention with families facing chronic and life-threatening conditions. This model offers a systemic view of healthy family adaptation to serious illness as a developmental process over time in relation to the complexities and diversity of contemporary family life, modern medicine, and existing flawed models of health-care delivery and access to care.

### CHAPTER OBJECTIVES

- Outline a comprehensive family systems model for assessment and clinical intervention with families facing chronic illness and disability.
- Describe the psychosocial demands of illness based on their pattern of onset, course, outcome, incapacitation, and level of uncertainty.
- Delineate the crisis, chronic, and terminal phases of illness, the transitions between phases, and the psychosocial developmental tasks associated with each phase.
- Discuss the interface of illness, individual, and family development; multi-generational legacies of illness and loss; and how these relate to coping and adaptation to chronic illness.
- Describe how health belief systems affect a patient's or family's response to illness.

## OVERVIEW OF THE FAMILY SYSTEMS-ILLNESS MODEL

Over the past 25 years, there has been growing interest in family-centered, collaborative, biopsychosocial models of health care (Blount, 1998; Doherty & Baird, 1983; Engel, 1977; McDaniel, Campbell, Hepworth, & Lorenz, 2005; McDaniel, Hepworth, & Doherty, 1992; Miller, McDaniel, Rolland, & Feetham, in press; Rolland, 1994; Seaburn, Gunn, Mauksch, Gawinski, & Lorenz, 1996; Wood, 1993). There is growing evidence for the mutual influence of family functioning and physical illness (Weihs, Fisher, & Baird, 2002) and the usefulness of family-centered interventions with chronic health conditions (Campbell, 2003). Weihs et al. (2002) summarized the increasing body of research regarding the impact of serious illness on families across the life cycle and the relationship of family dynamics to illness behavior, adherence, and disease course. In this report, a broad definition of family was used. Family was defined as a "group of intimates with strong emotional bonds . . . and with a history and a future as a group" (p. 8). Most illness management takes place within the context of the family environment. Social work interventions in health settings aim to help families adjust to and live with the demands of an illness or disability, assist families in navigating the health-care system, and enhance quality of life for the entire family.

There is a clear need for a conceptual model that provides a guide useful to both clinical practice and research, one that allows a dynamic, open communication between these disciplines. What is most needed is a comprehensive way to organize our thinking about all the complex interactions between biological illness, family, individual family members, and professionals involved in providing care. We need a model that can accommodate the changing landscape of interactions between these "parts of the system" over the course of the illness and the changing seasons of the life cycle.

Families enter the world of illness and disability without a psychosocial map. To master the challenges presented by an illness or disability, families must understand the impact of the condition on the entire family network. The Family Systems-Illness Model that was developed by Rolland (1984, 1987a, 1987b, 1990, 1994a, 1998) is based on a strength-oriented perspective, viewing family relationships as a resource and emphasizing possibilities for resilience and growth, not just liabilities and risks (Walsh, 1998). This model provides social workers with a framework for assessing the impact of an illness or disability on family life and for structuring interventions to meet the needs of family members.

Defined in system's terms, an effective psychosocial model for assessing the impact of illness on family life needs to encompass all persons affected by the condition. The first step to constructing such a model is to redefine the unit of care in terms of the family or caregiving system, as distinct from the ill individual (McDaniel, Hepworth, & Doherty, 1992). This is a departure from the medical model's narrow focus on the patient alone. By using a broad definition of family as the cornerstone of the caregiving system, as suggested by the IOM report (2002), we can describe a model of successful coping and adaptation based on family system strengths. By viewing the family as the unit of care, in which a broad range of family forms and dynamics is normative, social workers can apply a model that addresses the fit between family resources and strengths and the demands of the condition.

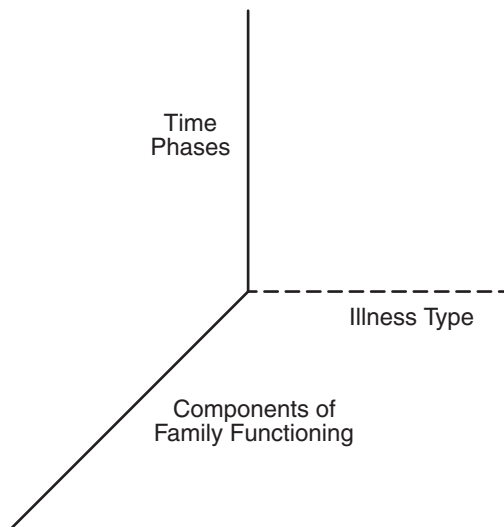
In situations of chronic disorders, a basic task for families is to create a meaning for the illness situation that preserves their sense of competency and mastery. At



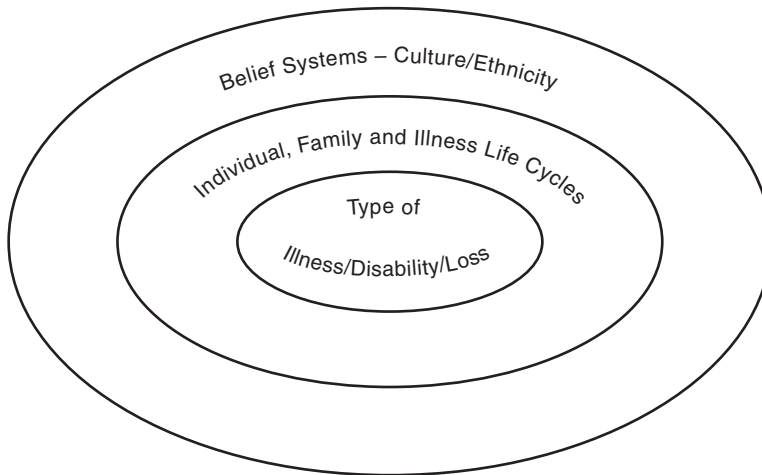
the extremes, competing ideologies can leave families with a choice between a biological explanation or one of personal responsibility (e.g., illness as retribution for wrong-doing). Families desperately need reassurance that they are handling illnesses appropriately (bad things do happen to good people). These needs often occur in the context of a vague or nonexistent psychosocial map. Many families, particularly those with untimely disorders, find themselves in unfamiliar territory and without guides. This highlights the need for a preventive, psychoeducational approach that helps families anticipate normative illness-related developmental tasks over time in a fashion that maximizes their sense of control and mastery.

To create a normative context for their illness experience, families need the following foundation. First, they need a psychosocial understanding of the condition in systems terms. This means learning the expected pattern of practical and affective demands of a disorder over the life course of the condition. This includes a timeframe for disease-related developmental tasks associated with different phases of the unfolding disorder. Second, families need to understand themselves as a systemic functional unit. Third, they need an appreciation of individual and family life-cycle patterns and changes to facilitate their incorporation of changing developmental demands for the family unit and individual members in relation to the demands of a chronic disorder. Finally, families need to understand the cultural, ethnic, religious, and gender-based beliefs that guide the type of caregiving system they construct. This includes guiding principles that define roles, rules of communication, definitions of success or mastery, and fit with beliefs of the health-care providers. Family understanding in these areas facilitates a more holistic integration of the disorder and the family as a functional family-health/illness system evolving over time.

The Family Systems-Illness Model addresses three dimensions: (1) “psychosocial types” of illness and disability, (2) major developmental phases in their natural history, and (3) key family system variables (Figure 11.1). It attends to the



**Figure 11.1** Three-Dimensional Model. From “Chronic Illness and the Life Cycle: A Conceptual Framework,” by J. S. Rolland, 1987a, *Family Process*, 26(2), pp. 203–221. Reprinted with permission.



**Figure 11.2** Family Systems-Illness Model. From *Families, Illness, and Disability: An Integrative Treatment Model*, by J. S. Rolland, 1994a, New York: Basic Books. Reprinted with permission.

expected psychosocial demands of a disorder through its various phases, family systems dynamics that emphasize family and individual life cycles, multigenerational patterns, and belief systems (including influences of culture, ethnicity, spirituality, and gender; Figure 11.2). The model emphasizes the match between the psychosocial demands of the disorder over time and the strengths and vulnerabilities of a family.

#### PSYCHOSOCIAL TYPES OF ILLNESS

The standard disease classification used in medical settings is based on purely biological criteria that are clustered in ways to establish a medical diagnosis and treatment plan rather than on the psychosocial demands on patients and their families. The alternative classification scheme presented here provides a better link between the biological and psychosocial worlds, and thereby clarifies the relationship between chronic illness and the family (Rolland, 1984, 1994a). The goal of this typology is to define meaningful and useful categories with similar psychosocial demands for a wide array of chronic illnesses affecting individuals across the life span.

*Onset* Illnesses can be divided into those that have either an acute onset, such as strokes, or a gradual onset, such as Alzheimer's disease. For acute-onset illnesses, affective and practical changes are compressed into a short period of time, requiring the family to more rapidly mobilize their crisis-management skills. Families able to tolerate highly charged emotional situations, exchange roles flexibly, problem solve efficiently, and utilize outside resources will have an advantage in managing acute-onset conditions.

*Course* The course of chronic diseases generally takes three forms: progressive, constant, or relapsing/episodic. With a progressive disease, such as Alzheimer's

or Parkinson's disease, the family is faced with a perpetually symptomatic family member for whom the disability worsens in a stepwise or gradual way. The family must live with the prospect of continual role change and adaptation to continued losses as the disease progresses. Increasing strain on family caregiving is caused by exhaustion, with few periods of relief from the demands of the illness, and by new caregiving tasks over time.

With a constant-course illness, the occurrence of an initial event is followed by a stable biological course, such as a single heart attack or spinal-cord injury. Typically, after an initial period of recovery, the illness is characterized by some clear-cut deficit or limitation. The family is faced with a semipermanent change that is stable and predictable over a considerable time span. Therefore, the potential for family exhaustion exists without the strain of new role demands over time.

Relapsing- or episodic-course illnesses, such as back problems and asthma, are distinguished by the alternation of stable low-symptom periods with periods of flare-up or exacerbation. Families are strained by both the frequency of transitions between periods of crisis and noncrisis and ongoing uncertainty about when the disorder might recur. Families must develop two modes of operation, one to cope with flare-ups and another to address periods of relative stability. Families must remain flexible as they alternate between these two forms of organization. The wide psychological discrepancy between low-symptom periods versus flare-up is a particularly taxing feature unique to relapsing diseases.

*Outcome* The extent to which a chronic illness leads to death or shortens a person's life span has a profound psychosocial impact. The most crucial factor is the initial expectation of whether a disease will cause death. On one end of the continuum are illnesses that do not typically affect the life span, such as allergies or arthritis. At the other extreme are illnesses that are clearly progressive and fatal, such as metastatic cancer. An intermediate, more unpredictable category includes both illnesses that shorten the life span, such as heart disease, and those that may bring sudden death, such as hemophilia. A major difference between these kinds of outcome is the degree to which the family experiences anticipatory loss and its pervasive effects on family life (Rolland, 1990, 2004).

*Incapacitation* Disability can involve impairment of cognition (e.g., Alzheimer's disease), sensation (e.g., blindness), movement (e.g., stroke with paralysis), stamina (e.g., heart disease), disfigurement (e.g., mastectomy), and conditions associated with social stigma (e.g., AIDS; Olkin, 1999). The extent, kind, and timing of disability imply sharp differences in the degree of family stress. For instance, the combined cognitive and motor deficits caused by a stroke necessitate greater family role reallocation than those caused by a spinal-cord injury, in which cognitive abilities are unaffected. For some illnesses, like stroke, disability is often worst at the beginning. For progressive diseases, like Alzheimer's disease, disability looms as an increasing problem in later phases of the illness, allowing a family more time to prepare for anticipated changes and an opportunity for the ill member to participate in disease-related family planning while still cognitively able (Boss, 1999).

The predictability of an illness, or the degree of uncertainty about the specific way in which it will unfold, overlays all other variables. For illnesses with highly unpredictable courses, such as multiple sclerosis, family coping and

adaptation, especially future planning, are hindered by anticipatory anxiety and ambiguity about what the family will encounter. Families able to put long-term uncertainty into perspective are best prepared to avoid the risks of exhaustion and dysfunction.

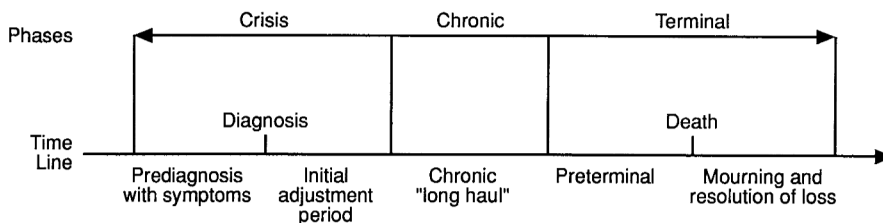
By combining the types of onset, course, outcome, and incapacitation into a grid, we generate a typology that clusters illnesses according to similarities and differences in patterns that pose differing psychosocial demands.

#### TIME PHASES OF ILLNESS

Too often, discussions of “coping with cancer,” “managing disability,” or “dealing with life-threatening disease” approach illness as a static state and fail to appreciate the dynamic unfolding of illness processes over time. The concept of time phases allows social workers and families to think longitudinally and to understand chronic illness as an ongoing process with normative landmarks, transitions, and changing demands. Each phase of an illness poses its own psychosocial demands and developmental tasks that require significantly different strengths, attitudes, or changes from a family. The core psychosocial themes in the natural history of chronic disease can be described in three major phases: crisis, chronic, and terminal (Figure 11.3, Table 11.1).

*The Crisis Phase* The crisis phase includes any symptomatic period before diagnosis through the initial readjustment period after a diagnosis and initial treatment planning. This phase presents a number of key tasks for the ill member and family. Moos (1984) describes certain universal, practical illness-related tasks, including: (a) learning to cope with any symptoms or disability, (b) adapting to health-care settings and treatment procedures, and (c) establishing and maintaining workable relationships with the health-care team. Also, there are critical tasks of a more general, existential nature. The family needs to: (a) create a meaning for the illness that maximizes a sense of mastery and competency, (b) grieve for the loss of health, (c) gradually accept the illness as permanent while maintaining a sense of continuity between their past and future, (d) pull together to cope with the immediate crisis, and (e) in the face of uncertainty, develop goals for the future.

During this initial adjustment period, health professionals have enormous influence over a family’s approach to and sense of competence in accomplishing these developmental tasks. Initial meetings and advice given at the time of diagnosis can be thought of as a “framing event.” Since families are so vulnerable at



**Figure 11.3** Time Line and Phases of Illness. From *Families, Illness, and Disability: An Integrative Treatment Model*, by J. S. Rolland, 1994a, New York: Basic Books. Reprinted with permission.

**Table 11.1**  
Phases of Illness Developmental Tasks

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Crisis Phase

1. Family understand themselves in systems terms
2. Psychosocial understanding of illness
  - a. In practical and emotional terms
  - b. In longitudinal and developmental terms
3. Family appreciation of developmental perspective (individual, family, illness life cycles)
4. Crisis reorganization
5. Create meaning that promotes family mastery and competence
6. Define challenge as shared one in "WE" terms
7. Accept permanence of illness/disability
8. Grieve loss of family identity before chronic disorder
9. Acknowledge possibilities of further loss while sustaining hope
10. Develop flexibility to ongoing psychosocial demands of illness
11. Learn to live with symptoms
12. Adapt to treatments and health care settings
13. Establish functional collaborative relationship with health care providers

Chronic Phase

1. Maximize autonomy for all family members given constraints of illness
2. Balance connectedness and separateness
3. Minimize relationship skews
4. Mindfulness to possible impact on current and future phases of family and individual life cycles

Terminal Phase

1. Completing process of anticipatory grief and unresolved family issues
  2. Support the terminally ill member
  3. Help survivors and dying member live as fully as possible with time remaining
  4. Begin the family reorganization process
- 

this point, clinicians need to be extremely sensitive in their interactions with family members. They should be aware of messages conveyed by their behavior in interactions with the family. This framing event has a powerful influence on the family's deciding of what is normal. For instance, if a clinician meets with parents separately from adolescents to give them information about a cancer diagnosis and prognosis, the parents may assume they were being instructed implicitly to protect their adolescent from any discussion of the illness. Social workers can encourage physicians to ask patients who they would like to include in important discussions, or can help reframe these experiences for families by asking them about their preferences.

With life-threatening conditions that can cause sudden death (e.g., heart attack), there is a higher premium on early frank conversation. Knowing an ill member's wishes concerning heroic medical efforts and life support can benefit everyone. For example, in one family, the father had serious heart disease. Everyone, including the father, became emotionally paralyzed by fear because end-of-life decision making had been avoided. Family consultations facilitated the father making his wishes known regarding the limits on life-saving efforts.

This relieved his family members because they knew his feelings if they had to make life and death decisions. For the father, making his wishes known not only gave him a sense of personal control over the end of his life, but also freed his energy to focus on living well and maximizing his physical well-being. Despite the short-run difficulty of having end-of-life discussions, it is important to keep in mind that many of the most wrenching end-of-life experiences for families occur when the wishes of a dying member are unknown or have been disregarded. With conditions, such as Alzheimer's disease, involving progressive dementia, there is added incentive for conversations before the affected person's cognitive impairment makes meaningful discussion impossible (Boss, 1999).

*Chronic Phase* The chronic phase, whether long or short, is the time span between the initial diagnosis/readjustment and the third phase when issues of death and terminal illness predominate. This phase can be marked by constancy, progression, or episodic change. It has been referred to as "the long haul," or "day-to-day living with chronic illness" phase. Often, the patient and family have come to grips psychologically and organizationally with permanent changes and have devised an ongoing coping strategy. The ability of the family to maintain the semblance of a normal life, attending as evenly as possible to both the illness and to normative developmental tasks, is key during this period. If the illness is fatal, this is a time of living in limbo. For certain highly debilitating but not clearly fatal illnesses, such as a massive stroke or dementia, the family can feel saddled by an exhausting problem "without end." Paradoxically, the family may feel its hope to resume a "normal" life can only be realized after the death of the ill member. The maintenance of maximum autonomy for all family members in the face of prolonged adversity helps to offset trapped, helpless feelings.

For long-term disorders, customary patterns of intimacy for couples become skewed by discrepancies between the ill member and the well spouse/caregiver (Rolland, 1994b). As one young husband lamented in a clinical meeting regarding his wife's cancer, "It was hard enough 2 years ago to absorb that, even if Ann was cured, her radiation treatment would make pregnancy impossible. Now, I find it unbearable that her continued slow, losing battle with cancer makes it impossible to go for our dreams like other couples our age." Normative ambivalence and escape fantasies often remain underground and contribute to "survivor guilt." Psychoeducational family interventions that normalize such emotions related to threatened loss can help prevent destructive cycles of blame, shame, and guilt.

*Terminal Phase* In the terminal phase of an illness, the inevitability of death becomes apparent and dominates family life. At this point, the family must cope with issues of separation, death, mourning, and beginning the reorganization process needed for the resumption of "normal" family life beyond the loss (Walsh & McGoldrick, 2004). Families that adapt best to this phase are able to shift their views of hope and mastery from controlling the illness to a successful process of "letting go." Optimal coping involves emotional openness as well as dealing with the myriad practical tasks at hand. This includes seeing this phase as an opportunity to share precious time together to acknowledge the impending loss, to deal with unfinished business, and to say good-byes. If they have not decided beforehand, the patient and key family members need to decide about such things as a living will, the extent of medical heroics desired, preferences about dying at



home, in the hospital, or at hospice, and wishes about a funeral or memorial service and burial.

#### TRANSITIONS BETWEEN PHASES

Critical transition periods link the three time phases. These transitions present opportunities for families to reevaluate the appropriateness of their previous life structures in the face of new illness-related developmental demands. Unfinished business from the previous phase can complicate or block movement through the transitions. Families can become permanently frozen in an adaptive structure that has outlived its utility (Penn, 1983). For example, the usefulness of pulling together in the crisis phase can become maladaptive and stifling for all family members in the chronic phase. An illness timeline delineates psychosocial developmental stages of an illness, each with its own unique developmental tasks. It is important for families to address normative phase-related tasks in sequence to optimize successful adaptation over the long haul of a chronic disorder.

#### THE NEW GENETICS AND AN EXTENDED ILLNESS TIMELINE

New genetic technologies are enabling physicians to test for increased risk of developing a serious and life-threatening illness before it actually occurs. This means that individuals and families now can be living with illness risk long before loved ones have developed symptoms of those illnesses (Miller et al., in press). This significantly increases the amount of time and energy families spend considering an illness and lengthens the illness timeline to include nonsymptomatic phases (Rolland & Williams, 2005). The nonsymptomatic phases are awareness, crisis I pretesting, crisis II test/posttesting, and long-term adaptation. These nonsymptomatic phases are distinguished by questions of uncertainty. Fundamental issues include: the potential amount of genetic knowledge medically available, decisions about how much of that information various family members choose to access (Street & Soldan, 1998), and living with the psychosocial impact of those choices.

For some, the nonsymptomatic crisis phase begins when predictive testing becomes available, continuing through the decision to pursue testing and initial posttesting adaptation. For others, this phase begins as individuals reach significant life cycle milestones and begin to consider testing. Sometimes, plans for having children raise fears of passing on a mutation and thus spark an interest in testing. Some women decide to be tested for hereditary breast and ovarian cancer genes when they reach an age that coincides with the age when another blood relative—a mother, aunt, or older sister—was diagnosed. During the posttesting phases, families need to accept the permanence of the genetic information. They must develop meanings that preserve their sense of competency and flexibility in the face of future uncertainty or loss (Werner-Lin, 2005).

After receiving genetic information, families may live in limbo for years in the long-term adaptation phase. Social workers can help families maintain mastery during this period by leading them to acknowledge the possibility, probability, or inevitability of loss, find meaning that transcends biological outcomes, and build family flexibility into planning that balances illness concerns with normative family developmental milestones.

The involvement of the health-care system is very different with predictive testing than with a diagnosed illness. This presents a major psychosocial challenge. Despite the enormous psychosocial impact of positive testing results, families usually have limited contact with health professionals after initial testing. This highlights the need for ongoing, family-centered, collaborative approaches to prevent isolation and fear. Families may benefit from periodic family consultations to provide emotional support, often timed with major life cycle transitions.

### CLINICAL AND RESEARCH IMPLICATIONS

The Family System-Illness Model provides a framework for assessment and clinical intervention by facilitating an understanding of chronic illness and disability in psychosocial terms. The interaction of the time phases and typology of illness provides a framework for a normative psychosocial developmental model for chronic disease that resembles models for human development. The time phases (crisis, chronic, and terminal) can be considered broad developmental periods in the natural history of a chronic disease. Attention to features of onset, course, outcome, and incapacitation provides markers that focus clinical assessment and intervention with a family. For instance, acute-onset illnesses demand high levels of adaptability, problem solving, role reallocation, and balanced cohesion. In such circumstances, helping families to maximize flexibility enables them to adapt more successfully.

This framework can help in research design. The typology and time-phase framework can facilitate research aimed to sort out the relative importance of different psychosocial variables across a spectrum of chronic disorders. Particular "psychosocial types" of disorders can be considered crudely matched as to onset, course, outcome, incapacitation, and level of uncertainty. Specific typology variables can be utilized to analyze and compare individual and family dynamics related to different conditions over time. Time phases can facilitate a methodology for longitudinal studies. Multiple observations can be spaced at intervals that correspond to different time phases.

The model is guided by awareness of the components of family functioning most relevant to particular types or phases of an illness and can therefore inform goal setting and treatment planning. Using a psychoeducational approach, social workers can work with families to create a psychosocial map, deciding on specific goals together to maximize a sense of control and realistic hope. This process empowers families in their journey of living with a chronic disorder. Also, this knowledge educates family members about warning signs that should alert them to request brief, goal-oriented treatment at the appropriate times. This framework is also useful for timing family psychosocial checkups to coincide with key transition points over the course of the illness or over the course of the individual family members' and the family's life cycles. For families with limited resources or access to psychosocial care, social workers can educate families in their limited time together about what to expect at nodal points in the illness journey to minimize future distress.

The model also informs evaluation of general functioning and illness specific family dynamics, such as the interface of the illness with individual and family development; the family's multigenerational history of coping with illness, loss, and other adversity; the family's health/illness belief system; the meaning of the illness to the family; social support, use of community resources; and the family's

capacity to manage illness-related crises or perform home-based medical care. At a larger systems level, the model provides a lens for clinicians to analyze shifts in relationships between health-care institutions, professionals, the patient, and family members.

#### PSYCHOEDUCATIONAL FAMILY GROUPS

Preventively oriented family psychoeducational or support groups for patients and their families (Gonzalez & Steinglass, 2002, Steinglass, 1998) are an increasingly utilized, cost-effective way to address illness concerns of families and can be designed to deal with different types of conditions (e.g., progressive, life-threatening, relapsing). They are generally time limited, meeting weekly or biweekly for four to eight sessions. Brief psychoeducational modules, timed for critical phases of particular "types" of diseases, enable families to digest manageable portions of a long-term coping process. Modules can be tailored to particular phases of the illness and to family coping skills necessary to confront disease-related demands. This provides a cost-effective preventive service aimed at identifying high-risk families.

Grounded in a family systems-based psychoeducational framework, these groups bring together families facing conditions with similar psychosocial demands. The goals of psychoeducational family groups are to help families cope as a team with the continued demands of chronic illness, to mobilize the ill individuals' natural support networks, and to reduce the negative effects of both normative and illness-related family stressors. In other words, "finding a place for the illness in the family while at the same time keeping the illness in its place" (Gonzalez et al., 1989, p. 80). This is achieved by providing informational support through collaboration with health-care providers, social networking, and skill building.

These groups emphasize a resilience perspective, focusing on family strengths and the development of positive coping techniques and problem-solving skills. This allows families to minimize negative and pathologizing views about their adaptation to illness management. Finally, the intervention addresses the needs of all family members, giving each participant the opportunity to voice concerns and to form cross-family alliances with others in similar family roles (Gonzalez & Steinglass, 2002; Steinglass, 1998). Social workers facilitating such groups may use tools such as social skills and problem-solving training, practicing these skills during group sessions, and encouraging families to bring their experiences with these skills back to the group for consideration.

#### FAMILY ASSESSMENT

As chronic illnesses become incorporated into the family system and all its processes, coping is influenced by illness-oriented family dynamics that concern the dimension of time and belief systems.

#### MULTIGENERATIONAL LEGACIES OF ILLNESS, LOSS, AND CRISIS: CONSTRUCTING A GENOGRAM

A family's current behavior, and therefore its response to illness, cannot be adequately understood apart from its history (Boszormenyi-Nagy & Spark, 1973; Bowen, 1978; Byng-Hall, 1995; Carter & McGoldrick, 1998; Framo, 1992; Walsh & McGoldrick, 2004). Social workers can use historical questioning and construct

genograms, or detailed family trees and timelines to track nodal events and transitions (McGoldrick, Gerson, & Schellenberger, 1999; see Appendix). This process helps clinicians gain an understanding of a family's organizational shifts and coping strategies as a system in response to past stressors, and, more specifically, to past illnesses. Such inquiry helps explain and predict the family's current style of coping, adaptation, and creation of meaning. A multigenerational assessment helps to clarify areas of strength and vulnerability. It also identifies high-risk families burdened by past unresolved issues and dysfunctional patterns that prevent families from adequately addressing the challenges presented by a serious condition.

A genogram oriented toward illness focuses on how a family organized around past stressors and tracks the evolution of family adaptation over time. It focuses on how a family organized itself as an evolving system, specifically around previous illnesses and unexpected crises. A central goal is to bring to light areas of consensus and "learned differences" that are sources of cohesion and conflict. Patterns of coping, replications, discontinuities, shifts in relationships, and sense of competence are noted. These patterns can be transmitted across generations as family pride, myths, taboos, catastrophic expectations, and belief systems (Walsh & McGoldrick, 2004). In one case involving a couple where the husband was diagnosed with basal cell carcinoma, the oncologist discussed a favorable prognosis. In spite of this reassurance, the wife believed her husband would die from this skin cancer. This resulted in increased marital discord and ultimately a couple's consultation. In the initial interview, when asked about prior experiences with illness and loss, the wife revealed that her own father had died tragically of a misdiagnosed malignant melanoma. This woman had a catastrophic fear based on both sensitization to cancer (particularly any related to the skin) and the possibility of human error by health professionals. Had the oncologist inquired about prior experiences at the time of diagnosis, earlier intervention would have been facilitated.

It is also useful to inquire about other forms of loss (e.g., divorce, migration), crisis (e.g., lengthy unemployment, rape, natural disaster), and protracted adversity (e.g., poverty, racism, war, political oppression). These experiences can provide transferable sources of resilience and effective coping skills in the face of a serious health problem (Walsh, 1998).

*Illness Type and Time Phase Issues* Whereas a family may have certain standard ways of coping with any illness, there may be critical differences in their styles and success in adaptation to different "types" of diseases. In a social work assessment, it is important to track prior family illnesses for areas of perceived competence, failures, or inexperience. Inquiry about experiences with different types of illness (e.g., life-threatening versus nonlife-threatening) may illustrate, for instance, that a family dealt successfully with nonlife-threatening illnesses, but reeled under the weight of metastatic cancer. Such a family might be well equipped to deal with less severe conditions but be particularly vulnerable to the occurrence of another life-threatening illness. Some families may lack familiarity with chronic illness. The following case consultation highlights the importance of family history in uncovering areas of inexperience.

### **Case Example**

Joe, his wife Ann, and their three teenage children presented for a family evaluation 10 months after Joe's diagnosis with severe asthma. Joe, aged 44, had been success-

fully employed for many years as a spray painter. Apparently, exposure to a new chemical triggered the onset of asthmatic attacks that necessitated hospitalization and occupational disability. Although somewhat improved, he continued to have persistent, moderately severe respiratory symptoms. Initially, his physicians had predicted that improvement would occur, but remained noncommittal as to the level of chronicity to be expected. Continued breathing difficulties contributed to increased symptoms of depression, uncharacteristic temperamental outbursts, alcohol abuse, family discord, and finally admission to an alcohol detoxification unit. In the initial assessment, after his discharge to outpatient psychiatric treatment, the social worker inquired as to the family's prior illness experience. This was the nuclear family's first encounter with chronic illness, and their families of origin had limited experience. Ann's father had died 7 years earlier of a sudden and unexpected heart attack. Joe's brother had died in an accidental drowning. Neither had experience with disease as an ongoing process. Joe had assumed that improvement meant "cure." In addition, Joe had a history of alcoholism that had been in remission for 20 years. Illness for both Joe and his wife had meant either death or recovery. The physician/family system was not attuned to the hidden risks for this family coping with the transition from the crisis to the chronic phase of his asthma, the juncture where the permanency of the disease needed to be addressed.

Tracking a family's coping capabilities in the crisis, chronic, and terminal phases of previous chronic illnesses highlights legacies of strength as well as complications in adaptation related to different points over the course of the illness. One man grew up with a partially disabled father with heart disease and witnessed his parents successfully renegotiate traditional gender-defined roles when his mother went to work while his father assumed household responsibilities. This man, now with heart disease himself, has a positive legacy about gender roles from his family of origin that facilitated a flexible response to his own illness.

Another family with a member suffering from chronic kidney failure functioned very well in handling the practicalities of home dialysis. However, in the terminal phase, their limitations with emotional expression left a legacy of unresolved grief. Tracking prior illness experiences in terms of time phases helps clinicians see both the strengths and vulnerabilities of a family, which counterbalances the assignment of dysfunctional labels. Social workers need to ask specifically about positive family-of-origin experiences with illness and loss that can be highlighted as family successes and used as models to adapt to the current situation.

While many families facing chronic disease have healthy multigenerational family patterns of adaptation, any family may falter in the face of multiple superimposed disease and nondisease stressors that occur in a relatively short period of time. With progressive, incapacitating diseases or the concurrence of illnesses in several family members, a pragmatic approach that focuses on expanded or creative use of supports and resources outside the family is most productive.

#### INTERFACE OF THE ILLNESS, INDIVIDUAL, AND FAMILY LIFE CYCLES

Addressing the impact of the illness over the life span provides a powerful way to construct a normative framework for serious illness. Individual and family life-cycle perspectives address development over time in discrete phases, each with expectable challenges to be mastered sequentially before continuing on to the

next phase. Illness frequently disrupts these normative challenges as family resources are directed toward illness management and treatment. To place the unfolding of chronic disease into a developmental context, it is crucial to understand the intertwining of three evolutionary threads: the illness, individual, and family development (see Rolland, 1987, 1994a).

#### INDIVIDUAL AND FAMILY DEVELOPMENT

It is essential to consider the interaction of individual and family development. A chronic disorder influences the development of the affected person and various family members in distinct ways depending on a number of factors, including age of onset of the illness, the core commitments in the affected person and each family member's life at that time, and the stage of the family life cycle. Life-cycle models can facilitate thinking proactively about the timing and nature of strains on the family unit and each member over the course of a major health problem.

*Life cycle* and *life structure* are central concepts for both family and individual development. Life cycle means there is a basic sequence and unfolding of the life course within which individual, family, or illness uniqueness occurs. Life structure refers to the core elements (e.g., work, childrearing, caregiving) of an individual's or family's life at any phase of the life cycle.

Illness, individual, and family development have in common the notion of phases, each with its own developmental challenges. Carter and McGoldrick (1998) have divided the family life cycle into six phases, where marker events (e.g., marriage, birth of first child, adolescence, children leaving home) herald the transition from one phase to the next. Also, the family life cycle can be viewed as oscillating between phases where family developmental tasks require intense bonding or relatively higher cohesion (e.g., early child rearing versus phases such as families with adolescents), during which time the external family boundary is loosened, often emphasizing personal identity and autonomy (Combrinck-Graham, 1985). Levinson (1986), in his description of individual adult development, describes how individuals' and families' life structures can move between periods of life structure transition and building/stability. Transition periods are sometimes the most vulnerable because previous individual, family, and illness life structures are reappraised in light of new developmental tasks that may require major discontinuous change rather than minor alterations. The primary goal of a life structure building/maintaining period is to form a life structure and enrich life within it based on the key choices an individual/family made during the preceding transition period.

These unifying concepts provide a base to think about the fit among illness, individual, and family development. Each phase in these three kinds of development pose tasks and challenges that move through periods of being more or less in sync with each other. The model distinguishes (a) the phases of the family life cycle, particularly the kind and degree of cohesion required; (b) the alternation of transition and life structure building/maintaining periods in the family and individual life cycles; and (c) periods of higher and lower psychosocial demands, requiring relatively greater and lesser degrees of family cohesion over the course of a chronic condition.

Generally, illness and disability tend to push individual and family developmental processes toward transition and increased cohesion. Analogous to the ad-



dition of a new family member, illness onset sets in motion an inside-the-family-focused process of socialization to illness. Symptoms, loss of function, the demands of shifting or acquiring new illness-related roles, and the fear of loss through death all require a family to focus inward.

The need for family cohesion varies enormously with different illness types and phases. The tendency for a disease to pull a family inward increases with the level of disability or risk of progression and death. Progressive diseases over time inherently require a greater cohesion than constant course illnesses. The ongoing addition of new demands as an illness progresses keeps a family's energy focused inward, often impeding or halting the natural life-cycle evolution of other members. After an initial period of adaptation, a constant-course disease (without severe disability) permits a family to get back on track developmentally. Relapsing illnesses alternate between periods of drawing a family inward and periods of release from immediate demands of disease. But the on-call nature of many such illnesses keeps part of the family focus inward despite asymptomatic periods, hindering the natural flow between phases of the family life cycle.

With major health conditions, definitions concerning normative family structure should be reconsidered. Enmeshment with blurred generational boundaries is touted as the hallmark of family dysfunction. Yet, the very real demands on older children and adolescents to assume adult functions in the interest of family survival must be distinguished from rigid pathological descriptions of "parentified" children. For instance, when a parent develops a serious disorder during a child-rearing phase of development, a family's ability to stay on course is most severely taxed. The impact is twofold: A new family burden is added as a parent is "lost." To meet simultaneous child-rearing and caregiving needs, an older child or grandparent may need to assume parental responsibilities. These forms of family adaptation are appropriate, if structural realignments are flexible, shared, and sensitive to competing age-related developmental needs. Frequently, however, family or cultural dictates put children, especially girls, in highly responsible roles before it is developmentally appropriate to do so. Social workers can help families set up culturally appropriate structures that do not overburden any one family member by naming expectations and helping families delegate tasks across a number of participating family members. Social workers can also aid families in enlisting neighbors, community members, and religious congregations in aiding families during particularly challenging times.

In clinical assessment, a basic question is: What is the fit between the psychosocial demands of a condition and family and individual life structures and developmental tasks at a particular point in the life cycle? Also, how will this fit change as the course of the illness unfolds in relation to the family life cycle and the development of each member?

From a systems viewpoint, at the time of diagnosis it is important to know the phase of the family life cycle and the stage of individual development of all family members, not just the ill member. Chronic disease in one family member can profoundly affect developmental goals of another member. For instance, an infant disability can be a serious roadblock to parents' preconceived ideas about competent child rearing, or a life-threatening illness in a young married adult can interfere with the well spouse's readiness to become a parent. Also, family members frequently do not adapt equally to chronic illness. Each member's ability to adapt, and the rate at which he or she does so, is related to his or her own developmental

stage and role in the family. When family members are in tune with each other's developmental processes, while promoting flexibility and alternative means to satisfy developmental needs, successful long-term adaptation is maximized.

By adopting a longitudinal developmental perspective, a clinician will stay attuned to future developmental transitions. Imagine a family in which the father (a carpenter) and primary financial provider has a heart attack. Dad's rehabilitation is uneventful, includes appropriate life-style modifications, and a return to work. The oldest son, aged 15, seems relatively unaffected. Two years later, his father experiences a second heart attack, leaving him disabled. His son, now 17, has dreams of going away to college. The specter of financial hardship and the perceived need for a "man in the family" creates a serious dilemma of choice for the son and the family, which surfaces with precipitously declining academic performance and alcohol abuse. In this case, there is a fundamental clash between developmental issues of separation/individuation and the ongoing demands of a progressive, life-threatening type of heart disease on the family. Further, there is a resurgence of fears of loss fueled not only by the recurrence, but also its timing with a major life-cycle transition for the oldest son. The son may fear that if he were to move away, he might never see his father alive again. This case demonstrates the potential clash between simultaneous transition periods: the illness transition to a more disabling, progressive, and life-threatening course; the adolescent son's transition to early adulthood; and the family's transition from the "living with teenagers" to "launching young adults" stage. At the time of initial diagnosis, inquiry about anticipated major transitions over the next 3 to 5 years and discussing them in relation to the specific kind of heart disease and its related uncertainties would help avert a future crisis.

The timing of chronic illness in the life cycle can be normative (e.g., expectable in relation to chronological and social time) or nonnormative (e.g., "off-time"). Coping with chronic illness and death are considered normally anticipated tasks in late adulthood, whereas their occurrence earlier is out of phase and developmentally more disruptive (Neugarten, 1976). For instance, chronic diseases that occur during the child-rearing period can be most challenging because of their potential impact on family financial and child-rearing responsibilities. The actual impact will depend on the "type" of illness and pre-illness family roles. Families governed by flexible gender-influenced rules about who is the financial provider and caregiver of children will tend to have an easier adjustment.

When a parent develops a major health condition during the child-rearing phases of the life cycle, a family's ability to stay on course is severely taxed. For more serious and debilitating diseases, such as a stroke, the impact of the illness is like the addition of a new infant member, one with "special needs" who will compete with those of the other children for potentially scarce family resources that are diminished by parental loss. Moreover, in two-parent families, the well parent must juggle child rearing demands with caregiving of a spouse (Rolland, 1994b).

With chronic disorders, an overarching family goal is to deal with the developmental demands of the illness without family members sacrificing their own or the family's development as a system over time. It is important to determine whose life plans were cancelled, postponed, or altered and when plans put on hold and future developmental issues will be addressed. In this way, clinicians can anticipate life-cycle nodal points related to "autonomy within" versus "subju-

gation to" the condition. Family members can be helped to strike a healthier balance with life plans that resolve feelings of guilt, over responsibility, and hopelessness and find family and external resources to enhance freedom, both to pursue personal goals and provide needed care for the ill member.

### HEALTH/ILLNESS BELIEF SYSTEM

When illness strikes, a primary developmental challenge for families is to create meaning for the illness experience that promotes a sense of mastery and competency (Kleinman, 1988; Rolland, 1987b, 1994a, 1997; Wright, Watson, & Bell, 1996; Wynne, Shields, & Sirkin, 1992). Since serious illness is often experienced as a betrayal of fundamental trust in our bodies and belief in our invulnerability (Kleinman, 1988), creating an empowering narrative can be a formidable task. Family health beliefs help us grapple with the existential dilemmas of our fear of death, tendency to want to sustain our denial of death, and attempts to reassert control when suffering and loss occur. They serve as a cognitive map guiding decisions and action, and provide a way to approach new and ambiguous situations for coherence in family life, facilitating continuity between past, present, and future (Antonovsky & Sourani, 1988; Reiss, 1981). Inquiry into and curiosity about family beliefs is perhaps the most powerful foundation stone of collaboration between families and health professionals (Rolland, 1998; Wright, Watson, & Bell, 1996). There is growing research evidence that family members' distress about a disease, such as cancer, can be more closely associated to perceived risk or appraisals of seriousness than objective characteristics of the disease (Miller, 1995; Thompson & Kyle, 2000).

In the initial crisis phase, it is essential for clinicians to inquire about key family beliefs that shape the family's narrative and coping strategies. This inquiry includes tracking (a) beliefs about normality and mind-body relationship, control, and mastery; (b) assumptions about what caused an illness and what will influence its course and outcome; (c) meanings attached by a family, ethnic group, religion, or the wider culture to symptoms (e.g., chronic pain; Griffith & Griffith, 1994; McGoldrick, Pearce, & Garcia-Preto, 2005), types of illnesses (e.g., life threatening), or specific diseases (e.g., AIDS); (d) multigenerational factors that have shaped a family's health beliefs; and (e) anticipated nodal points in the illness, individual, and family life cycles when health beliefs are strained or need to shift. A clinician should also assess the congruence of health beliefs within the family and its various subsystems (e.g., spouse, parental, extended family) as well as between the family and the health-care system and wider culture.

### BELIEFS ABOUT NORMALITY

Family beliefs about what is normal or abnormal, and the importance members place on conformity and excellence in relation to the average family, have far-reaching implications for adaptation to chronic disorders. Family values that allow having a "problem" without self-denigration have a distinct advantage, enabling one to seek outside help and yet maintain a positive identity in the face of chronic conditions. Families who define help seeking as weak and shameful undercut this kind of resilience. Essentially, with chronic disorders, in which problems are to be expected and the use of professionals and outside resources are

necessary, a belief that pathologizes this normative process can be seen as adding insult to injury.

Two excellent questions that can be used to elicit these beliefs are, "How do you think other average families would deal with a similar situation to yours?" and, "How would a healthy family ideally cope with your situation?" Families with strong beliefs in high achievement and perfectionism are prone to apply standards in a situation of illness in which the kind of control they are accustomed to is impossible. Particularly with untimely conditions that occur early in the life cycle, there are additional pressures to keep up with normative socially expectable developmental milestones of age peers or other young couples. The fact that life-cycle goals may take longer to achieve than anticipated or need revision requires a flexible belief about what is normal and healthy. To effectively sustain hope, particularly in situations of long-term adversity, families need to embrace a flexible definition of normality.

#### MIND-BODY RELATIONSHIPS

Varied conceptualizations of the mind-body relationship have been the subject of discourse and debate for millennia. Traditional mental health theories and research endeavors have been pathology based, tending to emphasize character traits or emotional states that affect body chemistry adversely. From this perspective, emotions can be seen to affect the body negatively, but possible positive influences of healthy attitudes are overlooked. More recently, the public has been increasingly drawn to popular literature citing the importance of positive attitudes in healing, emphasizing the unity of mind and body. They describe healing as a state of being, involving mind *and* body, rather than in strictly biomedical terms where something is done *to* the body. Social workers must be particularly mindful that families may be more familiar with and open to the positive possibilities as a powerful source of healing.

As social workers assess family beliefs about illness, it is useful to distinguish beliefs about the mind as a logical, thinking process that can determine actions that may help in healing the body (e.g., seeking medical care, changing diet or activity patterns) from those of the mind as a source of thought or energy that can directly impact body physiology. These beliefs about mind and spirit often extend beyond the individual to include family, community, or a higher spiritual force. Anthropologists have found tremendous diversity in the role of family, community, God, or nature as a source of healing. Such beliefs are typically expressed in the form of rituals. In our society, for example, a family's religious community will often organize a prayer service to promote healing for an ill member.

#### THE FAMILY'S SENSE OF MASTERY FACING ILLNESS

It is important to determine how a family defines mastery or control in general and in situations of illness (Taylor et al., 1991; Thompson & Kyle, 2000). Mastery is similar to the concept of *health locus of control* that indicates beliefs about influence over the course/outcome of an illness (Lefcourt, 1982). It is useful to distinguish whether a family's beliefs are based on the premise of internal control, external control by chance, or external control by powerful others.

Families with an internal locus of control believe they can affect the outcome of a situation. In illness, such families believe they have direct control of their health and have the power to recover from illness (Wallston & Wallston, 1978). An external orientation entails a belief that outcomes are not contingent on the individual's or family's behavior. Families that view illness in terms of chance believe that illness occurs as a matter of luck and that fate determines recovery. Those who see health control as in the hands of powerful others view health professionals, God, or sometimes powerful family members as exerting control over their bodies and illness course.

Family beliefs about mastery strongly affect each member's relationship with the illness and the health-care system, impacting compliance and preferences about family participation in treatment and healing processes. Families that view a disease's course/outcome as a matter of chance tend to establish marginal relationships with health professionals largely because their belief system minimizes the importance of their own or the professional's impact on a disease process. Also, families of lower socioeconomic statuses may receive inadequate care or lack insurance or access leading to a fatalistic attitude and lack of engagement with health-care providers who may not be trusted to help. Just as any psychotherapeutic relationship depends on a shared belief system about what is therapeutic, a workable accommodation among the patient, family, and health-care team in terms of these fundamental values is essential. Families that feel misunderstood by health professionals are often reacting to a lack of joining at this basic value level. Too often their healthy need to participate was ignored or preempted by a professional needing unilateral control (Rolland, 1998).

A family may adhere to a different set of beliefs about control when dealing with physical illness as opposed to typical day-to-day issues. Therefore, it is important to assess both a family's basic value system and beliefs about control for illnesses in general, chronic, and life-threatening illness, and finally the specific disease facing the family. For instance, regardless of the actual severity or prognosis in a particular case, cancer may be equated with death or a lack of control because of medical statistics, cultural myth, or prior family history. Alternatively, families may have enabling stories about a member or friend who, in spite of cancer and a shortened life span, lived a "full" life centered on effectively prioritizing the quality of relationships and goals. Clinicians can highlight these positive narratives as a means to help families counteract cultural beliefs that focus exclusively on control of biology as defining success.

The goodness of fit between family beliefs about mastery can vary dependent on the time phase of the condition. For some conditions, the crisis phase involves protracted medical interventions outside the family's direct control. This may be stressful for a family that prefers to tackle its own problems without outside control and "interference." The patient's return home may increase the workload but allow members to reassert more fully their competence and leadership. In contrast, a family guided more by a preference for external control by experts can expect greater difficulty when their family member returns home. Recognition of such normative differences in belief about control can guide an effective psychosocial treatment plan tailored to each family's needs and affirming rather than disrespecting their core values.

Social workers must be cautious about judging the relative denial or acceptance of painful realities. Often both are needed. The healthy use of minimization, or

selective focus on the positive, and timely uses of humor should be distinguished from denial. The skilled social worker must support both the usefulness of exaggerated hope and the need for treatment to control the illness or a new complication. There is greater incentive for a family to confront denial when there is hope that preventive action or medical treatment can affect the outcome or when an illness is entering its terminal phase. Yet, to cope with an arduous, uncertain course, families often need simultaneously to acknowledge the condition while minimizing treatment risks or the likelihood of a poor outcome.

#### FAMILY BELIEFS ABOUT THE CAUSE OF AN ILLNESS

When a significant health problem arises, it is natural to wonder, "Why me (or us)?" and "Why now?" (Lowery, Jacobsen, & Ducette, 1993; Taylor, 1983). We almost invariably construct an explanation or story that helps organize our experience. With limits of current medical knowledge, tremendous uncertainties persist about the relative importance of myriad factors leaving individuals and families to make idiosyncratic attributions about what caused an illness (Lewis & Daltroy, 1990). A family's beliefs about the cause of an illness should be assessed separately from its beliefs about what can affect the outcome. It is important to elicit each family member's explanation. Responses will generally reflect a combination of medical information and family mythology. Beliefs might include punishment for prior misdeeds (e.g., an affair), blame of a particular family member ("Your drinking made me sick!"), a sense of injustice ("Why am I being punished, I have been a good person"), genetics (e.g., cancer runs on one side of the family), negligence by the patient (e.g., careless driving) or by parents (e.g., sudden infant death syndrome), or simply bad luck.

Highly adaptive family narratives respect the limits of scientific knowledge, affirm basic competency, and promote the flexible use of multiple biological and psychosocial healing strategies. In contrast, causal attributions that invoke blame, shame, or guilt make it extremely difficult for a family to cope and adapt in a functional way. With a life-threatening illness, a blamed family member is implicitly, if not explicitly, held accountable if the patient dies. Decisions about treatment then become confounded and filled with tension. A husband who believes his drinking caused his wife's coronary and subsequent death may increase self-destructive drinking because of his profound guilt. A mother who secretly blames herself for their daughter's leukemia may be less able to stop a low-probability experimental treatment than the husband who sees further treatment as causing additional suffering to their terminally ill child (see Box 11.1).

#### BELIEF SYSTEM ADAPTABILITY

Because illnesses vary enormously in their responsiveness to psychosocial factors, both families and providers need to make distinctions between beliefs about their overall participation in a long-term disease process, their beliefs about their ability to control the biological unfolding of an illness, and the flexibility with which they can apply these beliefs. Families' experience of competence or mastery depends on their grasp of these distinctions. Optimal family and provider narratives respect the limits of scientific knowledge, affirm basic competency, and promote the flexible use of multiple biological and psychosocial healing strategies.



**Box 11.1**  
**Family Beliefs about Cause of Illness**

Lucy and Tom G., a young couple, have a child Susan, aged 5, who is terminally ill with leukemia. The pediatric oncologist offered the parents the choice between an experimental treatment with a low probability of success or halting treatment. Tom's position was "Let's stop; enough is enough." Lucy, on the other hand, felt, "We must continue; we can't let her die." The couple could not reach an agreement and the physician was immobilized. He requested a social work consultation for the couple.

When the consultant asked, "What is your explanation of how your daughter got leukemia?" the critical story emerged. Tom basically saw it as bad luck. Lucy, however, had a very different belief. During her pregnancy with Susan, Lucy's father had a heart attack and died several months later from a second episode. Lucy experienced this as a time of great stress and grief, which she felt adversely affected Susan's intrauterine life. After Susan's birth by normal delivery, Lucy was still mourning the loss of her father and felt that this affected the quality of her bonding with Susan and led to a hidden depression in her infant. Further, Lucy had read research linking depression with a lowering of the effectiveness of the immune system, which could, in turn, decrease normal surveillance and clearing of cancer cells from the body. She believed this combination of factors caused her child's cancer and that if she had been a more competent mother, this never would have happened. Lucy said she had never told this story to anyone, because no one had ever asked, and she was very ashamed. She had hoped for a cure, so that the whole issue could be resolved. She could not accept stopping treatment because, to her, it meant that Susan's death would then be her fault.

A family's belief in their participation in the total illness process can be thought of as independent from whether a disease is stable, improving, or in a terminal phase. Sometimes, mastery and the attempt to control biological process coincide, as when a family tailors its behavior to help maintain the health of a member with cancer in remission. This might include changes in family roles, communication, diet, exercise, and balance between work and recreation. Optimally, when an ill family member comes out of remission and as the family enters the terminal phase of the illness, participation as an expression of mastery is transformed to a successful process of letting go that eases suffering and allows palliative care to be provided.

Families with flexible belief systems are more likely to experience death with a sense of equanimity rather than profound failure. The death of a patient whose long, debilitating illness has heavily burdened others can bring relief as well as sadness to family members. Since relief over death goes against societal conventions, it can trigger massive guilt reactions that may be expressed through such symptoms as depression and family conflict. Clinicians need to help family members accept ambivalent feelings they may have about the death as natural.

Thus, flexibility both within the family and the health professional system is a key variable in optimal family functioning. Rather than linking mastery in a rigid way with biological outcome (survival or recovery) as the sole determinant of success, families can define control in a more "holistic" sense with involvement and participation in the overall process as the main criteria defining success. This is analogous to the distinction between curing "the disease" and "healing the

system." Healing the system may influence the course and outcome, but a positive disease outcome is not necessary for a family to feel successful. This flexible view of mastery permits the quality of relations within the family or between the family and health professional to become more central to criteria of success. The health provider's competence becomes valued from both a technical and caregiving perspective not solely linked to the biological course (Reiss & Kaplan-DeNour, 1989).

#### ETHNIC, RELIGIOUS, AND CULTURAL BELIEFS

Ethnicity, race, and religion strongly influence family beliefs concerning health and illness (McGoldrick, Pearce, & Garcia-Preto 2005; Walsh, 1999; Zborowski, 1969). Significant ethnic differences regarding health beliefs typically emerge at the time of a major health crisis. Health professionals need to be mindful of the belief systems of various other ethnic, racial, and religious groups in their community, particularly as these translate into behavioral patterns that differ from their own. Cultural norms vary in such areas as the definition of the appropriate "sick role" for the patient, the kind and degree of open communication about the disease, who should be included in the illness caregiving system (e.g., extended family, friends, professionals), who is the primary caretaker (almost always the wife, mother, daughter, or daughter-in-law), and the kind of rituals viewed as normative at different stages of an illness (e.g., hospital bedside vigils, healing, and funeral rituals). This is especially true for numerical minority groups (e.g., African American, Asian American, and Hispanic American) who experience discrimination or marginalization from the prevailing White American culture. Illness provides an opportunity to encourage role flexibility and shift from defining one female member as the caregiver to a collaborative caregiving team that includes male and female siblings/adult children.

Clinicians need to be mindful of cultural differences between themselves, the patient, and the family as a necessary step to forging a workable alliance that can endure a long-term illness (Seaburn, Gunn, Mauksch, Gawinski, & Lorenz, 1996). Disregarding these issues can lead families to distance themselves from health providers and available community resources, which is a major cause of noncompliance and treatment failure. Accepting that the patient retains final responsibility for decisions about his or her body requires a strong commitment to the core social work value of self-determination.

#### FIT AMONG HEALTH-CARE PROVIDER, HEALTH SYSTEM, AND FAMILY BELIEFS

It is a common but unfortunate error to regard "the family" as a monolithic unit that feels, thinks, believes, and behaves as an undifferentiated whole. Social workers should inquire both about the level of agreement and tolerance for differences among family members' beliefs and between the family and health-care system. Is the family rule: "We must agree on all/some values," or are diversity and different viewpoints acceptable? To what degree does the family feel the need to stay in sync with prevailing cultural or societal beliefs, or with family tradition?

Family beliefs that balance the need for consensus with diversity and innovation are optimal and maximize permissible options. If consensus is the rule, then individual differentiation implies disloyalty and deviance. If the guiding princi-

ple is "We can hold different viewpoints," then diversity is allowed. This is adaptive because it facilitates the use of novel and creative forms of problem solving that may be needed in a situation of protracted adversity, such as serious illness. Social workers can facilitate open communication and effective conflict resolution when members differ on major health-care/treatment decisions.

The same questions are relevant to the fit between the family, social worker, and health-care team. What are their attitudes about their own and the family's ability to influence the course/outcome of the disease? How does the health-care team see the balance between their participation in the treatment process and the family's involvement? If basic differences in beliefs about control exist, how can these differences be reconciled? These questions will inform the types of interventions social workers employ to help families facing chronic and terminal illness.

It is common for differences in beliefs or attitudes to erupt during any major life cycle or illness transition. For instance, in situations of severe disability or terminal illness, one member may want the patient to return home, whereas another prefers long-term hospitalization or transfer to an extended care facility. Since the chief task of patient caretaking is usually assigned to the wife/mother, she is the one most apt to bear the chief burdens in this regard. A family able to anticipate the collision of gender-based beliefs about caregiving with the potential overwhelming demands of home-based care for a dying family member and flexibly modify its rules would avert the risk of family caretaker overload, resentment, and deteriorating family relationships.

The murky boundary between the chronic and terminal phase highlights the potential for professionals' beliefs to collide with those of the family. Physicians can feel bound to a technological imperative that requires them to exhaust all possibilities at their disposal, regardless of the odds of success. Families may not know how to interpret continued life-saving efforts, assuming real hope where virtually none exists. Health-care professionals and institutions can collude in a pervasive societal wish to deny death as a natural process truly beyond technological control (Becker, 1973). Endless treatment can represent the medical team's inability to separate a general value placed on controlling diseases from their beliefs about participation (separate from cure) in a patient's total care.

#### CHALLENGES IN IMPLEMENTATION OF FAMILY-BASED RESEARCH

Interventions for families facing medical illness are currently being implemented in a number of settings, including hospitals, community health and mental health clinics, hospices, and wellness organizations (Campbell, 2003). It is important that social workers base the development of interventions on the best available research knowledge. A major challenge for family intervention research is the need to further develop research methods and protocols that demonstrate the relationship of family system dynamics to health-care outcomes and cost containment (Wiehs, Fisher, & Baird, 2002).

Despite advances in evidence-based knowledge, significant challenges persist, however, for conducting such systematic and rigorous intervention research (Kazak, 2002). Often, implementation of family-centered biopsychosocial research is more difficult in health-care settings (e.g., hospitals) focused primarily on the treatment and management of the diseased individual. While psychosocial

care may improve family functioning, this might not be the established goal of medical settings or health insurance corporations, both of which are concerned with biomedical cure and controlling costs. Family-based interventions, such as multifamily discussion groups (McFarlane, 2002) and collaborative family-oriented primary and tertiary care (McDaniel et al 2005; Weihs, Fisher, & Baird, 2002), have proven effective in health-care settings to: (a) promote patient and family coping and adaptation; (b) reduce medical and psychiatric morbidity for all family members; (c) contain overall health-care costs; and (d) facilitate collaboration between families and health care teams to increase treatment compliance. Despite this data, these interventions are rarely offered as part of routine care.

In the era of managed health care, evidence-based practice highlighting positive outcomes is essential in social work's fight to maintain a clear and integrated presence in hospitals and medical settings. By illustrating how family-based interventions facilitate illness management, ease the burden on health-care teams, and are cost-effective, social workers can join with other health-care professionals to advocate for collaborative models of health care that include such interventions as part of standard practice. Social workers can carve a unique niche for themselves in medical settings by working collaboratively to fill these methodological and clinical gaps and by conducting sound intervention research.

## CONCLUSION

Facing the risks and burdens of chronic illness or disability, the "healthiest" families are able to harness that experience to improve the quality of life. Families can achieve a healthy balance between accepting limits and promoting autonomy. For conditions with long-range risks, families can maintain mastery in the face of uncertainty by enhancing the following capacities: acknowledge the possibility of loss, sustain hope, and build flexibility into family life-cycle planning that conserves and adjusts major goals and helps circumvent the forces of uncertainty.

A serious illness, such as cancer, or a brush with death provides an opportunity to confront catastrophic fears about loss. This can lead to family members developing a better appreciation and perspective on life that results in clearer priorities and closer relationships. Seizing opportunities can replace procrastination for the "right moment" or passive waiting for the dreaded moment. Major health conditions, by emphasizing life's fragility and preciousness, provide families with an opportunity to heal unresolved issues and develop more immediate, caring relationships. For diseases in a more advanced stage, clinicians should help families emphasize quality of life by defining goals that are attainable more immediately and that enrich their everyday lives.

As the new era of genetics unfolds, families and clinicians are facing unprecedented complex clinical and ethical challenges (Miller, McDaniel, Rolland, & Feetham, in press). Families will increasingly be able to choose genetically informed knowledge of their future health risks or fate. Some key questions include: Which individuals and families will benefit by genetic risk screening and knowledge of their health risks or fate? How can we best help family members reach decisions about whether to pursue predictive testing? Who are the relevant family members to include in these decisions? Spouses or partners? Extended family? Our societal fixation on "the perfect healthy body" could meld seamlessly with technology and eugenics, forcing families living with disability, ill-

ness, or genetic risk to further hide their suffering in order to demonstrate the value of their lives and avoid increased stigmatization (Rolland, 1997, 1999).

Also, clinicians need to consider their own experiences and feelings about illness and loss (McDaniel, Hepworth, & Doherty, 1997). Awareness and ease with our own multigenerational and family history with illness and loss, our health beliefs, and our current life-cycle phase will enhance our ability to work effectively with families facing serious illness.

Living well with the strains and uncertainties of illness can be a monumental challenge. The Family Systems-Illness model offers a way to address this challenge and make the inevitable strains more manageable. Attending to the psychosocial demands of different kinds of conditions over time within a multigenerational, life cycle, and belief system context can provide a strength-based framework—a common language that facilitates collaborative, creative problem solving and quality of life for families facing illness, disability, and loss.

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## SUGGESTED LEARNING EXERCISES

### Case 11.1

You are called by the head nurse for the ICU to intervene with a patient and his mother who were disrupting the unit because the mother insists on staying at her son's bedside. The ICU's customary rules limit family visits to 10 minutes. The patient, Stavros, aged 42, was admitted with symptoms of intractable angina. He is first-generation Greek American, married for 15 years to Dana, who is from a Scandinavian background. A long-standing smoldering triangular conflict has existed for the couple in terms of Stavros's divided loyalties between his strong relationship to his family of origin, particularly his mother, and to his spouse. On admission, his mother began a 24-hour vigil by her son's hospital bed. Dana greatly resents her mother-in-law's seemingly intrusive behavior. Stavros's mother is critical of what she perceives as Dana's emotional coldness and relative lack of concern. Stavros feels caught between his warring mother and wife and complains of increased symptoms.

1. Thinking in terms of different ethnic traditions of the family members, including your own, how would you react to this case? Thinking systemically, how would you approach a consultation with the patient/family?
2. Thinking in terms of the intersection of three distinct belief systems—your work setting (hospital and ICU), yourself as a social worker, and your personal cultural/ethnic/family values, how might these affect your strategy in this case? What biases might interfere with your effectiveness? How could you avoid taking sides?

### Case 11.2

Mrs. L. tells you that she is concerned that her daughter Janice, aged 5, has been compulsively masturbating for the past 3 months and that it is an indication of sexual abuse. When the child assessment reveals no evidence of abuse, you in-

quire about other recent stressful events in the family. Only at that point does the mother reveal that her husband had a subtotal gastrectomy 9 months ago because of stomach cancer, and that 3 months earlier he had been rehospitalized for further tests that proved inconclusive. When Mrs. L. is asked what the children have been told, she reports that, after her husband's surgery, they had told the children only that "Daddy had a tummy ache, so the doctors removed Daddy's stomach so he'd feel better." Mrs. L. reveals that she herself worries constantly about her husband's condition, but that he won't come in to see the doctor and won't discuss his problems, stating that after the surgery, "He was adamant that he did not want ever to talk about it. He went back to work almost immediately and insisted that everything is fine." Asked if this medical crisis had any impact on the children, especially Janice, she replies, "Well, she doesn't tell me about any worries, but now that you ask, at dinner every night, when we say grace, Janice prays out loud for Daddy's stomach. But no one in the family comments on this."

1. Thinking in terms of healthy family communication in the face of threatened loss, how would you intervene in this case? Who would you try to convene and why?
2. In what ways would you handle communication with the children differently than with the couple?
3. How would you view the husband's personal decision to minimize his problem and keep it private in the context of other symptomatic family members?

### Case 11.3

Mr. and Mrs. S., both in their early 70s, live alone in their home of 40 years. Mrs. S. has had congestive heart failure for 5 years and more recently a progressive dementia caused by a series of minor strokes. A recent exacerbation of her condition has led to a hospitalization. The family physician feels the couple have reached their limits and has suggested a nursing home placement for Mrs. S. The family includes three adult children, Amy, John, and Beth. All live far away, are married, and raising children. Amy has come to visit her parents during her mother's hospitalization. Family history is significant in that when Mr. and Mrs. S. had their first child, Amy, Mrs. S.'s aging mother, who also had advanced heart disease, had been living with them for several years. At the time, Mr. S. felt that her mother should enter a home while Mrs. S. was strongly opposed. Eventually, Mrs. S. deferred to her husband's wishes. Her mother went to a nearby nursing home and died within a year. Mrs. S. feels the placement hastened her mother's demise and continues to blame her husband for forcing this "cruel decision." The family is in a stalemate about the current dilemma. Mr. S. and Amy are strongly opposed, while John and Beth, feel the physician's suggestion is correct and necessary.

1. How is the multigenerational story of Mrs. S.'s mother critical to understanding this case? How might it affect each family member's feelings about placing Mrs. S. in a nursing home?
2. Would you schedule a family meeting? How would you decide whether to include Mrs. S.? What about John and Beth, who are not in town?



3. How are gender norms a factor in this case? How might you address them with this family?
4. How are life-cycle issues (e.g., couple in later life, adult children in child-rearing phase with aging parents) pertinent, and how would you make them part of the consultative process?
5. What do you see as the choices for this family? How would you explore them in a collaborative manner?

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## APPENDIX: CONSTRUCTING A FAMILY GENOGRAM

Genograms provide graphic representations of family structure and patterns over several generations. They offer social workers a quick picture of complex family patterns, and can be used to generate hypotheses about the evolution of current challenges and to develop avenues for intervention. Genograms provide a useful clinical tool to frame family challenges as developing over generations and in complex family contexts, minimizing blame, and helping the family to move forward. Social workers can use the construction of a genogram in the practice context to elicit and track the family's story, highlighting important family and community members, patterns of illness and coping, and relational ties. McGoldrick et al. (1999) provide a standardized format for constructing a family genogram. Families may express some hesitancy in divulging family patterns, especially when there is no clear link between these patterns and their current concerns. However, families may also enjoy constructing a genogram (some may even ask for a copy to take home), and may approach it eagerly, giving the social worker clues as to the family's capacity for and interest in collaboration.

Social workers can use genograms creatively depending on their practice setting and the family's presenting problem. For example, in medical settings, the genogram can be targeted toward tracking family patterns of illness diagnosis and family response to highlight the particular strengths and challenges for the family in confronting a current diagnosis. This is how the genogram is used earlier in this chapter.

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## CHAPTER 12

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# Human Sexuality and Physical Intimacy

LES GALLO-SILVER

**S**EXUALITY AND PHYSICAL intimacy contribute to every individual's quality of life. Despite this, many people find these aspects of life difficult to discuss with health-care professionals. Understanding the development of humans as sexual beings, details of the human sexual response, and changes and challenges presented by medical illnesses and traumatic injuries can help social workers in health-care settings feel more comfortable and confident when addressing sexuality with patients and their partners. Often, the social worker is the only member of the health-care team who is willing and able to address issues of sexuality and physical intimacy in the context of communication, connection, and healing (Hazan & Shaver, 1987; McCabe, 1994; Schover, 2000). This chapter prepares health social workers for their crucial role in helping people preserve this important part of life in the face of injury or illness. To that end, the chapter provides a foundation of basic information about human sexuality and the impact of illness or injury.

Many words describe various aspects of sexuality and physical intimacy. For the purposes of this chapter, sexuality refers to the desire to have sexual intercourse and the body's responses to sexual stimulation; physical intimacy refers to physical acts of affection, comfort, and support. Sensuality refers to types of stimulation that are pleasing and pleasurable but do not necessarily have a sexual connotation. For example, some people find having their hair washed very pleasurable; using this chapter's definitions, this would be considered a sensual experience because the person who experiences pleasure from having his hair washed may not have any relationship to the person washing his hair or have any sexual interest in her.

### CHAPTER OBJECTIVES

- Introduce social workers to a perspective that focuses on psychosexual developments in the context of communication and interpersonal relationships

**Box 12.1**  
**Institutional Obstacles to Physical Intimacy**

Health facilities and related environments that assist the medically ill or injured often have policies and procedures that represent obstacles to physical intimacy. These policies and procedures reflect a lack of basic knowledge about human sexuality as well as an avoidance of sexual issues. An example is rules that discourage the partners of adult patients from sleeping or resting in bed with them. The same institution may consider it routine for parents to share the beds of their pediatric patients. This incongruity is most apparent in cancer treatment centers where both the adult and pediatric patients receive chemotherapy and may have a weakened immune system, yet are faced with disparate policies for overnight visitation and bed sharing.

as a companion to the more prominent Freudian-based theories that tend to be genitally focused.

- Guide social workers through an assessment that includes questions about sexual relationships and activities appropriate to health social work settings. Such questions are necessary to understand life and behavior but are often overlooked by health-care professionals because they are uncomfortable with the sexual content.
- Provide an understanding of the human sexual response and identify areas of preserved sexual functioning in persons with medical illness or injury in order to address issues of disenfranchisement by a culture that believes that people with physical problems are no longer sexual beings (see Box 12.1).
- Introduce social workers to sexual rehabilitation counseling techniques that focus on difficulties in sexual functioning and recovering that functioning or creatively accommodating for the impairment.
- Introduce social workers to macrolevel issues of creating sex-positive care environments and encourage social workers to learn how to provide sex-positive education, advocacy, and leadership in both inpatient and outpatient settings.

### DEMYSTIFYING HUMAN SEXUAL DEVELOPMENT

The natural biological sexual capabilities of humans is evident throughout the life cycle, even at an early age before the concept of sexual desire develops or intercourse occurs. For instance, infant boys experience erections and infant girls become lubricated (Hornor, 2004; Kelly & Hockenberg-Eaton, 1999; Ryan, 2000; Walker & Casale, 1997). At a very young age, children explore their bodies, including their genitals, with pleasure (Kaplan, 1974; A. Zoldbrod, 2003). Sensation, sexuality, and physical intimacy are basic aspects of the human experience.

Social workers are obligated by the NASW Code of Ethics to explore issues of suicidal thinking, domestic violence, and substance abuse. This exploration might be difficult for some, but few social workers would argue that they are not important to social work practice. Sexuality and physical intimacy, as healthy and



potentially healing aspects of the quality of life, require the same professional attention as these other issues.

Freud's pleasure principle, introducing the concept of libido, has influenced many social workers' professional thoughts about sexual development (Freud, 1922). Libido is a concept that includes sexual desire, fantasy, and the initial sensations of being sexually stimulated. Freud believed that libido was concerned with pleasure seeking to relieve sexual tension. Freud presents a theory that seems devoid of many interpersonal processes, such as love seeking, comfort, and receiving pleasure from another person. It is thus incongruent with social work's philosophy of preserving and enhancing the quality of life. An unfortunate consequence of viewing sexual feelings primarily as a way to release tension is that issues of sexuality and physical intimacy are considered to be outside of a person's day-to-day functioning and thus, by definition, less important than activities such as going to work or school or caring for children. Erickson's work on the formation of a person's identity from childhood to adulthood better represents sexuality and physical intimacy as aspects of the human experience by which people connect and communicate their thoughts and feelings (Erickson, 1968). At each developmental stage, people express their wish to be close to others through displays of physical affection, comforting, and, at times, sexual desire (Erickson, 1968). The gap between Freud's and Erickson's perspectives may arguably be bridged by W. Ronald D. Fairbairn's work; Fairbairn (1946) believed the libido was not seeking simple release but, rather, an object, a person with whom to intimately connect. The need to connect physically is rooted in the infant-parent relationship, which is partially based on touch and is each human's first experience of physical connection. Considering sexuality as relationship-based may lend it deeper meaning than if it is considered a purely pleasure-seeking activity. This idea demystifies human sexuality by placing it in an interpersonal context rather than one that is purely biological. This conceptualization is the basis of Zoldbrod's *Milestones in Sexual Development* (A. Zoldbrod, 1998, 2003).

Zoldbrod's *Milestones in Sexual Development* begins with birth and progresses to the parent's initial bonding experience with the infant. Parental love is communicated through touch, the foundation of empathy as the parent searches for the right response to her infant's cry. As the baby's cry is correctly interpreted, the baby develops a sense of trust in the world and a belief that his needs will be met, which allows the infant to be soothed by the parent. Because parents must help their infants with all their basic needs, such as bathing and feeding, the parents' attitude toward the baby's body becomes reflected in the baby's own attitude about his body and is therefore the foundation of body image. Body image is ultimately refined to include the establishment of gender identity.

As the growing child becomes more certain of his gender identity, he develops self-esteem and feels accepted. As he continues to develop, he becomes more aware of his effect on other people and realizes that his words and actions impact others. Thus begins the process of learning how to manage power within relationships with others. As the child enters puberty, he develops a sense of "owning himself"; that is, he is beginning to discover the parameters of autonomy and the concept of interdependence with others as an aspect of being his own person.

Adolescence is a time of sexual exploration. Parental permission to explore sexual issues is primarily a function of open communication, sharing, and recognition that their adolescent is experiencing intense sexual feelings. The exploration

of both sexual and emotional feelings remains within a social and interpersonal context and provides an opportunity to develop more sophisticated social skills. A key part of this journey of sexual development is the creation of sexual fantasies and masturbation. The final milestone in the Zoldbrod model is the development of loving sexual interpersonal relationships.

Zoldbrod's milestones ground sexual development in an interpersonal perspective—the parent-child relationship. The parent's care of the child's bodily needs and functioning, and the physical and emotional affection that travels with the child as he develops into an adolescent and then a young adult, position sexuality and physical intimacy more as an aspect of human communication and connection than one of sensation or pleasure seeking. Therefore, these milestones naturally progress from the love and touch of caring parents to loving and sexual relationships with others as adults (A. Zoldbrod, 1998, 2003). Parental touch responds to the needs of preverbal infants, both emotionally and physically, and becomes the foundation for empathy and trust. We learn that touch will soothe us and help us relax. Parents who talk to their children while diapering and bathing them convey the message that their child and the child's body are beautiful. This experience helps to form our first notions of positive body image (Clawson & Reese-Weber, 2003; Connolly, Slaughter, & Mealey, 2004; Ehrenberg & Ehrenberg, 1988). The pleasure of being touched is the basic foundation of human sexuality and physical intimacy (Frohlick & Meston, 2005).

However, despite this universal need, people with medical conditions are often sexually disenfranchised by the medical establishment. In the 1940s, Alfred Kinsey studied human sexual practices in the United States, providing data on the age of first sexual experience, prevalence and fluidity of same sex practices, frequency of sexual intercourse within marriage, and masturbatory behavior in adolescents and adults (Kinsey, Pomeroy, & Martin, 1948, 1953). Kinsey's research was revisited in recent years by Edward Laumann and his colleagues at the University of Chicago, who collected data to compare to Kinsey's (Laumann, Gagnon, Michael, & Michaels, 1994). Included among the changes indicated by the comparison of the two collections of data are that Americans had their first sexual experience at a younger age, more women were willing to report that they masturbated, heterosexual oral intercourse had become more prevalent, and more unmarried people were living together in sexual relationships. The sexual practices of people with medical illness or injuries, however, were not addressed by either study.

People with medical problems often become sexually disenfranchised when their sexual concerns are neither explored nor addressed (Gallo-Silver & Parsonnet, 2001; Kroll & Klein, 2001; McCabe, 1999). Health-care professionals tend to wait for patients and their partners to raise issues of sexuality and do not themselves initiate them (Esmail, Yashima, & Munro, 2002). This silence further isolates patients and their partners, sending the message that questions and concerns about sex are less than appropriate (Katzin, 1990; McInnes, 2003).

Discomfort with issues of sex and sexual expression may be based on patients' culture and religion and can make discussions about sexual issues and sexual enjoyment difficult and problematic. Helen Singer Kaplan (1974) described a constrictive upbringing by parents who were uncomfortable with sexual issues as a source of sexual alienation and adult difficulties in sexual functioning.

Successful professional intervention is influenced in part by the attitudes of patients and their partners. The functioning of the health-care team is also affected

by its members' cultural and religious backgrounds, often resulting in a reluctance to focus on the sexual relationship between patients and their partners. In addition, concern often exists that raising the issue of sex will alarm a patient or partner and be seen as inappropriate or unprofessional behavior. Social workers are trained to address difficult issues such as family violence, chemical dependence, and suicidal thoughts. Although these are difficult issues to discuss, they are seen as necessary issues for social workers' interventions. Health social workers need to be equally comfortable discussing sexuality and intimacy issues with patients and their partners to fully assess and address patients' psychosocial issues as well as to effectively plan programs and services for individuals, groups, and communities.

### THE INTIMACY OF HEALTH SOCIAL WORK

Health social work often requires a level of intimacy that social workers in other settings rarely experience. In acute care medical facilities, patients are often in bed and wearing hospital gowns or sleepwear when the social worker is present. In both outpatient and inpatient settings, as well as in nursing homes, the health social worker must often discuss a patient's body and its functions. Health social workers who are part of visiting nurse or hospice programs face situations in which their patients' bodies and functioning become part of the clinical focus, and most contact takes place in or near where patients sleep. The intimacy of health social workers' practice settings requires an acute sensitivity to the patient's need for privacy and her feelings of vulnerability. In most instances, the social worker is well advised to ask the patient's permission to join her at the bedside and empower her to convey when a comfortable time to be interviewed might be. Knocking on the door to the hospital or nursing home room, even if the door is open, sets a tone of respect and indicates that one is entering the patient's intimate environment. Eye contact is best maintained on an equal plane; that is, if a patient is in bed or seated in a wheelchair, the health social worker should also be seated and at the patient's eye level instead of forcing the patient to look up by standing next to him. Even for patients who come from cultures in which eye contact is considered impolite, being at the same level as the patient is almost always considered a sign of respect. Within these environments, patients may exchange information on body functioning and sexuality that is rarely, if ever, exchanged with social workers in other practice settings. Within these intimate contexts, it is important that all discussions about sexuality, sexual functioning, and physical intimacy address patients as persons with complete adult lives that happen to have been disrupted by illness or injury (Schover, 2000; Schover & Jensen, 1988).

### OBTAINING A SEXUAL HISTORY

Early in the AIDS epidemic and prior to the development of the current family of antiviral drugs, people with AIDS experienced long hospital stays. The health social worker's role in discharge planning and the profession's commitment to underserved and isolated communities provided an opportunity to educate other health-care professionals (Egan, 1993; Fahs & Wade, 1996; Mantell, Shulman, Belmont, & Spivak, 1989; Napoleone, 1988). Health social workers on the forefront of

AIDS intervention claimed as part of their professional roles counseling to heterosexuals, bisexuals, and gay women and men about safer sex practices and harm reduction (Berkman & Zinberg, 1997; Christ, Moynihan, & Gallo-Silver, 1995; Gallo-Silver, Raveis, & Moynihan, 1993; Weiner & Siegel, 1990). The goal of the counseling was to help people protect themselves without sacrificing physical love. The counseling utilized a sex-positive approach (Furstenberg & Olson, 1984; Samuel & Boyle, 1989). Health social workers accomplished this task by assessing a person's sexual practices with acceptance and respect and viewed the process as an integral part of their work. Similarly, a psychosocial assessment of a person challenged by any illness or injury that fails to address sexual issues is incomplete. The health social worker is the one member of the health-care team who is not specifically and exclusively focused on the patient's illness and injury in terms of treatment or procedures. Rather, the health social worker's focus is on emotional coping skills and practical problem solving. The social work relationship provides the most comfortable and safe environment and opportunity for patients and partners to discuss issues of sexuality and physical intimacy. Discussion about relationships and social supports is the natural time during a social work assessment to ask patients if they are sexually active and if they have partners (Fuentes, Rosenberg, & Marks, 1983; Gallo-Silver & Parsonnet, 2001; Weerakoon, Jones, Pynor, & Kilburn-Watt, 2004).

These assessments provide health social workers with opportunities to convey the message that sexuality and physical intimacy are natural and normal parts of life (Andrews, 2000). As a rule, people who have enjoyed their sexuality and the physical intimacy of their relationships want to recover and resume that aspect of their life. People who have had long-standing difficulties with their sexuality fear that their medical conditions will render these difficulties intractable. In either case, the support and empathy of a social worker can help individuals feel less alone and overwhelmed by issues of sexuality and physical intimacy. Gaining an understanding of a patient's most recent and current sexual relationships helps the social worker learn what has been lost, or perceived to have been lost, due to adverse health conditions. All assessments should elicit information about significant relationships (see Box 12.2 for suggested assessment questions and strategies).

The patient's partner is an important participant in understanding the sexual and affectionate aspects of their relationships. Interviewing the partner can elicit more information about a person's premorbid life functioning from his perspective (Post, Bloeman, & de Witte, 2005). Partners may be reluctant to approach issues of sex or physical intimacy out of the belief that by doing so, they are selfishly placing their own needs before those of their ill or disabled partner (Soloway, Soloway, Kim, & Kava, 2005; Wimberly, Carver, Laurenceau, Karris, & Antoni, 2005; Zunkel, 2002). The health social worker who is willing to address the issues of sexuality and physical intimacy with a partner can help normalize and validate concerns about how life has changed due to the illness or injury (Ecberg, Griffith, & Foxall, 1986). Box 12.3 provides a list of questions for partners and interview strategies.

The health social worker's approach to obtaining a sexual history and ultimately helping the patient and his partner problem solve around sexual issues is based in supportive counseling techniques. The health social worker uses questioning to increase the couple's understanding of their thoughts, feelings,

**Box 12.2**  
**Suggested Social Work Assessment Questions  
and Strategies for Patients**

1. A patient's demographics enable the health social worker to integrate questions about sexuality and physical intimacy into a psychosocial assessment. If a patient is married, a social worker might say: "Your admission sheet indicates that you are married. How long have you been married? Do you have children? What are their ages? Are you currently sexual active?" Or: "Your admission sheet lists an emergency contact person; what is this person's relationship to you? Is this person a relative, friend, or partner? Are you currently sexually active with your partner?" Some patients will be gay or lesbian. Therefore, discussions of wives and husbands that presume the patient is heterosexual are an obstacle to open and helpful discussions about sexual issues. The term partner is more gender neutral.
2. Patients define sexual activity and physical intimacy in an individual way. Asking patients how they define sexually active or physically intimate can be accomplished in a respectful and professional manner, for example: "Thank you for sharing with me that you have a partner and that prior to your illness or injury you have been sexually active. Do you feel comfortable enough to share with me exactly what you mean when you say sexually active?"
3. Patients' will want to share sexual material with health-care professionals because they have concerns, worries, or distress about the impact of their illnesses or injury on their sexual functioning. Health social workers can share their discomfort with the issue, even their embarrassment if their disclosure helps to put patients at ease. The reason to explore sexual issues is to diminish a sense of isolation and to help patients gain access to medical information and interventions that might improve their functioning. Health social workers demonstrate this by making the purpose of the discussion clear: "I appreciate you sharing such personal issues with me. It is a little awkward for me to ask you these questions about sexual activity. My goal in exploring the issue with you is to help you identify areas where you may want help and facilitate getting specialized help for your concerns."
4. Sometimes a patient's concerns are not specifically about how her body functions but how she looks to others and her perceived loss of attractiveness and desirability. These feelings can be very depleting to people because they diminish self-esteem. At times these feelings can impede a person's commitment to treatment or rehabilitation and can be an aspect of depression (McCabe & Taleporos, 2003; Sundquist & Yee, 2003; Tanyi, 2002). The health social worker's interventions are empathic: listening, tolerating silence, and not presenting an obstacle to exploration by quickly reassuring the patient: "Your feelings about the way you look are very important. You have shared with me how much distress this causes you. I don't think there are any quick or easy solutions but I do think that discussing these issues can bring us closer to finding some solutions."

concerns, and needs, identifies patients and partners who want further intervention, and collaborates with other health-care professionals to access specialized services.

In addition to this process-oriented outline for assessment, there are other interventions, more commonly used in health-care settings, that employ a medical

**Box 12.3**  
**Suggested Social Work Assessment Questions  
 and Strategies for Partners**

1. Understanding the couple's experience of sexuality and physical intimacy is a part of the initial foundation of their relationship. The health social worker needs to engage the partner in sharing how he or she met the patient to learn how the relationship unfolded emotionally. The questions: "What were the reasons the two of you became a couple; at what point did you decide to become a couple; and what was it like in the beginning of the relationship?" focus the partner on the emotional underpinning of the relationship and ultimately the sexual underpinnings of the relationship as well (Anastasia, 1998; Brackney, 1979; McCabe, 1994; McCabe & Mckern, 2003; Weijmar-Schulz & Van de Wiel, 2003).
2. Relating emotional commitment to the expression of physical love through sexuality and physical intimacy helps a partner understand the health social worker's interest in this area of their lives. The health social worker's questions need to reflect this interpersonal approach: "My next question is a logical one but also a very personal one and I want to avoid any embarrassment for you or for me, how has your relationship grown over the years in the areas of sexuality and physical intimacy? What has this been like for the two of you before your partner became ill/was injured? What types of touching and affection can/do the two of you share now?"
3. The health social worker needs to ascertain the importance of sexuality and physical intimacy for the partner at this time in his or her and the patient's life. "How important was making love/sex to you and your partner before the illness/injury? What do you miss now? Are you interested in finding out how you and your partner might be able to return to what the two of you enjoyed before the illness/injury?"
4. The health social worker's interventions are empathic: listening, tolerating silence, and not presenting an obstacle to exploration by quickly reassuring the partner or changing the subject: "Thank you for giving me a very clear understanding of how much the two of you share and how close the two of you are, sexuality and physical intimacy are an important part of a couple's life and perhaps as we talk further with you and your partner we can find some solutions and/or some specialized services to help the two of you retain/reclaim the physically intimate aspects of your relationship."

model. The health social worker needs to be aware of how other health professionals may approach issues of sexuality and physical intimacy.

The ALARM Model for Sexual Functioning assessment focuses on sexuality and physical intimacy from the standpoint of a medical model and is often used by nurses (Anastasia, 1998). ALARM is an acronym for: A—assessment of sexual activity in terms of frequency, type of sexual practice, and sexual preferences; L—assessment of libido or emotional and physical desire for sexual activity and overall interest in sex; A—assessment of the individual's ability to become aroused, the physical changes, particularly to the genitals, when sexually stimulated, and the ability to achieve orgasm; R—assessment of the feeling state and emotional and physical satisfaction following sex and the resolution, or the bodies ability to return to a resting or relaxed state after sexual activity; and M—assessment of the medical history that has or could impact sexual functioning (Andersen, 1990).



Similar to the ALARM assessment, the PLISSIT Model is also often used in health-care settings (Anastasia, 1998) and is an acronym for: P—giving the patient and partner permission to discuss sexual issues by forming a trusting and open environment; LI—providing limited information about the illness or injury's impact on sexual functioning; SS—offering specific suggestions on how to enhance sexual functioning; and IT—making appropriate referrals for intensive sex therapy (Annon, 1976).

Health social workers help other health professionals understand how certain terminology and phrasing might confuse patients who may be too uncomfortable to ask for clarification. Given the number of euphemisms used for sexual activities; definitions can vary from individual to individual.

### **Case Example**

Mr. Moore, age 76, was answering his nurse clinician's questions about his lifestyle as a prelude to having his prostate removed because of cancer. When asked if he was sexually active, Mr. Moore indicated he was not, not mentioning the masturbatory rituals he had used since his wife's death 4 years earlier. He was worried about erectile dysfunction after the surgery but felt it was inappropriate to tell anyone on the health-care team that he masturbated regularly and would miss it were he unable to continue doing it. The social worker focused counseling on Mr. Moore's loneliness. Mr. Moore began to feel comfortable enough to revisit the issue of his sexuality. The health social worker facilitated a meeting with his nurse clinician to address his concerns about erectile capacity without specifically talking about masturbation.

## CHILDHOOD SEXUAL ABUSE

Peoples' sexual histories can be fraught with joy, contentment, resignation, or disappointment. Once a health social worker uses his skill set to normalize issues of sexuality and physical intimacy and validate them as a natural part of life; other issues can be uncovered. Sadly, not all children are touched with parental tenderness and affection. Researchers estimate that 1 in 3 women and 1 in 7 men were sexually abused as children (Finkelhor, 1984; Maltz, 2001, 2003; Russell, 1999). Childhood sexual abuse is an umbrella designation for a series of behaviors that include vaginal and anal penetration by a penis, finger, hand, or other object; receptive or active oral sex; fondling and masturbation; invasion of privacy when bathing and toileting; sexually provocative behavior and nudity; and exposure to and involvement in pornography (Johnson, 2004). Survivors of childhood sexual abuse often feel violated by the health-care system (Jehu, 1992). The requirement that a patient remove his or her clothes and appear inadequately dressed in a hospital gown, x-rays and other radiographic tests that require a person to stay still or be posed in certain ways, and invasive examinations such as a gynecological or digital-rectal exams can all evoke feelings and thoughts about childhood sexual abuse that the person has previously avoided or not acknowledged (Druacker, & Spradlin, 2001; Galllo-Silver & Weiner, 2005; Hobbins, 2004; P. Sansone, Skaife, & Rhodes, 2003; R. Sansone, Gaither, & Sansone, 2001).

At times, the health social worker becomes aware of a history of childhood sexual abuse when working with a patient who is in distress or having difficulty

copied with the health-care environment. Helping a patient feel safe in these circumstances is achieved by increasing her sense of control over a given situation. All medical procedures require some form of consent. Consent needs to be described as an event that can be rescinded or altered according to the patient's wishes. The following case examples depict how health social workers can use their clinical skills to help this emotionally fragile population.

### **Case Example**

Ms. Brown screamed to her social worker that she would not agree to a mammogram because she can't bear to be touched. Ms. Brown began to sob and kept repeating, "no touching, no touching," as she rocked back and forth in her chair. The social worker reassured Ms. Brown that she was safe, that no one would force her to have a mammogram, but that her doctor had requested it because she indicated she had found a lump in her breast. Haltingly, Ms. Brown described having been sexually abused by her mother. Ms. Brown did not have her mammogram that day, but following counseling with her social worker, she agreed to it with the condition that the social worker would be near to ensure her safety.

### **Case Example**

Mr. Allen was slowly recovering from a stem cell transplant to treat cancer. He had undergone intensive chemotherapy and needed the transplant to help his bone marrow recover from the treatment. He became reluctant to change his pajamas, would not bathe, and struggled whenever he was being examined. His social worker, who had provided counseling to him in anticipation of the transplant, indicated that Mr. Allen's behavior was not consistent with how he had coped with his cancer prior to the transplant. After a medical reason for his change in behavior was ruled out, the social worker continued to help Mr. Allen become more aware of his feelings and thoughts. The simple questions "what is troubling you about the staff touching you? Do you think you could put it into words for me?" helped Mr. Allen share that his father would fondle him when he was young, telling him that his skin was smooth and soft. Mr. Allen's loss of all body hair frightened him because it made him feel that his body had reverted back to the body his father had molested. Continued counseling and psychiatric intervention with medication helped Mr. Allen manage the remaining course of his treatment.

The exploration of childhood sexual abuse in the health-care setting is appropriate when the history represents an obstacle to care as illustrated in these two cases. The ability to respond empathetically to the patient's disclosure of his abuse is the social worker's most important skill when working with this population. The nature of the experiences described is often difficult to hear and can provoke considerable anxiety for the health social worker and other health-care professionals. It is both respectful and supportive for survivors of childhood sexual abuse to know that their histories are hard to hear. The pacing of the questioning is essential because survivors can overwhelm themselves and be retraumatized by sharing too much information at one time. Sharing information keeping this pacing in mind will help the survivor feel cared for rather than rejected when the health social worker sets a limit on how much material will be

discussed (Briere & Elliott, 2003; Burnside et al., 2004; Gallo-Silver & Weiner, 2005; Monahan & Forgash, 2000; Schacter et al., 2004; Weaver et al., 1994).

## THE HUMAN SEXUAL RESPONSE

The hormonal surge of adolescence increases the skin's sensitivity to touch (Neufeld, Klingbell, Borgen, Silverman, & Thomas, 2002). Sensitivity to touch remains intact in the face of aging and illness (Creti & Libman, 1989; Gelfand, 2000; Kingsberg, 2000). Even seriously ill people can respond to the sensual experience of bed baths, the application of moisturizers to their feet, and the assistance with repositioning their body in bed. For people with spinal cord injury, the part of their body above the point of spinal injury remains highly sensitive. Some people with spinal cord injury indicate that their skin's sensitivity seems heightened by the other areas that lack full sensation (Sipski, 1998).

Human sexual response can also be seen as a neurological process. The centers of the brain interpret stimulation and send messages to the body to respond. The brain interprets both touch and other types of stimulation. For instance, some people receive a great deal of pleasure from eating chocolate. For some, eating chocolate can be a sensual experience. The brain stores this person's thoughts about chocolate and the tongue's and palate's response to the texture and sweetness (Small, Zatorre, & Dagher, 2001). The brain is the repository of learning, experience, and recollection, all of which have a memory component (Arnow & Zeki, 2000). The brain stores a variety of sexual memories (Karma, Lecours, & Leroux, 2002), including the memory of the physical sensations related to excitement, arousal, and orgasm; the memory of sexual and masturbatory fantasies; and the memory of actual sexual experiences (Cranston-Cuevas & Barlow, 1990; Holstege, Georgiadis, & Paans, 2003; McKenna, 1999). Masturbatory fantasies are thought to change only superficially as people mature; their basic concept remains constant throughout the life span (Green & Mosher, 1985; Hurlbert & Whittaker 1991; Lukianowicz, 1960; Mosher, 1980; Nutter & Condon, 1985; Rowan, 2000). As part of the long-term memory bank, sexual memories are resilient and retrievable (Jones & Barlow, 1990). The ability to retrieve these memories can help medically ill and injured people enhance their sexual responsiveness through the use of masturbatory fantasies.

Masters and Johnson divided human sexual response into interdependent phases (Masters & Johnson, 1966, 1970). The four identified phases expanded existing knowledge of human sexuality beyond the previous notions of impotence and frigidity. The latter two terms have not added to our understanding of sexual dysfunction and have pejorative connotations that may add to patients' feelings of hopelessness and rejection. The phases determined by Masters and Johnson include the desire phase, which encompasses the feelings and thoughts about sex and sexual feelings; the excitement phase, which involves increased blood supply to the genitals, erection of the penis, and lubrication of the vagina during sexual stimulation; the orgasm phase, with rapid muscle spasms, increased heart and respiratory rate, change in body temperature, and ejaculation; and the resolution phase, which is the body's return to a resting heart rate and a decrease in the supply of blood to the genitals.

Medical illnesses and injuries can disrupt some of these phases, but it is rare for all to be markedly disrupted (Black, 2004; Boone & Kelly, 1990; Ide, 2004; Katz,

2005; McCabe & Taleporos, 2003; McInnes, 2003). Because not all phases are disrupted, sexual rehabilitation for people with medical illnesses or injuries is possible. Sexual rehabilitation is the process of helping a medically ill or injured person restore and resume sexual functioning. A rehabilitative approach identifies the phase or phases that remain intact and helps patients maximize their responsiveness and enjoyment by building on the strengths of the remaining phases (Gallo-Silver, 2000; Kaplan, 1974, 1983; Schover & Jensen, 1988). Sex therapists using this model focus on cognitive and behavioral techniques that help to obviate sexual concerns and worries (Gallo-Silver, 2000).

The phases of sexual response developed by Masters and Johnson are considered to be linear in nature. For this reason, some sex therapists consider them to be more relevant for men than for women. Basson (2001), for example, considers women's sexual responses to be more cyclical than those of men. Basson's sexual response cycle for women begins and ends with emotional intimacy that creates receptivity to sexual stimulation. The cycle continues to subjective arousal that is both emotional and physical, which leads in turn to objective arousal and responsive desire (similar to Masters and Johnson's phase of excitement), followed by orgasm, resolution, and emotional and physical satisfaction. Emotional and physical satisfaction can engender further emotional intimacy. In Basson's formulation, emotional intimacy is both the beginning and end point of the cycle of sexual functioning. Sex therapists whose interventions are based on Basson's conceptualization use a strengths-based approach that identifies those aspects of the response cycle that are intact as building blocks to sexual and emotional satisfaction.

It is easy for a patient challenged by a changed body and functioning to be discouraged about and fearful of sexual issues. A strengths-based approach presents this same patient with a measure of hope and possibilities for a different approach to sexuality. A rehabilitation approach based on Basson's model would focus on the interpersonal and intrapsychic issues that likely represent obstacles to comfort and enjoyment of physical intimacy. Basson's cycle of sexual response more closely mirrors Fairbairn's and Zoldbrod's more interpersonally based theories, which view sexual expression as a form of human communication and connection. It should be noted that the gender patterns outlined here are not invariable.

#### A DEVELOPMENTAL PERSPECTIVE

Our culture tends to view sexuality as the domain of the young, able, slim, and well. Although some baby boomers (individuals born in the post-World War II period from 1945 to 1968) consider sexually active older adults a new phenomenon, Kinsey in the 1940s, as well as Laumann in the 1990s, found individuals of both genders to be sexually active and satisfied with the quality of physical intimacy in their lives into their 80s and 90s (Kinsey, Pomeroy, & Martin, 1948, 1953; Laumann et al., 1994). Kinsey's findings are more illuminating because the median age of survival during the period of his research was lower than it is at present, and medicine was less able to address serious medical problems. Social workers should consider all patients as sexual beings because sexuality is basic to the human con-

dition. This will ensure that no group (e.g., those over 80, those with physical disabilities, and so on) is desexualized and assumed to be sexually inactive.

#### OLDER ADULTS

After a certain age, women begin to produce less estrogen. The decreased estrogen levels can diminish vaginal lubrication and the walls of the vagina may become thicker and less elastic. Desire, which is to some extent hormonally determined, might diminish, and some women report less intense orgasms as they age (Dennerstein & Leher, 2004; Dennerstein, Leher, Dudley, & Burger, 1999). However, hormone replacement therapy remains controversial due to empirical evidence that it can increase risk for breast and ovarian cancers (Aubuchon & Santoro, 2004; Chen et al., 2004; Ching & Lip, 2002; Durna et al., 2004). Postmenopausal women may benefit from vaginal lubricants or moisturizers to facilitate comfortable sexual intercourse.

As men age, they may require more tactile stimulation to achieve erections, and erections may be less rigid. The intensity of their orgasm may also diminish, as might the quantity of their ejaculates. Men may also require longer periods of time to achieve erections following an orgasm before the next attempt. Erectile dysfunction medications are said to be effective for men who have difficulties due to natural aging, medical problems, or emotional obstacles to becoming aroused.

Laumann et al. (1994) suggested that partner availability might be a more important obstacle to sexual activity for older adults than the physical sequelae of aging. Older adults who do not have partners may masturbate as their primary sexual activity. Masturbation is often a part of their sleep ritual. There is evidence to suggest that masturbation among older adult women without partners is almost as high as that of adolescent males (Laumann et al., 1994). Health-care staff who work in congregate living settings often report their discomfort in encountering a patient who is masturbating. Social workers can educate staff about masturbation in older adults and, in so doing, help normalize the experience.

Persons in congregate living situations, such as assisted-living residences, supportive senior apartments, nursing homes, and chronic care institutions, at times form sexual relationships with other residents. Nursing homes and chronic care facilities often do not permit unmarried patients to share rooms, but couples in love find ways to have private time, nonetheless. While it is important for institutions to protect vulnerable patients from being sexually exploited, some rules about privacy and sexual activity are more reflective of society's discomfort with sex rather than a need to protect. Social workers should advocate for patients who are competent to consent to sexual activity to have the privacy they desire in ways that are still consistent with the institutional policy and procedures.

Gay and lesbian older adults, whether in assisted-living, nursing homes, or chronic care environments, may feel particularly isolated (D'Augelli, Grossman, Hershberger, & O'Connell, 2001; Grossman, D'Augelli, & Hershberger, 2000; McMahon, 2003). The AIDS epidemic has left some gay men without the support of groups of male friends. Gay and lesbian adults in congregate or assisted-living situations often feel they cannot be themselves or talk openly about their sexual preferences, even though they may have led open lives prior to entering a facility

or group living situation (Spitzer, Neuman, & Holden, 2004). Social workers can enable gay and lesbian persons to adjust to new living situations, including feeling safe and able to be themselves without the threat of being ostracized or scapegoated. It is crucial for the social worker to model acceptance for the other residents and for the staff. Health social workers can educate other members of the health-care team about patients' needs for additional information about sexuality.

### **Case Example**

Mr. Jones, who is 80 years old, was in the recovery area after a cardiac catheterization to clear several blockages in his arteries. At the bedside was his "friend," Ms. Thomas, age 75. His doctor visited and told him that he would recover well and could return to his regular activities in the following few weeks, but that he should not overly exert himself during that period. The doctor did not mention sexual intercourse, and neither Mr. Jones nor Ms. Thomas felt comfortable bringing it up, although they previously had made love a few times a month. Once home, they were fearful of even cuddling because they had heard stories of people dying of heart attacks during sexual activity. They were reassured after their social worker began her session with Mr. Jones by asking about his relationship with Ms. Thomas and made it clear that talking about their sexual relationship was important.

### **Case Example**

Ms. King, who is 75 years old, was recovering from a hysterectomy after ovarian cancer, and she struggled with feeling less feminine. Her physician indicated that she was recovering nicely and told her that, because she was postmenopausal and therefore beyond childbearing, the surgery would have a negligible effect on her life. Ms. King decided not to ask her doctor how her surgery might affect her sexual activity with her female partner. With empathy and respect, the social worker sought a better understanding of Ms. King's relationship with her partner. A joint session with the couple prior to discharge from the hospital helped them explore the issue of physical intimacy in a direct and frank manner. Ms. King's doctor was then asked to explain the medical issues that would impact their sexual functioning and how those issues could be accommodated. The social worker provided this couple with reading material about sexual activity and heart problems and arranged for them to meet with the physician in order for them to get specific information.

### **YOUNG ADULTS**

Health-care professionals are ethically obligated to inform patients that recommended treatment may interrupt or impair their fertility. Often, these discussions fail to address the sexual challenges that treatment presents, leaving the young adult with many unanswered questions about the impact of his illness or treatment on his ability to function sexually. Some illnesses such as testicular and gynecological cancer and cancer of the penis affect both the functioning of the genitals and their appearance (Anderson, Woods, & Copeland, 1997; Nazareth, Lewin, & King, 2001; Opjordsmoen, Waehre, Aass, & Fossa, 1994). The health so-



cial worker can advocate to ensure that complete and comprehensive information is given to patients, which is a crucial first step in helping them cope. Advocacy is an important leadership function of social workers on health-care teams. It is essential for health social workers to be informed about the impact of the illness, injury, and or treatment to the patient's genitals prior to her being told the information by physicians or nurses (Fuentes, Rosenberg, & Marks, 1983; Weerakoon et al., 2004). Being present when this discussion occurs maximizes the health social worker's ability to shape discussions that may be distressing and difficult for the patient.

Young adults struggle with issues of attractiveness and desirability. Body image issues can create crises of self-esteem in people who do not currently have a partner or who have had limited sexual experiences (Horgan & MacLachlan, 2004; Ide, Watanabe, & Toyonaga, 2002; Lawrence, Fauerbach, Heinberg, & Doctor, 2004; McCabe & Taleporos, 2003).

Appearance changes are painful for both genders. Although they may occur at any age, young adulthood is often seen as a time for entering long-term relationships, marriage, and child rearing, and therefore, people experiencing changes during this period may be particularly vulnerable. Amputation of a limb and facial disfigurement can be profoundly disorganizing to a person's self-esteem as they often have an immediate impact on how others interact with the affected person (Horgan & MacLachlan, 2004; Lawrence et al., 2004; McCabe & Taleporos, 2003; Monga, Tan, Ostermann, & Monga, 1997).

### **Case Example**

Ms. Dean, a 22-year-old woman, underwent an amputation of her left leg above her knee after a car accident. About the same time, her boyfriend decided to end their relationship. While waiting to be fitted with a prosthesis, she frequently canceled appointments and often missed her out-patient physical therapy appointments. She told her social worker that there was little point in keeping her appointments, and that she would rather just stay in a wheelchair. Counseling with her social worker helped her mourn the loss of both her boyfriend and her leg. Support and education helped Ms. Dean feel more in control and more willing to accept her prosthesis. Counseling continued as an integral part of her physical therapy. Ms. Dean gradually began to pay more attention to her appearance. She told her social worker that she felt more confident to socialize with her friends and that she hoped to meet the "right person" with whom to begin a new relationship.

Although prosthetic devices can assist the young adult amputee in looking "normal" in clothing that covers the prosthetic limb, in intimate situations the loss of the limb becomes apparent. This reality can affect how the young adult approaches and cooperates with the required physical therapy and prosthetic fittings. The health social worker's role is often to permit and witness the young adult to mourn the lost body part, and confront her fears of how the loss will affect her sexual relationships. Education about the normal or typical process of adjusting to an amputation and the provision of supportive counseling either before or directly after a physical therapy session can help the young amputee begin to integrate his experience (Bodenheimer, Kerrigan, Garber, & Monga, 2000; Shell &

Miller, 1999). The goal of the health social worker's interventions is for the patient to accommodate to the loss of the limb as part of an ongoing process of adjustment. The young adult's adjustment to facial disfigurement is accompanied by a tendency to become socially isolated and anxious about meeting new people including new health-care professionals (Bianchi, 1997; Monga et al., 1997; Whitehead, 1993). The health social worker can build a relationship of trust by maintaining eye contact with the patient and acknowledging the difficulty posed by facial disfigurement. Helping a facially disfigured young adult gain social confidence can be accomplished by helping her develop strategies to put people at ease and address hurtful reactions to her disfigurement in an open and direct manner. The social worker can help young adults who are challenged by amputation or facial disfigurement consider issues of sexuality and physical intimacy and manage social situations in general.

### ADOLESCENTS

Adolescence is a time of rapid emotional and physical changes. A major feature of adolescence, and the engine for the emotional upheaval during this stage of development, is the increased production of testosterone and estrogen. The development of pubic hair, breasts, and muscle mass present adolescents with intense changes in body image. As for young adults, medical illness and injury further complicate adolescents' relationships with their own bodies and their developing sexuality (Berman et al., 1999; Greydanus, Rimsza, & Newhouse, 2002). Given the many changes that are characteristic of adolescent physical development, the additional changes due to illness and injury serve to separate affected adolescents from their peers. The validation and normalization of adolescents sharing with their peers thoughts and concerns about bodily changes are often unavailable to adolescents challenged by illness or injury. In some ways, the relationship with the health social worker becomes the environment for validation of and normalization to the special circumstances caused by illness or injury. Adolescents with complex medical needs often struggle with intensified issues of independence from parents, who are by necessity involved in their ongoing care. Parents' increased involvement in adolescents' lives and physical needs can delay their acknowledgment of their children's maturation and sexual development. Health social workers often educate parents about the additional struggles of their adolescent and his experience with sexuality and physical intimacy.

### Case Example

Mr. North, age 15, had been challenged by a variety of physical problems due to cerebral palsy. He shared a friendship with Ms. White, also 15 and challenged by cerebral palsy. They met each other at their medical clinic. The respective parents were aware that their children had formed a close friendship. They were observed by a medical assistant kissing and touching each other in what the two assumed was a private place. The medical assistant told Ms. White's mother, believing Ms. White needed to be "protected." The social worker intervened when Ms. White's mother complained about Mr. North to clinic staff. Gently but empathically, the social worker helped the mother place her daughter's behavior and

the behavior of her male friend in the perspective adolescence. The mother had not focused much on her daughter's body changes, beyond helping her understand her menstrual cycles, purchase a bra, and learn to address her personal hygiene activities. The mother indicated to the social worker that she never considered her daughter might have "those" thoughts. Similarly, Mr. North's parents were aware that he was masturbating but had not discussed sexual development or feelings with him.

The health social worker could help the two families communicate with one another about many difficult issues using empathy as well as an even-handed neutrality. In this instance, normalizing adolescent behavior helped the parents realize that all parents of adolescents struggle with these same issues.

Birth control can also be an issue when considering the safety of conceiving a child while undergoing chemotherapy. It is unclear what would be the long-term side-effects of chemotherapy on the developing fetus. For this reason, people treated for cancer are asked to practice birth control.

### **Case Example**

Mr. Crane, a 19-year-old with lymphoma, proudly walked into the clinic and announced to his social worker that the doctors were "wrong" and that his chemotherapy would not prevent him from having children. He indicated that he and his girlfriend had made love the night before and that everything was about the same as it had been.

Mr. Crane was confused by the euphemistic and medical language used to discuss his illness—he thought that infertility meant he could not have an erection. The use of clear and accurate terms is essential in discussing sexual issues to a population that may be sexually naive. It is part of the health social worker's advocate role to inform other health-care professionals when a patient does not understand the information given to him or when he might misconstrue information.

## SPECIFIC ISSUES IN WORKING WITH COUPLES

Hospital stays have become progressively shorter, because of improvements in the medical profession's ability to treat illnesses, the expansion of outpatient services, and the demands of medical insurers (see Chapters 11 and 19). Families have become more involved in the practical care of both acutely ill and chronically ill persons. The shift of care from health-related facilities to patients' homes has often had unintended, negative consequences for couples.

### THE "PARENTIFICATION" OF THE WELL PARTNER

Medical illnesses and traumatic injuries place patients in a vulnerable position and increase their dependence on others, both practically and emotionally. The well partner often must monitor the patient's condition, supervise medications, provide transportation to physician visits and treatments, assist with bathing and toileting, and participate in physical and occupational therapies. As the level of practical and personal care increases, partners often report that they feel like

parents rather than romantic partners. Other health-care professionals are often unaware of this shifting dynamic in couple relationships as the well partner begins to focus on the details of the care, treatment, and progress of the sick partner. A social worker's awareness of this potential "parentification" of the well partner can help diminish the isolation and loneliness that develops among couples. The health social worker's use of problem-solving skills engages the partner in an exploration of what aspects of physical intimacy could be integrated into the daily care routines. The activity is identified by the partner and the health social worker than works on assisting the couple to consider ways to incorporate physical intimacy into these activities. This might include adding massage to bathing activities, or kissing during assisting the patient with meals.

### Case Example

Ms. Richards was recovering from a gunshot wound that left her paralyzed from the waist down. Her partner Mr. Barry had visited her daily, participating in her therapy at the acute care rehabilitation center. Ms. Richards complained to her social worker that, while Mr. Barry was attentive and helpful, the affection and physicality of their relationship had suffered. Mr. Barry had learned how to help Ms. Richards with her personal care. He would be driving her to her outpatient physical therapy appointments after her discharge from the hospital. He had learned all about her medications. The social worker met with Mr. Barry and asked him how he thought he and his partner were adjusting to her spinal cord injury. He indicated that he had learned a lot, wanted to help Ms. Richards in every way, but missed aspects of their previous life together. When the social worker asked what he meant, Mr. Barry began to cry, relating how he felt more like his partner's father than her lover. He recalled how he loved to hold her and caress her breasts. Mr. Barry seemed quite embarrassed to have shared this with the social worker. The social worker reassured him and suggested that since the spinal cord injury did not change Ms. Richards' breasts in any way, and since touching them would not hurt her in any way, perhaps that was something they could still share. Perhaps he could just pull the curtain around her bed, giving them enough privacy to show how much they loved each other.

Straightforward suggestions can give a couple permission to physically demonstrate their love. The health social worker can work collaboratively with occupational therapists to help couples feel more "normal" in the face of traumatic injuries that affect day-to-day self-care functioning as well as issues of sexuality.

### PHYSICAL INTIMACY AS AN ASPECT OF COUPLE COMMUNICATION

Medical illness and traumatic injury can have an enormous impact on a couple's ability to communicate, share, and understand one another. If communication problems existed before the health crisis, they likely would not improve under the challenge of poor health or disability. Physical intimacy for people with medical conditions requires verbal communication. Often, couples need to relearn how to listen to each other so they can rekindle the physical intimacy they enjoyed before the crisis. Adjusting to a changed body and body image requires sensitivity and clarity, both of which are best achieved through good communication.

The Speaker/Listener Technique (Markham, Stanley, & Blumberg, 1994) was developed to help couples improve their ability to communicate and share their thoughts, concerns, and worries. The technique entails teaching couples how to concentrate on the words that the other person is saying instead of focusing on how they should respond. Couples are instructed to try to paraphrase what their partner has said and then inquire whether their interpretation accurately reflected their partner's statement. The couple takes turns completing the exercise. For couples who need more structure, the speaker may hold a card, which is called the "floor." The term "holding the floor" means that only the person with the card is allowed to speak at that time. The Speaker/Listener Technique can be taught at the bedside or in a clinic exam room.

### THE AFFECTS OF MEDICAL ILLNESSES AND TRAUMATIC INJURIES ON SEXUALITY AND PHYSICAL INTIMACY

Illness and injury often disrupt aspects of the human sexual response, but rarely do they disrupt them entirely. Many people retain functioning in at least one of the major phases (i.e., desire, excitement, or orgasm) of the response.

Many anecdotal stories exist about people who suffer heart attacks during sexual activity. Although instances of cardiac arrest during sexual intercourse are uncommon, people with heart disease often approach the issue of physical intimacy with fear and dread (Debusk, 2000). Cardiovascular disease, hypertension, and diabetes often diminish the body's sensitivity to touch and stimulation, secondary to diminished blood flow. This has its greatest impact on the genitals, which require increased blood supply to achieve erection of the penis or lubrication of the vagina. At the same time, however, diminished blood flow would not likely affect the desire for sexual stimulation or the overall quality of orgasm.

Although desire is highly governed by hormones, it also may be affected by systemic problems. This is because emotional vibrancy and vigor also play a part in the desire phase. People in renal failure lose energy and stamina due to the build-up of impurities in the blood that would ordinarily be cleansed by the kidneys. While dialysis can assume the functioning of the kidneys, the process leaves the body fatigued and diminishes its overall response to stimulation. Therefore, erectile and lubrication capabilities are impaired, although orgasm is largely unaffected (Schover, 2000; Schover & Jensen, 1988).

Pulmonary disease robs the body of energy, which in turn diminishes feelings of desire. While able to be stimulated to the excitement or arousal phase of response, people with pulmonary disease sometimes do not have the lung capacity to tolerate orgasm, and the quality and intensity of their orgasms are diminished (Haas & Hass, 2000; Walbroehl, 1992).

Cancer is a generic term for a number of illnesses, all of which involve cells multiplying and growing out of control (see Chapter 18). Women with breast or gynecological cancers may experience diminished desire, problems with excitement or arousal, and diminished quality of orgasm. Men with prostate cancer are challenged by diminished desire and erectile difficulties, yet they retain orgasmic functioning. Men with testicular cancer retain desire and erectile capabilities, but report some diminished quality of orgasm. People with colorectal cancers and bladder cancer experience problems with erection and lubrication,

but retain desire and orgasm. Women treated for bladder, cervical, and other gynecological cancers may experience changes in the shape or size of the vaginal vault. This may necessitate the use of dilators to maintain and stretch the contours of the vagina. Dilators are used until the penis can comfortably be inserted into the vagina. Health-care professionals may recommend vaginal intercourse as a way of preserving the vagina's contours. This is a sex-negative recommendation because it places women in the position of having uncomfortable and painful intercourse in the short run for longer term sexual comfort. People with leukemia or lymphomas experience a loss of desire, some fatigue-related erectile or lubrication dysfunctions, yet retain orgasm. People with brain tumors can experience a loss of desire, but often retain some ability to achieve erection or lubrication, as well as orgasm (American Cancer Society, 1998; Schover, 1999).

Spinal cord injury disrupts the individual's ability to feel below the injury. Desire remains intact and erections and lubrication occur, but the individual is not able to feel these changes. The body can experience a diminished orgasm, but once again, the person does not feel this in the same way as before the injury. Because orgasm is a total body response and thus not confined to the genitals, people can experience orgasmic feelings in parts of the body that are above the injury. Kroll and Klein (2001) say that skin over areas that retain feeling express some of the orgasmic reactions.

### Case Example

Mrs. Carter, a 35-year-old woman paralyzed from the neck down in a diving accident, both wished and feared that her husband would find "sexual release in the arms of another woman." Her words were made more poignant by the fact that she could no longer embrace her husband. Her husband felt that touching his wife below the area of paralysis was like touching a "dead thing." Prior to her accident, the Carters enjoyed a strong relationship, had a 6-year-old son, and made love at least once a month. Mr. Carter was taught how to give his wife a bed bath. He noticed that the nipples of her breasts would become erect when he washed her, and he reacted to this by becoming aroused. Confused but intrigued by what he saw, he sought out the social worker to talk about his feelings and concerns. The social worker, by taking a sexual history, established herself as someone whom one could talk to about physical intimacy. She encouraged Mr. Carter to talk to his wife about being touched. Mrs. Carter wept when she learned that her husband had found bathing her a sensual experience. Gradually, bath time became a time of physical sharing and closeness. Mrs. Carter reported feeling the skin on her face and neck become pleurably hot and her lips and ears more sensitive to her husband's touch. The social worker pointed out that whether Mrs. Carter was feeling orgasmic reactions or if she was creating them independent of her husband's touches is less important than their increased sharing and connection.

The social work profession encourages a strengths-based perspective. Supportive and educational social work interventions focus on the aspects of sexual functioning that remain intact while at the same time respecting the loss or impairment of certain sexual abilities. The social worker who is able to help peo-



ple feel comfortable with sharing their sexual feelings can help them locate reactions that can serve as building blocks to more satisfying physical intimacy.

#### IMPACT ON STAMINA

The loss of overall physical stamina caused by cancer, AIDS, pulmonary disease, multiple sclerosis, and other chronic medical problems can impair the body's ability to respond to sexual stimulation (Ferrando et al., 1998; Harden, 2005; Parish, 2002; Schmidt, Hofmann, Niederwieser, Kapfhammer, & Bonelli, 2005; Walbroehl, 1992). As the body moves from an aroused state to orgasm, heartbeat and respiration increase. Cardiologists have compared the energy needed for sexual activity to that of climbing two flights of stairs or walking three miles on level ground (Brody & Pruet, 2003; Debusk, 2000; Thorson, 2003). Energy conservation is a crucial element in enabling people with a medical illness or injury to resume or return to sexual activity. Accommodations in love-making positions transfer more of the "work" of sexual intercourse to the well partner (Haas & Haas, 2000).

Fatigue is a major obstacle to sexual activity for people with challenging medical conditions. Fatigue is a physiological phenomenon that does not respond to sleep or rest and is often intensified by increased inactivity. Tiredness is usually muscular in nature and can be resolved by sleep and rest. While it is counterintuitive to be active when fatigued, exercise can work to offset fatigue. It is important that people be able to identify the times at which they experience higher energy levels so they can plan for physical intimacy.

For people with pulmonary disease, the morning is a time to clear secretions that have built up in the lungs during sleep. Once secretions have been cleared, many people feel more energetic. For people who are challenged by paralysis, either due to stroke or spinal cord injury, and are wheelchair-bound, energy levels may seem higher when they move from bed to their wheelchairs. Physical intimacy for people who require the use of wheelchairs is often more easily undertaken while they are in their chairs rather than in bed because the chair provides both physical and emotional support (a person may feel more confident in his chair), and offers more mobility than the chair.

People undergoing kidney dialysis undergo the procedure on 3 consecutive days and then break for 2. Usually, people will experience a bit more energy on the morning of the second day after dialysis (Camsari et al., 1999; Reynolds & Postlethwaite, 1996; Uttley, 1996). Those undergoing chemotherapy for cancer also have breaks between treatments, during which their body recovers from the side effects of the chemotherapy. The days just before the next administration of chemotherapy are often days of higher energy (Burt, 1995; Hughes, 2000; Wood & Tombrink, 1983). Health social workers aware of the relationship between treatment and energy level, are better able to help couples preserve the sense of normalcy achieved when they are able to resume being physically intimate.

People with HIV often have few symptoms of the virus in the early stages of their infections. Medications that inhibit the growth of the virus may present side effects such as fatigue and some gastric complaints that may diminish sexual vibrancy (Roak, Webster, Darrow, & Stempel, 2005). The challenge for people with HIV is integrating harm-reduction practices into their sexual routines to limit the chance that they will infect others. The use of barriers, including condoms for

men, dental dams for women, and spermicides, require a thoughtful and planned approach to sexual activity.

#### IMPACT OF COMPLICATIONS FROM MEDICATIONS

Medicines that effect sexual functioning are said to have "sexual side effects." Medications can disrupt any of the phases of sexual response (Dickman, 2003, Kaplan, 1983).

Because medical illness and traumatic injury can cause mood disorders, patients may be prescribed antidepressant or anxiolytic medications. Antidepressant medications may diminish sexual desire. Men who experience erectile dysfunction due to prostate cancer, diabetes, or cardiovascular disease may experience depression in response to their inability to achieve erection. The treatment of prostate cancer, diabetes, and cardiovascular disease may include the prescription of additional medications, such as hormonal treatment and antihypertensive medications, which can diminish desire, cause erectile dysfunction, and diminish the intensity of orgasm. The inclusion of antidepressant medication to the list that may inhibit sexual desire may cause men to feel sexually "shut down." Although erectile dysfunction medications can help a man achieve better quality erections, and thus rekindle his desire, erectile dysfunction medications cannot improve the quality of orgasms that have been impaired by medications or nerve damage.

Like men, women can experience depression in reaction to cancer, diabetes, and cardiovascular disease. This depression compounds the impact of illness on the body's ability to function sexually. Chemotherapy induces permanent menopause in women ages 35 to 40 in about half of cases. Chemotherapy-induced menopause occurs about 70% of the time in women ages 40 to 45 and 80% of the time in women between the ages of 45 and 50 (Poniatowski, Grimm, & Cohen, 2001). Transient menopause is much more common.

Some gynecological cancers require removing a woman's ovaries, a procedure called an oophorectomy (Schover, 1997). The treatment for breast cancer that is estrogen-receptor positive can lead to early menopause in women among premenopausal women (Chen et al., 2004; Schover, 1997, 1999). By virtue of their effects on estrogen production and metabolism, these treatments may affect vaginal lubrication and the elasticity of the vaginal walls.

Most antidepressants, beta blockers, and antihypertensive medications cause problems in women similar to those in men (Dickman, 2003; Schover, 2000). Diminished desire, loss of ability to lubricate naturally, and diminished quality of orgasm have been reported by women on these medications. Currently, no widely accepted treatment for female sexual dysfunction has been developed that appreciably improves women's response to stimulation. Some herbal combinations depend on plant estrogens to improve a woman's sexual functioning (Rowland & Tai, 2003). These preparations come as a salve to be directly applied on the vaginal wall and clitoris. Some of these preparations have a mild irritant that draws blood to the genitals, and others, which must be obtained by prescription, contain progesterone. The latter come either in a salve form applied to the abdomen or in a ring-shaped vaginal insertion that slowly releases hormones. It should be cautioned, however, that none of these methods has FDA ap-

proval, and social workers should refer patients who are contemplating using these approaches to their physicians.

Social workers should ensure that patients are aware of the sexual side effects of their medications and medical regimes and feel empowered to talk to their physicians about their concerns. This is important even if no viable alternatives to the prescribed medications are available. When patients are able to mourn the losses that illness, injury, and treatment cause, they feel more in control of their conditions. Requesting erectile dysfunction medications or asking a physician to revisit the issue of hormonal replacement or enhancement requires self-advocacy. An important role of health social workers is to help people learn how to communicate with their physicians about sexual issues. At times, role playing can be an effective method to help people practice new ways of communicating in stressful situations.

#### SEXUAL REHABILITATION OF THE MEDICALLY ILL OR TRAUMATICALLY INJURED PERSON

Sex therapy addresses pervasive problems and obstacles to physical intimacy, which may be psychogenic or emotional in nature. The goal of sex therapy is to help patients establish a new, improved baseline of functioning. Sexual rehabilitation counseling also focuses on the impact of medical illness or injury on sexual functioning and intimacy. Its goal is to help individuals restore or return to their baseline functioning or to accommodate a changed baseline of functioning (Gallo-Silver, 2000).

Sexual rehabilitation counseling includes a number of cognitive and behavioral interventions, including safe-touch exercises, the *prolonged kiss*, "dressing" for bed, self-exploration and self-pleasuring exercises, sensate focus or sensual massage exercises, and altering coital positions to accommodate a changed body (Gallo-Silver & Parsonnet, 2001; Schover, 2000).

*Safe-Touch Exercises and Body Mapping* Consistent with the concept that physical intimacy and sexuality have their foundations in touch, sexual rehabilitation counseling may employ a series of safe-touch exercises. Safe-touch exercises were devised to help people who were sexually traumatized by rape, incest, and childhood sexual abuse regain comfort with being touched (Maltz, 2003). Several of these exercises can be useful in helping couples challenged by illness or injury. "Back-writing" involves having the medically challenged person trace a word on the back of his partner using the tip of his finger. The word is traced over and over again until the partner is able to correctly name the word being traced. The exercise is then reversed with the partner tracing a word on the back of the medically challenged person.

Another exercise is a variation of the child's game "Red-Light-Green-Light," in which the medically challenged person gives cues to her partner about where on her body it feels good to be touched (green light), which touches are not comfortable (red light), and which touches are okay at times (yellow light).

Body mapping is based on a similar concept to the exercise just described. An outline of the body is drawn using three colors (green, red, yellow), and the partner then has a map of the parts of the body the medically ill person enjoys being touched.

*The Prolonged Kiss and the Second Kiss* Couples under duress due to medical problems may kiss each other in a quick, almost perfunctory, and, at times, parental manner. The *second kiss* exercise is based on the premise that the couple will be more aware and connected to each other if they kiss a second time. Typically, the second kiss is held for a longer period of time, and the couple tends to feel greater emotional resonance from the second kiss.

*Dressing for Bed* Many people wear old t-shirts, the underwear they wore that day, or tattered and old sleepwear to bed. A seemingly superficial behavioral intervention is to have new clothes to sleep in. These may brighten the mood at a stressful time of the day.

*Self-Exploration and Self-Pleasuring Exercises* Self-exploration and self-pleasuring, or masturbation, are basic behaviors to discover enjoyable sensations (Lukianowicz, 1960; Rowan, 2000). While many cultures and religions prohibit masturbation, it remains a primary way in which men and women discover their sexuality and orgasmic capabilities. Sexual rehabilitation counseling gives medically challenged individuals permission to explore and regain comfort with their changed bodies. Self-pleasuring exercises are included as part of bathing (Gallo-Silver & Parsonnet, 2001). The exercises are then duplicated in a bed or chair. Ultimately, the medically challenged person instructs the partner on what feels good and how to best stimulate her body.

From this foundation, couples frequently turn to sensate focus exercises. Sensate focus exercises are a series of sensual massage techniques that help couples whose sexual activity has been interrupted by illness or injury. Developed by Masters and Johnson (1970), the exercises avoid direct genital massage until the couple has become more comfortable caressing other parts of the body (Kaplan, 1974, 1987; Masters & Johnson, 1970). Altering coital positions to avoid injured or "red-light" areas of the body helps medically challenged individuals conserve energy and helps couples feel safe and secure so they can enjoy physical intimacy with one another.

Sexual rehabilitation exercises have a self-help aspect to them as well. Instructional texts provide easy-to-follow, systematic instructions with drawings that help couples understand exercises. Many of these materials focus on opposite sex couples, but can be easily adapted for same sex couples.

#### CREATING SEX-POSITIVE ENVIRONMENTS OF CARE

The health social worker is a problem solver. Privacy is a major obstacle to physical intimacy in institutional settings. Policies and procedures that insist hospital room doors remain open at all times are changed when patients have a communicable infection or needs protection, such as when they are recovering from a bone marrow or organ transplant. Policies and procedures that frown on adult visitors climbing into bed with adult patients are not used on pediatric floors, where it is routine for parents and their children to be in bed together. Discomfort about physical displays of affection also changes on obstetric units, on which the staff helps to provide a romantic setting for new parents. The contradiction between how intimacy is fostered in these settings for everyone but adults with medical illnesses or injuries is not always apparent to other health professionals. Health so-

cial workers advocate for “bending the rules” on an individual, case-by-case basis. Often, educating the staff about the patient’s and partner’s needs for privacy emphasizes the couple’s love and devotion for one another. Social workers can define a couple’s privacy as part of a supportive care plan that addresses the symptoms of loneliness and sadness about separation. At times, the health social worker is able to change policy with a creative idea that helps their co-professionals understand patient’s needs for privacy and physical contact.

### **Case Example**

The health social worker reported in oncology multidisciplinary rounds that patients frequently wanted more “alone” time with their partners. Even when patients’ doors were closed, the staff entered without knocking or while they were knocking. The social worker pointed out that health-care staff were used to looking at closed doors for special instructions related to protecting the patient and others from infection. The social worker proposed that when the partner was visiting they could place a cardboard cutout of a cupid on the door. In this way, the staff would be aware that the partner was with the patient and wanted privacy. The staff instituted the change and the social worker’s suggestion became part of the facility’s marketing campaign.

Hospital libraries for patients and professionals generally contain few, if any, books on physical intimacy and sexuality. Health social workers can advocate for enriching the libraries by including these materials. Social workers who perform home visits can provide a list of books or pamphlets that can assist patients and their partners to remain physically close. People with chronic and acute illness or injuries do not have routine access to urologists and gynecologists with a knowledge base in sexual difficulties. Social workers can address these gaps by developing education programs to which they invite local experts to meet with patients and their partners in a group setting.

## **CONCLUSION**

Issues of sexuality and physical intimacy are greatly affected by cultural norms. It is beyond the scope of this chapter to explore these issues in detail but it is important to consider how cultural norms change depending on a mixture of scientific discovery and political influences. Homosexuality was once considered a psychiatric illness by many in the mental health professions; physicians once believed that masturbation caused a host of physical and psychological conditions and that the only “healthy” reason for sexual intercourse was procreation and specialists in child abuse and health-care professionals once believed that childhood sexual abuse rarely, if ever, occurred. Nonetheless, the changes in attitudes about these and other sexual issues are by no means universal. The ideas of health-care professionals and the community are often based on religious beliefs, cultural conventions at the time or the person’s specific ethnic or cultural group, and the basic scientific understanding of people as sexual beings. All of these factors may change, become more widely influential, or lose influence depending on the political and cultural climate at the time. Nonetheless sexual issues are quintessentially human issues. When, by reason of culture, politics, or ignorance, the

human aspects of sexuality are overlooked or replaced by viewing sexuality as a completely biological function, an important aspect of quality of life is diminished. People challenged by medical illness and injuries suffer many losses; among them a sense of being entitled to be sexual beings. One of the health social worker's roles is to humanize the health-care experience. Helping the medically ill and injured reclaim their ability to connect with their loved ones; communicate their love physically; receive the loving touch of others; and feel pleasurable physical sensations is a part of humanizing the health-care environment.

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## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 12.1

Identify one policy or procedure within your current internship setting that is an obstacle to physical intimacy. Develop a strategy to change the policy. Whom do you have to meet with to begin this process? What would be the best environment for this discussion: a private meeting, team meeting, rounds? How many alternatives can you devise that preserve some of the policy but enhance a person's opportunities for physical intimacy?

### LEARNING EXERCISE 12.2

Divide the class into dyads. With eyes closed, trace a word on your partner's palm until he or she guesses the word.

### LEARNING EXERCISE 12.3

Write down your own sexual history. Read it silently to yourself. How difficult would it be to share this information with a stranger? What would a stranger need to do, say, or demonstrate to help you feel more comfortable with a discussion of your history? Share your thoughts with the class.

### LEARNING EXERCISE 12.4

With what type of client or patient would you feel most comfortable discussing sexual issues and why? With what type of client or patient would you feel most uncomfortable discussing sexual issues and why?

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## CHAPTER 13

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# Substance Use Problems in Health Social Work Practice

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**S**UBSTANCE USE PROBLEMS are widespread in our society and are present across persons with diverse age, gender, sexual orientation, racial, cultural, and socioeconomic backgrounds. Social workers, regardless of the setting in which they work, are likely to encounter clients with substance use problems. Given the health effects of substance use, social workers in health-care settings are particularly likely to encounter this population. Whether patients present with physical illnesses directly related to substance use (e.g., cirrhosis of the liver) or with health problems with no obvious link to substance use, it is crucial that health social workers be aware of the potential role of substance use in clients' health, treatment, and social needs (Abbott, 2002). This chapter provides health social workers with basic knowledge and core skills necessary to address substance use problems across a variety of clients and health-care settings.

### CHAPTER OBJECTIVES

- Define terms and diagnostic categories used to describe substance use problems.
- Identify the prevalence of substance use and problems across sociodemographic groups.
- Present information about the psychoactive and health effects of substances that are commonly used.
- Provide an overview of prominent approaches to assist people experiencing substance use problems and research regarding their use in practice.
- Provide general information to guide screening for substance use problems and brief intervention to address these problems in health-care settings.

## DEFINITION OF TERMS

A variety of expressions are used to describe substance use problems in lay and professional writing and conversation. *Addiction*, *drug abuse*, and *alcoholism* are but a few common terms. It is widely agreed, however, that these and other terms are not always used in a consistent fashion (National Institute on Alcohol Abuse and Alcoholism [NIAAA], Center for Substance Abuse Prevention [CSAP], & Public Health Service, 1995; White, 1998). Yet, the use of a stable vocabulary is essential. Additionally, because of the particular role of health social workers as translators between health-care systems and patients (see Chapter 9 in this *Handbook* for a discussion of communication), it is especially important to use language in a clear, concise, and consistent manner. Thus, this chapter begins with clarification of terms and expressions.

This entire domain is often referred to as the *substance abuse field* or the *addictions field* (van Wormer & Davis, 2003). While both labels provide a shortcut to describing the field, it is important to note that they also can take on other meanings depending on the context. *Substance abuse*, although commonly used to denote a range of substance use problems, distinguishes a specific disorder in the *Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV)*; American Psychiatric Association, 1994). *Addiction* most commonly implies a severe level of problematic substance use that involves dependence. Furthermore, addiction is often applied to problematic behaviors other than substance use (e.g., gambling). In this chapter, the discussion is limited to the behavior of problematic psychoactive substance use; however, it is not restricted to substance use that meets the criteria for specific disorders, but rather, the discussion includes all levels of problematic use. Accordingly, the expression *substance use problems* is used to designate the entire range of problematic substance use. At times, when brevity and grammar require it, the term *substance abuse* is used in a general way to denote all levels of substance use problems.

The term *substance* refers to both legal and illegal psychoactive substances that affect the central nervous system (CNS) when consumed. Users experience pleasure or diminished pain through the alteration of mood, cognition, perception, memory, or consciousness. Alcohol, nicotine, and caffeine are legal psychoactive substances. The term *drug* is most often used to refer to illegal "street" psychoactive substances (e.g., marijuana, cocaine, heroin) and prescribed medications used illegally. The acronyms AOD (alcohol and other drugs) and ATOD (alcohol, tobacco, and other drugs), however, emphasize that alcohol and tobacco are themselves drugs. These acronyms assist in countering the popularly held myth that street drugs are different from, and more dangerous than, alcohol and tobacco. In this chapter, the term *substance* denotes both legal and illegal psychoactive substances. Although caffeine, a stimulant, is widely used, it "does not ordinarily pose a threat to health or an impairment to functioning" (McNeece & Barbanall, 2005, p. 16) and, therefore, is not included in the discussion of legal drugs.

It is important to note that there are levels of problematic substance use that do not meet the criteria for a diagnosable disorder, but nonetheless may require attention. Standard terminology exists for designating amount of use and potential risk. For example, research on and clinical screening for problematic alcohol use generally defines *current use* as at least one drink in the past 30 days; *binge use* as five or more drinks on the same occasion at least once in the past 30 days; and *heavy use* as five or more drinks on the same occasion at least 5 different days in the past 30 days, according to the Substance Abuse and Mental Health Services

Administration (SAMHSA, 2004); however, NIAAA (2004a) has recently revised the definition of binge drinking to consumption that elevates blood alcohol concentration (BAC) to .08 gram percent and higher. This BAC is typically achieved among men by consuming five drinks or more in a 2-hour period and among women by consuming four drinks or more in a 2-hour period.

*Intoxication, withdrawal, craving, tolerance, dependence, and addiction* are important terms that describe various aspects of the experience of using psychoactive substances. Intoxication describes a reversible state caused by the recent use of a substance that is typically characterized by a substance-specific constellation of physiological, behavioral, and cognitive-emotional changes. Withdrawal, on the other hand, describes substance-specific behavioral, physiological, and cognitive-emotional changes that result from stopping or reducing substance use, particularly when use has been significant and long-term. Withdrawal typically involves the opposite experiences that are associated with intoxication of the substance consumed (e.g., the euphoria of cocaine intoxication is countered by feelings of depression in cocaine withdrawal) and occurs with the following psychoactive substances: alcohol; nicotine; cocaine; opioids; amphetamines and related substances; and sedatives, hypnotics, or anxiolytics. Craving, or the intense desire to use the substance, often occurs while in the state of withdrawal to alleviate symptoms (American Psychiatric Association, 1994). After using a substance over time, individuals develop *tolerance* when they must use more of the substance to achieve the same effect previously achieved with a smaller amount (Wilcox & Erickson, 2005). The terms *addiction* and *dependence* are not easily or consistently defined. In many instances, they imply the presence of both tolerance and withdrawal; however, the actual diagnosis of substance dependence does not necessarily require the experience of tolerance or withdrawal (American Psychiatric Association, 1994).

## DIAGNOSTIC CATEGORIES

The *Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV; American Psychiatric Association, 1994)* classifies substance-related disorders into two groups. Substance use disorders are defined by a pattern of problematic substance use and include the diagnostic categories of substance abuse and substance dependence. Substance-induced disorders refer to the patterns of physiological, behavioral, cognitive, and emotional responses to substance ingestion and substance use cessation. These include substance intoxication and substance withdrawal as well as substance-induced mental disorders (e.g., delirium, persisting dementia, persisting amnesic disorder, psychotic disorder, mood disorder, anxiety disorder, sexual dysfunction, sleep disorder).

The *DSM-IV* provides general criteria that apply across substances for substance abuse, dependence, intoxication, and withdrawal. Additionally, it provides specific information for each of these diagnoses across 11 different classes of substances. This section describes general criteria for substance use disorders.

### SUBSTANCE ABUSE

This disorder is characterized by repeated use of a substance that leads to negative consequences but is not severe enough to meet the criteria for substance

**Table 13.1**  
*DSM-IV* Diagnostic Criteria for Substance Abuse

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- A. A maladaptive pattern of substance use leading to clinically significant impairment or distress, as manifested by one (or more) of the following occurring within a 12-month period:
1. Recurrent substance use resulting in a failure to fulfill major role obligations at work, school, or home.
  2. Recurrent substance use in situations in which it is physically hazardous.
  3. Recurrent substance-related legal problems.
  4. Continued substance use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of the substance.
- B. The symptoms have never met the criteria for Substance Dependence for this class of substance.
- 

*Source: Diagnostic and Statistical Manual of Mental Disorders, fourth edition, by American Psychiatric Association, 1994, Washington, DC: Author, pp. 182–183.*

dependence diagnosis. Nicotine and caffeine are not included among the substances that can meet criteria for abuse. Specific *DSM-IV* criteria for substance abuse are presented in Table 13.1.

#### SUBSTANCE DEPENDENCE

This disorder is characterized by a constellation of symptoms indicating that the individual continues to use the substance although significant negative consequences result. The individual repeatedly seeks and consumes the substance and may experience tolerance for and withdrawal from the substance. Individuals who meet the criteria for substance dependence disorder are not diagnosed with substance abuse disorder. Specific criteria are presented in Table 13.2.

The terms *alcoholism* and *drug addiction* are generally interchangeable with *substance dependence*. *Alcoholic* and *addict* are terms used to describe the person with alcohol dependence disorder or another substance (generally illegal) dependence disorder, respectively. These terms are part of a common vocabulary within many self-help groups such as Alcoholics Anonymous (AA) and can be important identifying labels for those active in these groups. Nonetheless, these labels can also be stigmatizing. It is preferable to replace the terms *alcoholic* and *addict* with *person with alcohol (or other substance) dependence*.

#### COMMONLY USED SUBSTANCES

Media representations of substance abuse tend to convey stereotypes that focus on persons with limited incomes in inner cities selling and using illegal drugs (Cornelius, 2002). While there is no doubt that drug use is a problem for the inner city, its reach and magnitude go far beyond the confines of urban areas with high rates of poverty and include diverse racial, cultural, gender, and income groups. Furthermore, it is the use of legal drugs, tobacco and alcohol, across socioeconomic groups and regions that represent the most prevalent and costly component of drug-related problems (SAMHSA, 2004). This section provides information about the epidemiology and the psychoactive and health effects of legal and illegal sub-

**Table 13.2**  
*DSM-IV* Diagnostic Criteria for Substance Dependence

A maladaptive pattern of substance use, leading to clinically significant impairment or distress, as manifested by three (or more) of the following, occurring at any time in the same 12-month period.

1. Tolerance, as defined by either of the following:
  - a. A need for markedly increased amounts of the substance to achieve intoxication or desired effect.
  - b. Markedly diminished effect with continued use of the same amount of the substance.
2. Withdrawal, as manifested by either of the following:
  - a. The characteristic withdrawal syndrome for the substance.
  - b. The same (or a closely related) substance is taken to relieve or avoid withdrawal symptoms.
3. The substance is often taken in larger amounts or over a longer period than was intended.
4. There is a persistent desire or unsuccessful efforts to cut down or control substance use.
5. A great deal of time is spent in activities necessary to obtain the substance, use the substance, or recover from its effects.
6. Important social, occupational, or recreational activities are given up or reduced because of substance use.
7. The substance use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance.

*Source: Diagnostic and Statistical Manual of Mental Disorders, fourth edition, by American Psychiatric Association, 1994, Washington, DC: Author, p. 181.*

stances that are commonly used in problematic ways. Epidemiological data based on the 2003 National Survey on Drug Use and Health (SAMHSA, 2004) are summarized by age groups in Tables 13.3 through 13.6.

Psychoactive substances are categorized in multiple ways (e.g., according to their chemical properties or their effects on the central nervous system). The following section uses the categorization system employed by SAMHSA in their annual survey, the National Survey on Drug Use and Health (NSDUH). The section begins with a discussion of alcohol and tobacco, the two substances for which prevalence and cost (both for the individual and society) are greatest. It then turns to a discussion of selected illegal substances.

## ALCOHOL

The 2003 NSDUH indicates that about half of all Americans aged 12 and older report current use of alcohol (SAMHSA, 2004). More than 50% of American adults have a close family member who has met the diagnostic criteria for alcohol dependence (Dawson & Grant, 1998). Among children under the age of 18 in the United States, approximately one in four is exposed to alcohol abuse or alcohol dependence in the family (Grant, 2000). In the United States and worldwide, alcohol is one of the most widely used and dangerous drugs. While recent research suggests that low levels of alcohol use may be beneficial in reducing risk of coronary heart disease, the mechanisms through which such influence is exerted are

**Table 13.3**  
Percentage of Substance Use among Persons Ages 12 to 17 by Demographic Characteristics: 2003

Demographic Characteristics	Type of Substance Use														
	Alcohol			Tobacco			Marijuana			Inhalants			Psychotherapeutics		
	Lifetime	Past Month	Binge Use, Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month
Total	42.9	10.6		34.5	14.4		19.6	7.9		10.7	1.3		13.4	4.0	
Gender															
Male	41.9	11.1		36.1	15.6		20.1	8.6		10.9	1.1		12.8	3.7	
Female	43.9	10.1		32.9	13.3		19.0	7.2		10.5	1.5		14.1	4.2	
Hispanic Origin and Race															
Not Hispanic or Latino	42.4	10.9		34.8	15.3		19.6	8.1		10.7	1.2		13.4	4.1	
White	44.8	12.8		37.5	17.4		20.5	8.8		11.7	1.2		14.3	4.2	
African American	36.1	4.6		27.0	8.8		17.8	5.9		6.8	0.8		11.2	3.4	
American Indian	45.1	12.4		50.1	26.8		34.2	15.3		11.8	2.0		17.2	5.9	
Asian	27.7	3.2		18.6	4.1		8.0	3.0		9.4	1.1		6.7	2.8	
Two or more races	40.5	10.8		36.7	16.5		23.4	10.5		11.1	2.4		13.3	4.7	
Hispanic or Latino/a	45.3	9.4		33.1	10.3		19.2	6.8		10.6	1.8		13.3	3.6	

Source: 2003 National Survey on Drug Use and Health: National findings (Office of Applied Studies, NSDUH Series H-25, DHHS Publication No. SMA 04-3964), by the Substance Abuse and Mental Health Services Administration, 2004, Rockville, MD: Author.



**Table 13.4**  
**Percentages of Substance Use among Persons Ages 18 to 25 by Demographic Characteristics: 2003**

Demographic Characteristics	Type of Substance Use															
	Alcohol			Tobacco			Marijuana			Cocaine			Psychotherapeutics			
	Lifetime	Past Month	Binge Use, Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month	
Total	87.1	41.6	41.6	74.8	44.8	44.8	53.9	17.0	17.0	15.0	2.2	2.2	29.0	6.0	6.0	
Gender																
Male	87.6	51.3	51.3	79.5	51.7	51.7	57.2	21.0	21.0	17.4	2.9	2.9	30.7	6.8	6.8	
Female	86.5	31.8	31.8	70.0	37.8	37.8	50.6	13.0	13.0	12.5	1.5	1.5	27.4	5.2	5.2	
Hispanic Origin and Race																
Not Hispanic or Latino	88.0	42.7	42.7	75.9	46.6	46.6	56.2	18.2	18.2	14.7	2.2	2.2	30.4	6.4	6.4	
White	90.7	47.8	47.8	80.5	50.5	50.5	59.1	19.1	19.1	17.6	2.7	2.7	35.1	7.4	7.4	
African American	78.6	24.2	24.2	61.3	34.0	34.0	49.0	16.4	16.4	3.1	0.2	0.2	13.9	2.5	2.5	
American Indian	85.5	41.6	41.6	87.6	64.9	64.9	69.6	27.3	27.3	31.5	3.1	3.1	38.0	10.9	10.9	
Asian	79.0	27.8	27.8	55.7	28.0	28.0	34.0	9.3	9.3	7.4	0.6	0.6	14.9	3.5	3.5	
Two or more races	90.7	40.0	40.0	79.4	48.8	48.8	65.7	22.9	22.9	17.7	5.5	5.5	35.2	7.2	7.2	
Hispanic or Latino/a	82.9	36.5	36.5	69.4	36.3	36.3	43.5	11.6	11.6	16.2	2.2	2.2	22.7	4.4	4.4	

Source: 2003 National Survey on Drug Use and Health: National findings (Office of Applied Studies, NSDUH Series H-25, DHHS Publication No. SMA 04-3964), by Substance Abuse and Mental Health Services Administration, 2004, Rockville, MD: Author.

**Table 13.5**  
**Percentages of Substance Use among Persons Ages 26 and Older by Demographic Characteristics: 2003**

Demographic Characteristics	Type of Substance Use															
	Alcohol			Tobacco			Marijuana			Cocaine			Psychotherapeutics			
	Lifetime	Past Month	Binge Use, Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month	Lifetime	Past Month	Past Month	
Total	88.0	21.0	21.0	77.6	29.3	29.3	41.2	4.0	4.0	16.3	0.8	0.8	19.5	1.9	1.9	
Gender																
Male	92.7	30.1	30.1	86.3	36.0	36.0	47.2	5.6	5.6	20.7	1.2	1.2	21.2	1.8	1.8	
Female	83.6	12.6	12.6	69.8	23.1	23.1	35.8	2.5	2.5	12.2	0.4	0.4	17.9	2.0	2.0	
Hispanic Origin and Race																
Not Hispanic or Latino	89.2	20.6	20.6	79.5	30.1	30.1	43.0	4.2	4.2	16.7	0.8	0.8	20.1	1.8	1.8	
White	91.1	21.2	21.2	82.6	30.4	30.4	44.6	4.3	4.3	17.5	0.7	0.7	21.8	1.9	1.9	
African American	83.7	20.6	20.6	70.7	33.1	33.1	40.7	4.8	4.8	15.0	1.7	1.7	12.7	1.4	1.4	
American Indian		30.5	30.5	83.4	40.0	40.0	48.4	5.8	5.8	19.6	0.8	0.8	23.7	3.3	3.3	
Asian	71.2	8.8	8.8	46.8	12.2	12.2	16.1	0.3	0.3	3.8	0.2	0.2	7.7	1.2	1.2	
Two or more races	86.5	20.6	20.6	85.2	35.5	35.5	60.3	6.3	6.3	26.2	1.0	1.0	24.8	0.9	0.9	
Hispanic or Latino/a	78.3	23.8	23.8	62.7	22.9	22.9	26.8	2.7	2.7	13.2	0.8	0.8	15.1	2.4	2.4	

Source: 2003 National Survey on Drug Use and Health: National findings (Office of Applied Studies, NSDUH Series H-25, DHHS Publication No. SMA 04-3964), by Substance Abuse and Mental Health Services Administration, 2004, Rockville, MD: Author.

**Table 13.6**  
Percentages of Substance Use among Older Adults by Age Groups: 2003

Age Groups	Alcohol		Tobacco		Psychotherapeutics	
	Past Month	Binge Use, Past Month	Lifetime	Past Month	Lifetime	Past Month
55–59	52.9	15.5	80.9	26.4	14.2	0.3
60–64	46.2	11.9	80.6	20.1	9.0	0.6
65 or older	34.4	7.2	71.4	13.2	3.6	0.5

Source: 2003 National Survey on Drug Use and Health: National findings (Office of Applied Studies, NSDUH Series H-25, DHHS Publication No. SMA 04-3964), by the Substance Abuse and Mental Health Services Administration, 2004, Rockville, MD: Author.

unclear and may include patterns of drinking, type of drink consumed, and other possible factors related to socioeconomic background, general health, and behaviors that support health (NIAAA, 1999, 2000). Problematic use of alcohol leads to deleterious effects on biological, psychological, and social well-being. Furthermore, its effects may extend beyond the individuals engaged in problematic alcohol use to their families and communities.

Alcohol is a CNS depressant that, unlike many other psychoactive substances, is thought to affect multiple CNS neurotransmitter systems (Moak & Anton, 1999). Kranzler and Anton (1994) suggest that the relationships between alcohol and neurotransmitter systems are likely to vary across subtypes of persons with alcohol use problems. Relatedly, individuals vary in their levels of vulnerability toward alcohol use disorders. Research suggests that genetics account for approximately 60% of total vulnerability (Prescott & Kendler, 1999). Thus, close relatives of persons with alcohol use disorders should be educated about their increased risk.

*Epidemiology* As displayed in Tables 13.3 through 13.6, the 2003 NSDUH indicates that young adults aged 18 to 25 experience the highest rates of problem drinking (SAMHSA, 2004). Approximately 41.6% of this group reported binge drinking in the past month, and 15.1% reported heavy alcohol use in the same time period. Within this group, men were more likely than women to report binge (51.3% versus 31.8%) and heavy (21.2% versus 9.0%) alcohol use. African American young adults were least likely to report binge (24.2%) and heavy (5.4%) use. White American young adults aged 18 to 25 reported the highest rates of problematic alcohol use (47.8% and 19% for binge and heavy use, respectively).

In the same survey, adolescents aged 12 to 17 reported alcohol use at rates that are cause for concern. Approximately 34.3% used alcohol in the past year and 10.6% of the same group had engaged in binge drinking in the past month. Gender differences in drinking rates were less significant among adolescents than among young adults. Interestingly, girls aged 12 to 17 reported greater lifetime alcohol use than boys (43.9% versus 41.9%). Rates of past month binge use were comparable for boys and girls (11.1% and 10.1%, respectively). Among racial/ethnic\* groups, Asian adolescents reported the lowest rates of lifetime use (27.7%)

\*The groups may be ethnic or racial in composition, but for simplicity, the term *racial* will be used in the remainder of the chapter.

and past month binge use (3.2%). African American youth also reported relatively low binge use rates (4.6%). Hispanic American, American Indian, and White American adolescents reported the highest levels of lifetime use (approximately 45%), however, Hispanic American persons aged 12 to 17 were less likely to engage in binge drinking than were White Americans and American Indians in this age group (9.4% versus 12.8% and 12.4%).

After a peak in young adulthood, rates of alcohol use, binge use, and heavy use slowly decline as adults age (SAMHSA, 2004). Between the ages of 26 and 64, current alcohol use decreases from 61.7% to 46.2%. Likewise, rates of binge and heavy alcohol use slowly decrease as adults become older (from 38.0% to 11.9% for binge drinking and from 11.4% to 2.5% for heavy drinking). Men and women aged 26 and older differed in their reported rates of binge drinking (30.1% versus 12.6%). Among racial groups within the same age range, American Indian adults report the highest rate of binge drinking (30.5%), Asian adults report the lowest rate of binge drinking (8.8%), and all other racial groups report rates between 20.6% and 23.8%.

Over 7% (7.2%) of adults aged 65 and older reported binge drinking and 1.8% reported heavy drinking (SAMHSA, 2004). Although these rates are relatively low when compared with younger and middle-aged adults, alcohol use in older populations constitutes a serious problem that should not be overlooked. Older adults have unique vulnerabilities that put them at greater risk of negative outcomes when using even relatively small amounts of alcohol. For example, individuals in this group may reach higher blood alcohol content with less alcohol consumption than individuals in other groups (NIAAA, 2004a). Additionally, alcohol use may increase the risk of falls among older adults and recovery from such incidents can be difficult (Center for Substance Abuse Treatment [CSAT], 1998).

*Health Effects* The health effects of alcohol use are wide ranging and staggering. Alcohol has an effect on multiple organs and systems and is associated with several types of cancer. Illnesses that are a direct result of or are severely exacerbated by alcohol use account for 20% to 40% of patients in urban hospitals (NIAAA, 2000). Alcohol is often involved in violence, injury, and trauma, leading to significant and repeated contacts with the health-care system. Research suggests that alcohol is associated with 67% of partner assaults, 37% of rapes, 50% of homicides, and 40% of traffic fatalities (NIAAA, 2000). Perhaps the most telling evidence of alcohol's negative impact on health is the fact that average life span is decreased by 10 to 15 years for persons with alcohol dependence (Schuckit & Tapert, 2004).

Considerable research demonstrates that chronic heavy drinking is a leading cause of cardiovascular illnesses (NIAAA, 2000). In fact, heart disease is the leading cause of early mortality among those with alcohol dependence (Schuckit & Tapert, 2004). Men with alcohol dependence are two times more likely than men without alcohol dependence to die from atherosclerotic and degenerative heart disease; women with alcohol dependence are four times more likely to die from these diseases than those without alcohol dependence (McNeece & DiNitto, 2005). Although consumption of alcohol in low to moderate amounts (not more than two drinks per day for men and one drink per day for women) is associated with lower risk of coronary heart disease among certain groups, it is unclear that the alcohol itself causes the lower risk (NIAAA, 1999, 2000). As noted previously,

it may be that consistent low consumption of alcohol is a proxy for other explanatory factors such as higher socioeconomic status, better preventive health care, and differences in patterns or type of alcohol consumption (NIAAA, 2000).

Liver disease is commonly associated with alcohol use. According to the 10th Special Report to the U.S. Congress on Alcohol and Health (NIAAA, 2000), "long-term heavy alcohol use is the leading cause of illness and death from liver disease in the United States" (p. 198). The liver is central to human survival and health because it both processes key nutrients and assists the body's defense system to filter toxins from the blood. Long-term moderate to heavy alcohol use is associated with changes in the liver that are described in three phases, together known as Alcoholic Liver Disease. Fatty liver, the first phase of the disease, is generally reversible with abstinence. The second phase of alcoholic liver disease, alcoholic hepatitis, is characterized by inflammation of the liver. Cirrhosis, or scarring of the liver, is the final phase of this disease. The prognosis for persons who have both alcoholic hepatitis and cirrhosis is poor, with a death rate over a 4-year period greater than 60% (Chedid et al., 1991). Alcohol also plays a significant role in other types of liver diseases. For example, alcohol consumption may enhance acetaminophen liver toxicity, and, although the specific mechanism is unknown, alcohol consumption is associated with greater severity of hepatitis C (NIAAA, 2000).

People who have alcohol dependence are at increased risk for cancer, especially of the head, neck, esophagus, and stomach and lung cancer occurs at higher rates in this group, even after controlling for smoking status. Although not yet well understood at a physiological level, it is clear that heavy alcohol use has a significant effect on the immune system. Infections that are a result of immune deficiency, such as pneumonia, occur at higher rates among persons who are heavy alcohol users than among the general population. HIV rates are higher among persons who abuse alcohol, but it is not known whether this is a result of risky sexual behavior while under the influence of alcohol, or if alcohol consumption itself increases susceptibility to the infection (NIAAA, 2000).

Chronic alcohol use can lead to multiple neurological disorders. Neuropathy, a disorder of the nerves in which an individual experiences pain and numbness in the legs and feet, is associated with heavy alcohol use. Wernicke's syndrome and Korsakoff's psychosis are also related to heavy use. They often occur in combination and are characterized by confusion, inability to learn new material, and other cognitive deficits (McNeece & DiNitto, 2005).

Risk of Fetal Alcohol Syndrome (FAS) and other alcohol exposure related disorders are of particular concern for women of childbearing age. Drinking alcohol during pregnancy increases the risk of spontaneous abortion, low birth weight, small brain volume, heart defects, varying levels of mental retardation, and facial abnormalities. Although binge drinking is associated with increased risk to the fetus, no amount of alcohol consumption during pregnancy has been established as safe (Stratton, Howe, & Battaglia, 1995).

## TOBACCO

Although it is common knowledge that tobacco is toxic, and that its nicotine component is extremely addictive, tobacco use is often not included in the substance abuse literature. And yet, no other psychoactive substance is associated with the

morbidity and mortality of tobacco (Slade, 1999). The National Institute on Drug Abuse (NIDA; 2001a) reports that "Tobacco kills more than 430,000 U.S. citizens each year—more than alcohol, cocaine, heroin, homicide, suicide, car accidents, fire, and AIDS combined" (p. 3). In spite of high rates of use, known negative health consequences, and the fact that treatment works (NIDA, 2001a), health providers rarely offer smokers assistance with quitting (U.S. Public Health Service [USPHS], 2000). Furthermore, individuals who have other substance use problems or serious mental illness are even less frequently offered assistance with smoking cessation, even though they may have a greater need for services than the general population (Grant, Hasin, Chou, Stinson, & Dawson, 2004).

The reasons for this treatment failure are complex. Until recently, few effective treatments for smoking cessation had been identified. Furthermore, health-care systems did not support their consistent delivery (USPHS, 2000). However, research conducted by Lemon, Friedman, and Stein (2003) with 2,316 participants from the Drug Abuse Treatment Outcome Study (DATOS) who reported consumption of cigarettes at the beginning of the study and who participated in follow-up interviews suggests that smoking cessation is positively associated with increased abstinence from illegal drug use at 12 months after completing substance use treatment. While it should be noted that those who smoke less were more likely to stop and that those who completed treatment were more likely to be in this sample, the research can "raise questions about the clinical myth that nicotine dependence should be treated only after stabilization of the primary drug dependence" (p. 1330). Similarly, smoking cessation efforts may be particularly relevant among people living with HIV among whom smoking may negatively affect immune functioning over time and increase risk of infections of the respiratory tract (Chiasson, 1994).

Initial ingestion of nicotine can result in unpleasant experiences such as headaches and nausea. Tolerance to these symptoms develops quickly, however, and regular users report that tobacco helps with relaxation and concentration (Slade, 1999). Addiction occurs with regular use, and withdrawal symptoms such as irritability, sleep disturbances, craving, and cognitive deficits can occur for a month or more following cessation of use (NIDA, 2001a).

*Epidemiology* The 2003 NSDUH estimated that 29.8% of the U.S. population aged 12 and older were current users of tobacco products. Adolescents aged 12 to 17 reported current use rates of 14.4%. Boys were more likely than girls to report use (15.6% versus 13.3%). American Indian adolescents reported the highest rates of tobacco use (26.8%) and Asian youth reported the lowest rates (4.1%) of all racial groups.

Similar to patterns of alcohol use, current tobacco use rates peaked during young adulthood. Among persons aged 18 to 25, 44.8% reported using tobacco in the past month. Rates of use among gender and racial groups in this age group varied similarly to those seen among adolescents. Men used at rates greater than women (51.7% versus 37.8%). Asian and African American young adults reported the lowest rates of current use (28.0% and 34.0%, respectively), whereas American Indian and White American young adults reported the highest rates of current use (64.9% and 50.0%).

Among persons aged 26 and older, 29.3% reported current tobacco use. Men continued to use at rates greater than women (36.0% versus 23.1%).



*Health Effects* The negative effects of tobacco on health and the health-care system are legion. Approximately 8.6 million Americans suffer from at least one serious illness caused by smoking and annual estimates indicate that smoking is responsible for economic losses of \$75 billion in excess medical expenditures (Centers for Disease Control and Prevention [CDC], 2004). Cigarette use is strongly associated with lung cancer, heart disease, and chronic pulmonary obstructive disease (emphysema and chronic bronchitis). Smokers are at increased risk for stroke and peripheral vascular disease, and many cancers of the mouth, throat, larynx, and esophagus are related to cigarette use (NIDA, 2001a; Slade, 1999). NIDA (2001a) reported that "cigarette smoking is the most important preventable cause of cancer in the United States" (p. 5).

It is estimated that approximately 20% of pregnant women in the United States smoke throughout their pregnancies (NIDA, 2001a), an alarming statistic given that maternal smoking is associated with a variety of adverse pregnancy outcomes, including abruption of the placenta (separation from the uterine wall), low birth weight, premature delivery, and increased risk of sudden infant death syndrome (SIDS; NIDA, 2001a; Slade, 1999). In a large study examining the prenatal effects of multiple substances, Shiono et al. (1995) concluded that "In the United States, cigarette smoking remains the single largest preventable cause of adverse pregnancy outcomes" (p. 26).

#### CANNABIS

Among the U.S. population age 12 and older, approximately 10.6% and 6.2% reported marijuana use in the past year and month, respectively (SAMHSA, 2004). These prevalence rates make marijuana the most commonly used illegal drug. Stephens (1999) noted that "despite the prevalence of use there is a surprising small literature on the problematic use of cannabis" (p. 126). Literature examining the effects of marijuana is conflicting and most purported findings are in need of replication. For example, some longitudinal studies have found that heavier marijuana use in adolescence is associated with less stability in adult roles (Kandel, Davies, Karus, & Yamaguchi, 1986), however, it is unclear whether these outcomes are due to marijuana use, or if they are better explained by other substance use or preexisting differences between heavy marijuana users and others (Stephens, 1999).

Cannabis is most often smoked, but is sometimes mixed into food. Users may experience mild euphoria, relaxation, and enhancement or distortion of perceptual experiences. Intoxication often involves impairment in attention and short-term memory. Typically lethargy and sleepiness occur as the effects wear off (Stephens, 1999). Addiction can occur as a result of long-term use in some people (NIDA, 2004a) and some authors report that clinicians are encountering "more marijuana-dependent patients than ever before" (Gold, Frost-Pineda, & Jacobs, 2004, p. 177).

*Epidemiology* As previously noted, the 2003 NSDUH reported that 6.2% of persons aged 12 or older were current users of marijuana. Among illegal substance users specifically, 75.2% reported that they had used marijuana, making it the most commonly used illegal substance. This was true across broad age groups; however, it is interesting to note that 12- and 13-year-olds reported current use of psychotherapeutics (prescription-type medications used nonmedically; 1.8%)

and inhalants (1.4%) at rates greater than marijuana (1.0%). Rates of cannabis use peaked for 18- to 25-year-olds with 17% reporting current use. Male young adults reported higher current use rates (21.0%) than female young adults (13.0%). This gender difference continued among persons aged 26 and older with 5.6% of men and 2.5% of women reporting current use. Among adolescents, the gender differences were in the same direction, but were less substantial with 8.6% of boys and 7.2% of girls reporting current use.

Asian and African American youth ages 12 to 17 reported the lowest rates of current use (3.0% and 5.9%, respectively), whereas American Indian youth, White American youth, and youths who identified as two or more races reported the highest rates (15.3%, 8.8%, and 10.5%, respectively). These three groups continued to report current use at rates higher than those of other groups among persons ages 18 to 25; however, noteworthy percentages of African American, Hispanic American, and Asian young adults also reported current marijuana use, as identified in Table 13.4.

*Health Effects* Few conclusive negative health effects directly related to marijuana use exist. One primary concern is related not to the psychoactive ingredients of marijuana, but rather, to the preferred mode of its administration (Stephens, 1999). Like tobacco, marijuana is frequently smoked and appears to pose similar health risks such as increased rates of respiratory problems and cancer (NIDA, 2002a; Slade, 1999). Research examining marijuana use during pregnancy has produced mixed findings. Some studies have shown that smoking marijuana during pregnancy is associated with low birth weight (Hatch & Bracken, 1986; Zuckerman et al., 1989); however, a large multicenter study found that when tobacco use was controlled for, marijuana use was not related to low birth weight or preterm delivery (Shiono et al., 1995).

## COCAINE

Cocaine is a powerful stimulant currently used by approximately 1% of persons aged 12 and over in the United States (SAMSHA, 2004). It is most commonly sold as a white powder and can be snorted, injected, or smoked. Immediate effects include: mental alertness; increased energy; euphoria; and increased heart rate, blood pressure, and body temperature. With high duration and doses of stimulants, individuals may experience *stimulant delirium*, which can include symptoms of disorientation, confusion, anxiety and fear; in episodes of high doses individuals may also experience symptoms of psychosis and paranoia and behavioral compulsions (Kosten & Sofuoglu, 2004).

The onset, duration, and intensity of these effects depend on the route of administration. For example, crack cocaine, easily processed by cooking powder cocaine with water and ammonia or sodium bicarbonate (baking soda), is smoked, resulting in a rapid and intense high within a matter of seconds (Kosten & Sofuoglu, 2004; NIDA, 1999a). Snorting powder cocaine generally elicits effects within 20 minutes; intravenous injection generally elicits effects in 30 seconds (Kosten & Sofuoglu, 2004).

*Epidemiology* In 2003, 14.7% of U.S. persons aged 12 and older reported that they had used cocaine during their lifetimes. Men were more likely than women to report both lifetime use (18.3% versus 11.3%) and current use (1.3% versus 0.6%).

Among adolescents aged 12 to 17, however, girls reported greater lifetime and current use than boys (2.7% versus 2.5% and 0.7% versus 0.5%, respectively). Youth who identified as being of two or more races, White American, or Hispanic American reported the highest rates of current cocaine use (0.7% to 0.8%) whereas the lowest rate of current use (0.1%) was reported by African American adolescents.

Current cocaine use peaked among 22-year-olds (2.6%). Young adult men (aged 18 to 25) reported current use rates of 2.9%, whereas 1.5% of women aged 18 to 25 reported current use. As with adolescent racial groups, African American young adults reported the lowest rate of current cocaine use at 0.2%. This trend changed, however, among adults aged 26 and older with African Americans reporting the highest current use rate (1.7%).

*Health Effects* Heavy use of cocaine and other stimulants often result in health problems involving multiple systems. Cardiovascular and gastrointestinal illnesses are common, as are problems with the central nervous system and reproductive system (Weaver & Schnoll, 1999). McNeese and DiNitto (2005) identify the cardiovascular risks associated with cocaine overdose (e.g., cardiac arrest and death); however, Weil and Rosen (1993) assert that although cocaine can burden the heart's functioning, cocaine-related deaths are uncommon and that the primary negative effects of problematic cocaine use are psychological and social rather than physiological.

Research suggests that cocaine is particularly dangerous when used in combination with alcohol. The body transforms cocaine and alcohol into a substance (cocaethylene) that is more toxic than either drug alone. This mixture results in more deaths than any other two-drug combination (NIDA, 1999a).

Many studies have documented that babies born to women who use cocaine during pregnancy are prematurely delivered, of low birth weight, and have smaller head circumferences than babies not exposed to cocaine in utero (NIDA, 1999a). Due to methodological limitations, however, it has been difficult for research to tease out the effects of cocaine from those of other co-occurring conditions such as maternal use of other substances, lack of prenatal care, and low socioeconomic status (Singer, 1999). Furthermore, NIDA (1999a) asserts that predictions about "crack babies" suffering profound irreversible damage has proven to be a "gross exaggeration" because most of these children have been able to recover from earlier deficits (p. 6). They do caution, however, that more sophisticated research techniques are now demonstrating an association between fetal cocaine exposure and later subtle deficits in behaviors such as concentration and blocking out distractions.

## HEROIN

In 2003, approximately 119,000 Americans (0.1% of the population) over the age of 12 reported current heroin use (SAMHSA, 2004). In spite of the relatively small number of users, it represents a serious and significant public health problem. Heroin can be smoked, snorted, injected under the skin ("skin-popping") or injected into a vein ("mainlining"). Users generally experience a pleasurable sensation or "rush" followed by a period of drowsiness and mental cloudiness. Although heroin has long been associated with marginalized groups of people,

the 1990s saw its use spread to middle- and upper-middle-class people (Stine & Kosten, 1999).

Heroin belongs to a class of substances known as opioids that are agents with morphine-like and morphine-blocking activity. Prescription medications belonging to this class include morphine, codeine, oxycodone (OxyContin), Darvon, and Demerol. For epidemiological purposes, these prescription medications are covered in the psychotherapeutics section that follows, however, they tend to produce effects similar to those of heroin.

*Epidemiology* In 2003, 1.6% of persons in the United States ages 12 and older reported that they had used heroin in their lifetime. Predictably, lifetime use rates were highest for those ages 26 and older (1.7%), and lowest for those ages 12 to 17 (0.3%). Young adults ages 18 to 25 reported a lifetime heroin use rate of 1.6%.

*Health Effects* NIDA (2000) states that “one of the most detrimental long-term effects of heroin is addiction itself” (p. 3). Regular users experience tolerance, need to administer higher doses to get the desired effects, and develop physical dependence. If heroin is not readministered, painful physiological withdrawal symptoms may occur for up to a week. These symptoms include restlessness, muscle and bone pain, insomnia, gastrointestinal disturbance, involuntary leg movements, and cold flashes (NIDA, 2005a). Overdose leading to death is possible, and is a significant risk for street users who do not know the purity level of the heroin they have obtained. For heroin injectors there is the risk of acquiring blood-borne viruses such as HIV and hepatitis C, particularly when needles are shared. Collapsed veins, liver disease, abscesses, infection of the heart lining and valves, and pulmonary complications are possible outcomes of long-term heroin use (NIDA, 2000).

Studies indicate that infants born to women with heroin dependence are more frequently premature, tend to be low in birth weight, and often experience a range of perinatal complications and abnormalities (McNeece & DiNitto, 2005). Maternal heroin use is also associated with miscarriage and a greater risk of SIDS. Detoxification from opiates should be avoided in pregnant women in order to avoid spontaneous abortion or premature delivery. Infants born to women who are engaged in methadone treatment can be treated safely if they show signs of physical dependence (NIDA, 2000).

## HALLUCINOGENS

Hallucinogens comprise a broad group of over 100 different substances that share the capacity to affect a variety of sensory distortions and hallucinations. Historically, select hallucinogens have been used among some groups as part of religious and spiritual rituals. For example, mescaline, derived from the peyote cactus, is used by certain Native Indian peoples of Mexico and is also a central component of rituals in the Native American Church (Durrant & Thakker, 2003).

Hallucinogens commonly known in the United States include LSD, PCP, mushrooms, and “ecstasy” (MDMA). Ecstasy is a designer drug that is tailor-made to produce specific effects. It is known as “party drug” and a “yuppie psychedelic” and can produce both stimulant and hallucinogenic effects (McNeece & DiNitto, 2005). Users may experience mild euphoria and expanded mental perspective

and insight. Negative effects include confusion, sleep disruption, anxiety, and paranoia, sometimes weeks after taking the substance. Physiological symptoms such as dehydration, blurred vision, teeth clenching, chills, sweating, and nausea have been observed (McNeece & DiNitto, 2005).

*Epidemiology* In 2003, an estimated one million Americans aged 12 and older reported current hallucinogen use and 3.9 million persons reported using hallucinogens in the past year. Among past year users, 2.1 million people reported using Ecstasy, 0.6 million reported using LSD, and 0.2 million people reported using PCP (SAMHSA, 2004).

Among racial groups, African American adolescents and young adults reported the lowest rate of lifetime hallucinogen use (1.8% and 7.4%) in their age groups. Among persons ages 26 and older, Asian adults reported the lowest lifetime use rate (3.4%), although use by African American adults remained low (7.2%) when compared with hallucinogen use by White American adults (16.7%), and by persons identifying as two or more races (20.3%).

*Health Effects* With the exception of Ecstasy, hallucinogens pose few known health risks. The use of LSD has been associated with enduring psychoses, but it is unclear the extent to which LSD is causal (Abraham, Aldridge, & Gogia, 1996). During the acute hallucinogenic state, there is the risk of accidental injury or death. This is particularly true with PCP use as paranoia and confusion are associated with its acute effects (Stephen, 1999).

Taken in high doses, MDMA is associated with hyperthermia and can lead to cardiovascular, kidney, and liver failure. Neurotoxicity has been demonstrated in animals and though studies have not definitively shown the same results in humans (NIDA, 2005c), clinical reports have documented toxic effects and fatality associated with Ecstasy use (Dar & McBrien, 1996).

## INHALANTS

Inhalants are breathable chemical vapors found in many common items and household substances. Examples include gasoline, paint, cleaning fluids, glue, marking pens, lighter fluid, and lacquer thinner. These substances are sniffed or “huffed” for their psychoactive effects. While the effects of each of the particular substances can vary, intoxication generally resembles that of alcohol and may include stimulation and euphoria, followed by disinhibition, agitation, and lightheadedness. With increased volume of vapor inhalation, anesthesia and unconsciousness can result (NIDA, 2005b).

*Epidemiology* Because of their accessibility and affordability, inhalants are often a substance of choice for young people. In 2003, an estimated 1.3% of American youth aged 12 to 17 reported current inhalant use (SAMHSA, 2003). Among the same group, 10.7% reported lifetime use. Lifetime rates were similar for boys (10.9%) and girls (10.5%), but some differences were found between races. Reporting rates for lifetime use were highest among American Indian (11.8%) and White American (11.7%) youth, and lowest among African American youth (6.8%). Among all adolescents, 13- and 14-year-olds were the most likely to report

inhalant use in the past month (1.8%), and past year (5.7%), respectively (SAMHSA, 2004).

*Health Effects* Inhalants are extremely toxic, and potentially lethal. Over 700 deaths, mostly of teens and preteens, were reported to the National Inhalant Prevention Coalition between 1996 and 2001 (CSAP, 2003). Negative health effects include damage to the brain, lungs, kidneys, and liver, and inhalant use has been associated with sudden death, known as *sudden sniffing death syndrome* (NIDA, 2005b).

#### PSYCHOTHERAPEUTICS

Psychotherapeutic medication is the second most commonly used illegal substance today. In 2003, 2.7% of Americans aged 12 and older reported current use of these substances. Psychotherapeutics include the nonmedical use of prescription-type pain relievers, tranquilizers, stimulants and sedatives. These comprise numerous kinds of substances that are obtained either with a prescription or illegally "on the street." Classes of these substances most commonly abused include opioids (e.g., morphine, codeine, OxyContin), CNS depressants (barbiturates and benzodiazepines), and stimulants (e.g., Dexedrine, Ritalin, metham-phetamine; NIDA, 2001b, 2005d). Opioid users, depending on the dose administered, often experience euphoria followed by a significant decrease in tension and anxiety (Stine & Kosten, 1999). CNS depressants provide a calming and sedating function (Brady, Myrick, & Malcolm, 1999), whereas stimulants cause an increase in alertness, attention, and energy along with a feeling of euphoria (Weaver & Schnoll, 1999).

*Epidemiology* Among persons aged 12 and older in the United States, 20.1% reported that they had used psychotherapeutics in their lifetime (SAMHSA, 2004). Men reported slightly higher lifetime rates than women (21.6% versus 18.8%), and young adults aged 18 to 25, when compared with other age groups, reported the highest lifetime use rate (29.0%). Young adults also reported the highest current use rate (6.0%) among age groups. Persons aged 26 and over reported the lowest current use rate at 1.9%. Four % of adolescents (aged 12 to 17) reported current use of psychotherapeutics.

Overall, men reported slightly greater current and lifetime use rates of psychotherapeutics than women (2.7% versus 2.6% and 21.6% versus 18.8%). This gender pattern varied, however, when examined by age groups. Girls aged 12 to 17 were more likely than boys of the same age to report current use and lifetime use (4.2% versus 3.7% and 14.1% versus 12.8%, respectively). This gender pattern switched, however, among 18- to 25-year-olds with men reporting current and lifetime use rates (6.8% and 30.7%) higher than those of women (5.2% and 27.4%). Among adults aged 26 and older, women were more likely than men to be current users (2.0% versus 1.8%), but men were more likely than women to report lifetime use (21.2% versus 17.9%).

Among youth aged 12 to 17, Asian adolescents reported the lowest current and lifetime rates of psychotherapeutic use (2.8% and 6.7%) and American Indian adolescents reported the highest rates of the same (5.9% and 17.2%). American



Indian persons continued to report high current and lifetime psychotherapeutic rates during young adulthood (10.9% and 38.0%), but these rates decline somewhat for those 26 years and older (3.3% and 23.7%). Current and lifetime rates reported by Asian young adults (3.5% and 14.9%) and those 26 years and older (1.2% and 7.7%) continue to be lowest when compared with other racial groups. The only exception is that among young adults, African American young adults reported current and lifetime use rates (2.5% and 13.9%) that were slightly lower than those of Asian young adults.

*Health Effects* The health consequences of psychotherapeutics are widely varied, because the substances themselves have such wide variation in chemical and psychoactive properties. Opioids, prescribed to treat pain, include morphine, Codeine, OxyContin, Demerol, and Darvon. Long-term use of these and other opioids can result in tolerance, physical dependence, and addiction. If use is abruptly reduced or stopped, withdrawal symptoms such as restlessness, insomnia, irritability, diarrhea, nausea, and cold flashes may occur (NIDA, 2001b). Severe intoxication or overdose is potentially lethal and requires immediate medical attention (Stine & Kosten, 1999).

CNS depressants, prescribed to treat sleep and anxiety disorders, include barbiturates and benzodiazepines such as Valium, Librium, Xanax, and Klonopin. Tolerance for these substances develops when they are taken over time, and physical dependence and withdrawal are also a risk. If used in combination with alcohol, they can slow respiration and the heart, possibly leading to death. Benzodiazepines must be used cautiously with older adults because their use is a risk factor for falls causing fractures, and cognitive impairment (NIDA, 2001b).

Prescription-type stimulants include various amphetamines such as Dexedrine, Preludin, Ritalin, and Benzedrine. Users may experience euphoria, decreased appetite, and heightened energy. Irregular heartbeat, high body temperature, and cardiovascular failures or seizures are associated with taking high doses of stimulants (NIDA, 2005d).

Methamphetamine is closely related to the substance amphetamine; however, its effects on the CNS are greater (NIDA, 2004b). Highly addictive, it produces a high of longer duration than that of cocaine. It can cause a variety of serious health effects including rapid heart rate and increased blood pressure. Methamphetamine overdose leads to hypothermia and convulsion and without proper medical attention, can result in death. Research suggests that use during pregnancy may lead to prenatal complications and premature delivery, as well as altered patterns of neonatal behavior (NIDA, 2002b).

#### PROMINENT APPROACHES TO CONCEPTUALIZE AND ADDRESS SUBSTANCE USE PROBLEMS

Interventions to address substance use problems are informed and shaped by a variety of factors. Conceptual models that explain the development of substance use problems tend to articulate and advocate for specific interventions and desired outcomes. For example, a conceptualization of substance use problems as the result of a disease which can be treated through spiritually based recovery is prominent in 12-step approaches, such as AA (Miller & Hester, 1995; Schilling &

El-Bassel, 1998), while conceptualizations of substance use problems as the result of learning processes are prominent in cognitive-behavioral approaches (Longabaugh & Morgenstern, 1999; Marlatt & Gordon, 1985). With attention to evidence-based practices, this section briefly describes prominent approaches and modalities to assist people experiencing substance use problems and then provides more detailed discussion of screening and brief interventions that are likely to be employed by social workers in health-care settings.

#### RECONCILING DIVERSE PERSPECTIVES

Divisions occur among proponents of particular approaches (Miller & Hester, 1995). Commitment to particular approaches and conceptual frameworks are formed in complex ways. These commitments may be shaped by evaluation of available evidence, personal preferences, one's own treatment and recovery experiences, and affiliations based on training and association (Borden, 2000). The following overview of prominent approaches focuses specifically on their conceptual tenets, implications for intervention, and the available evidence that supports them. Further, while intense divisions exist among proponents of particular approaches, no one approach has been shown to be effective in serving all persons (Miller & Hester, 1995).

The terms *systematic or informed eclecticism* have been used to describe the process through which social workers and other service providers should approach making decisions about which models to employ to effectively help people (Hepworth, Rooney, & Larsen, 2002; Miller & Hester, 1995). This process involves systematically considering available evidence to guide intervention, with preference for approaches that are evidence-based, comprised of clearly described strategies and techniques, consistent with social work ethics, fall within the social worker's competencies, and are culturally competent (Hepworth et al., 2002). To facilitate this process of systematic or informed eclecticism, this discussion addresses available evidence regarding each of the approaches.

#### MORAL AND TEMPERANCE PERSPECTIVES

Throughout the course of history, many perspectives have informed approaches to understanding and intervening to address substance use problems. Numerous authors describe the evolution of understanding regarding problematic substance use (McNeece & DiNitto, 2005; Miller & Hester, 1995; Schilling & El-Bassel, 1998). Early models conceptualized problematic substance use as a moral issue, reflecting moral weakness, sin, and volitional disregard for social norms of behavior (McNeece & DiNitto, 2005; Miller & Hester, 1995). The temperance movement emerged in the United States in the late 1800s and advocated for the judicious, moderate use of alcohol, based on its potential for harmful consequences (Miller & Hester, 1995). Differing perspectives exist on the role of the temperance movement in contributing to a moralistic view of problematic substance use. Some authors assert that "the core of the temperance model is that the cause of alcohol problems is alcohol itself" (Miller & Hester, 1995, p. 3). This conceptualization would suggest that limiting access to alcohol by making it more costly or less available and encouraging moderation and abstinence would be useful interventions (Miller & Hester, 1995). Others assert that, "prior to the activities of the

Temperance Movement, a force that eventually led to the adoption of Prohibition in the United States, the consumption of alcohol was not necessarily considered to be a sinful act" (Marlatt, 1985b, p. 182). This conceptualization of the role of the temperance movement puts particular emphasis on the moral perspective of problematic substance abuse with attention to the lack of self-control of the individual (Marlatt, 1985b). The moral perspective informs interventions that focus on punishment, through social and legal consequences (Miller & Hester, 1995).

#### DISEASE MODELS

Early in the nineteenth century, Benjamin Rush, a physician in the United States, proposed a disease framework for understanding alcohol use problems (Marlatt, 1985a). This framework further evolved through the twentieth century. In 1935, Alcoholics Anonymous began and contributed to disseminating the conceptualization of alcoholism as a disease, rather than as a moral failing (Kinney & Leaton, 1991; Schilling & El-Bassel, 1998). In the 1940s, E. M. Jellinek and his colleagues at Yale University also contributed to the formulation of the current disease model of alcoholism (Kinney & Leaton, 1991; Marlatt, 1985a). One way of conceptualizing elements of the disease model is reflected in the perspective of William Silkworth, known as a friend of AA: "an obsession of the mind and an allergy of the body" (Kinney & Leaton, 1991, p. 54). This conceptualization reflects recognition of the psychological and biological components of the disease perspective; however, as argued by Miller and Hester (1995), the 12-step approach also incorporates considerable emphasis on spirituality as a primary component of recovery.

The conceptualization of problematic substance use as a persistent medical condition has continued to evolve with recognition that it is influenced by biological, environmental, behavioral and genetic components (Alterman, McLellan, O'Brien, McKay, 1998; O'Brien & McLellan, 1996). A similar conceptualization is presented in a recent publication by the Center for Substance Abuse Treatment (CSAT; 1999b), which describes "an emerging biopsychosocial-spiritual model" (p. 8). Conceptualizations such as this recognize that complex, intersecting factors influence the onset and course of substance use problems, and, as with other chronic health conditions, require multifaceted intervention strategies (CSAT, 1999b; Leshner, 1997). Further, as with other chronic health conditions, long-term treatment is required to address addiction as "a chronic, relapsing illness" (Leshner, 1997, p. 45; O'Brien & McLellan, 1996).

Several intervention strategies emerge from the conceptualization of substance use disorders as a disease. Among the most prominent are Alcoholics Anonymous and other Twelve Step approaches (see Box 13.1). While research regarding 12-step approaches is limited, a recent review of available research suggests that participation in AA and NA is associated with increased abstinence and self-efficacy and enhanced socialization; augmenting 12-step meeting attendance with participation in additional group-related activities seems to add to effects (Humphreys et al., 2004). Additionally, findings from this review also suggest that self-help group participation is best considered as *continuing care* rather than as a replacement for acute professional treatment. While focused on facilitating attendance at AA meetings and incorporating elements of the 12-step approach, findings of Project MATCH, the largest clinical trial of alcohol treatment that has been conducted to date, with 1726 clients over 10 years, suggest that 12-Step Facilitation conducted by

**Box 13.1****The Twelve Steps of Alcoholics Anonymous**

1. We admitted we were powerless over alcohol—that our lives had become unmanageable.
2. Came to believe that a Power greater than ourselves could restore us to sanity.
3. Made a decision to turn our will and our lives over to the care of God *as we understood Him*.
4. Made a searching and fearless moral inventory of ourselves.
5. Admitted to God, to ourselves and to another human being the exact nature of our wrongs.
6. Were entirely ready to have God remove all these defects of character.
7. Humbly asked Him to remove our shortcomings.
8. Made a list of all persons we had harmed, and became willing to make amends to them all.
9. Made direct amends to such people wherever possible, except when to do so would injure them or others.
10. Continued to take personal inventory and when we were wrong promptly admitted it.
11. Sought through prayer and meditation to improve our conscious contact with God, *as we understood Him*, praying only for knowledge of His will for us and the power to carry that out.
12. Having had a spiritual awakening as the result of these steps, we tried to carry this message to alcoholics, and to practice these principles in all our affairs.

*Source: A Brief Guide to Alcoholics Anonymous* (p. 13), by Alcoholics Anonymous World Services, 1972, New York: Author. Used with permission.

a therapist is as effective as Cognitive-Behavioral and Motivational Enhancement Therapy (Donovan, Carroll, Kadden, DiClemente, & Rounsaville, 2003).

Numerous pharmacotherapies have emerged to assist people experiencing substance use problems. Among the most well-known are nicotine patches or gum, which can be helpful to people with nicotine addiction (NIDA, 1999b); disulfiram, which may have effectiveness in reducing alcohol relapse among older adults with high motivation and social support and among people entering a treatment contract in which a significant other; naltrexone, which has shown promise in treating alcohol and opiate use problems; methadone, levo-alpha-acetylmethadol (LAAM), and buprenorphine, which have been effective in treating opioid dependence; and selective serotonin reuptake inhibitors (SSRIs), which have been effective in enhancing alcohol treatment retention, reducing alcohol consumption among clients experiencing co-occurring anxiety, and reducing cocaine consumption among clients engaged in methadone treatment (Alterman et al., 1998). Combining medication with psychosocial interventions, which are further discussed below, reflects a multifaceted approach to address “addiction as a prototypical psychobiological illness, with critical biological, behavioral, and social-context components” (Leshner, 1997, p. 46).

#### PSYCHOLOGICAL MODELS

Prominent psychological models of understanding substance abuse include behavioral and cognitive perspectives (Miller & Hester, 1995). One such model is

Relapse Prevention, in which “addictive behaviors are viewed as overlearned *habits* that can be analyzed and modified in the same manner as other habits” (Marlatt, 1985a, p. 9, emphasis in the original). As described by Marlatt, the analysis of these habits involves the examination of factors which contribute to maintaining the behavior such as antecedents in the situation or environment (e.g., relational conflicts, social influences, emotions), expectations about the outcome of substance use (e.g., anticipation of positive consequence of consumption), and previous experiential learning about the substance (e.g., observations of peers and family members using substances, positive reinforcement of behavior through enjoyable effects of consumption, negative reinforcement of behavior through relief of distress with consumption). The analysis also includes examination of consequences of the behavior (e.g., ways in which substance use is reinforced to encourage the behavior and ways in which negative outcomes may discourage behavior), with particular attention to the social context and role of interpersonal components associated with substance using behavior.

Another central element of this model is its perspective on relapse, or reengaging in substance use behavior. In fact, Marlatt (1985a) distinguishes a *lapse* or a single experience of returning to prior behavior from a *relapse* or a more complete experience of returning to prior behavior. In this model, “a single slip (mistake)” is not seen “as an indication of total failure” (p. 32). Thus, the notion of being in or out of control of substance use is not viewed dichotomously and efforts are made to use lapses and relapses as learning experiences that can inform future relapse prevention strategies (Larimer, Palmer, & Marlatt, 1999; Marlatt, 1985a).

The phrase *abstinence violation effect* is used by Marlatt (1985a) to describe the cognitive and affective responses a person may experience when he is committed to absolute abstinence but then engages in substance use. Once committed to total abstinence, a person who engages in substance use may be more likely to experience negative affective states (e.g., guilt) and self-blaming cognitions or cognitions that reinforce lack of self-control; such experiences may increase his risk for relapse (Larimer et al., 1999; Marlatt, 1985a; Miller, Westerberg, Harris, & Tonigan, 1996; for review, see Dimeff & Marlatt, 1998). Interventions based on Relapse Prevention’s conceptualization of substance use problems focus on assisting clients with identification of situations that may increase their risk of relapse, strengthening their abilities to cope with or modify such situations, addressing expectations regarding anticipated outcomes of substance use, strengthening self-efficacy, reducing the intensity of the abstinence violation effect through cognitive interventions, and fostering learning from lapses and relapses (Larimer et al., 1999).

NIDA (1999b) describes Relapse Prevention as a *scientifically based approach*. Findings from Project MATCH suggest that Cognitive-Behavioral Therapy (CBT) was as effective as 12-Step Facilitation and Motivational Enhancement Therapy (Miller & Longabaugh, 2003). Additionally, a review of research on Relapse Prevention presents positive findings of several studies which suggest that this approach can help increase the period of abstinence, reduce the severity of relapse, and have comparable effectiveness with a 12-step approach with both alcohol and other drug use (Dimeff & Marlatt, 1998). While there is research support for Relapse Prevention, Dimeff and Marlatt note that there have been some mixed findings. For example, of seven studies that specifically examined “relapse prevention,” three yielded positive findings, while four yielded mixed

findings. Last, they note findings indicating that supportive therapy may be more effective in alcohol-related outcomes than Relapse Prevention with clients who have lower levels of verbal learning ability (Dimeff & Marlatt, 1998; Jaffe et al., 1996).

#### MOTIVATION AND CHANGE THEORY PERSPECTIVES

Motivation and change theory perspectives emphasize understanding the motivation for, as well as the nature and processes of, change.

*Motivational Interviewing* First published in 1991, Miller and Rollnick's motivational interviewing model focuses on why people change behavior rather than on why they do not (Miller & Rollnick, 1991, 2002). While specific principles and methods are associated with motivational interviewing, Miller and Rollnick's recent revisions place greater weight on the spirit of the approach. They focus on three primary components that contribute to the spirit of the approach: *collaboration, evocation, and autonomy* (p. 34). These components are contrasted with their opposing counterparts: *confrontation, education, and authority* (p. 35). A spirit of collaboration aims to create an egalitarian partnership between the social worker and the client, rather than a confrontational, argumentative relationship. The aim is "to create a positive interpersonal atmosphere that is conducive but not coercive to change" (p. 34). Rather than presuming that the client lacks awareness, information, or competencies, and then attempting to impart them to the client, in motivational interviewing, the worker aims to evoke from the client his perspectives, interests, and sources of motivation. The presumption of evocation is that change is facilitated by eliciting *intrinsic motivation* regarding what is most meaningful to the client and his aims. Last, rather than focusing on an authoritarian relationship in which the social worker tells the client what to do, motivational interviewing recognizes that the client has a choice regarding accepting assistance and that ultimately he will be responsible for making a behavior change. As further described by Miller and Rollnick, "when motivational interviewing is done properly, it is the client rather than the counselor who presents the arguments for change" (p. 34).

Building upon the spirit of the approach, the following four principles inform motivational interviewing:

1. Express empathy
2. Develop discrepancy
3. Roll with resistance
4. Support self-efficacy (p. 36)

This discussion summarizes Miller and Rollnick's (2002) descriptions of these principles. The expression of empathy draws on the work of Carl Rogers with an emphasis on reflective listening, as well as the recognition that ambivalence about change is normal. In developing discrepancy, the social worker aims to assist the client with exploration of the difference between the current situation and his future goals. In this process, again, it is the client, rather than the social worker, who provides the reasons for change. This process is facilitated by eliciting the client's perspectives regarding the discrepancies and then amplifying his



perspectives to facilitate change and to resolve ambivalence. Central to the idea of rolling with resistance is that "argumentation is counterproductive" (p. 39). In fact, according to Miller and Rollnick, when a client displays "resistance," it should be taken as a cue to the social worker that the current approach should be modified. Last, self-efficacy is supported by two main elements: the social worker's belief that change is possible and the recognition that ultimately the client will be responsible for the change. These two ideas are interwoven, "To assert that a person is responsible for deciding and directing his or her own change is to assume that the person is capable of doing so" (p. 41).

A recent review of literature examining the effectiveness of motivational interviewing indicates that in 14 out of 18 clinical trials with people experiencing diverse substance use problems and health risks (e.g., polydrug use; amphetamine, cocaine, marijuana, or opiate use; co-occurring mental health and substance use problems; HIV risk), motivational interviewing yielded significant positive outcomes (Miller, Yahne, & Tonigan, 2003). Motivational Enhancement Therapy, a four-session adaptation of motivational interviewing, was conducted over 12 weeks of treatment in Project MATCH (Donovan et al., 2003; Miller & Longabaugh, 2003). Findings of Project MATCH indicate that Motivational Enhancement Therapy (MET) is as effective as CBT and 12-Step Facilitation; however, given the brevity of the MET intervention, it is deemed a more cost-effective intervention (Miller & Longabaugh, 2003). Finally, Britt, Hudson, and Blampied (2004) review numerous clinical trials of motivational interviewing which support its effectiveness in yielding positive outcomes with a wide range of health behaviors (e.g., smoking cessation, bulimia nervosa, weight reduction among women with Type 2 diabetes, increased physical exercise, and improved consumption of fruits and vegetables).

While numerous reviews support the effectiveness of motivational interviewing, the findings have not been unanimous. Dunn, Deroo, and Rivara's (2001) review suggests 60% effectiveness across 29 studies. They underscore the importance of further attention to target problems other than substance use and further consideration of the theoretical tenets of motivational interviewing that seem to effect change. Striving to understand the mechanisms through which motivational interviewing facilitates change and its intersections with environmental factors (e.g., familial and social support of change efforts) are central questions to be addressed in ongoing research (Dunn, et al., 2001; Heather, 2005).

*Transtheoretical/Stages of Change Model* The transtheoretical model provides a framework for understanding the incremental processes that facilitate intentional changes in behavior (DiClemente & Velasquez, 2002). Central to this model is the idea that people experience five stages in the process of making changes in their behaviors, thus the name, stages of change (DiClemente & Velasquez, 2002; Prochaska, DiClemente, & Norcross, 1992). The five stages of change include precontemplation, contemplation, preparation, action, and maintenance (see Box 13.2).

Key tenets of the stages of change model involve the following concepts. First, the model holds that the change process can begin before a person has identified that she has a problem (precontemplation) and proceeds with increased recognition of a problematic behavior (contemplation) to considerations about how change might be approached (preparation) to engaging in behavior change

**Box 13.2**  
**Five Stages of Change**

- *Precontemplation*: Have no intention of changing behavior in the foreseeable future. Many people are unaware or underaware of their problems during this stage.
- *Contemplation*: Are aware that a problem exists and are seriously thinking about overcoming it but have not yet made a commitment to take action. Contemplators typically experience ambivalence and often weigh the “pros and cons of the problem and the solution to the problem.”
- *Preparation*: Intend to take action in the next month, but have been unsuccessful in taking action in the past year.
- *Action*: Modify behavior, experiences, or environment in order to overcome problems. They have successfully altered the addictive behavior for a period from 1 day to 6 months.
- *Maintenance*: Work to prevent relapse and consolidate the gains attained during action.

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Adapted from “In Search of How People Change: Applications to Addictive Behaviors,” by J. O. Prochaska, C. C. DiClemente, and J. C. Norcross, 1992, *American Psychologist*, 47(9), pp. 1103–1114.

(action) and finally to making a sustained behavioral change (maintenance). Second, relapse, as “the rule rather than the exception with addictions,” leads to a spiral model of progression through the stages of change (Prochaska et al., 1992, p. 1104). In this spiral model, a person who has taken action and experienced a relapse may return to the contemplation or preparation phase and then continue again to proceed through the stages of change (Prochaska et al., 1992). Similar to the Relapse Prevention model, relapse is viewed as an opportunity for learning rather than as a failure (Prochaska & Prochaska, 1999). As further described by Prochaska and Prochaska (1999), people who attempt to stop smoking typically engage in 3 to 4 action efforts over a period of 7 to 10 years before achieving sustained maintenance. While not setting people up for failure by expecting relapse, it is important to frame relapse in terms of lessons that can be learned, to provide feedback for clients regarding the time required to achieve sustained behavioral change, and to assist clients with maintaining self-efficacy and reengaging in change efforts (DiClemente, 1991; DiClemente & Velasquez, 2002; Prochaska & Prochaska, 1999; Prochaska et al., 1992).

Last, DiClemente and Velasquez (2002) describe the importance of matching the intervention strategy to the client’s stage of change. For example, a client who does not view his drinking habits as problematic and is not considering changing them would be considered to be in the precontemplation stage. In this stage, action-oriented steps are likely to be premature and to yield limited success (Prochaska et al., 1992). Rather than proceeding with action-oriented steps, motivational interviewing strategies (e.g., empathic, reflective listening; recognizing the client’s autonomy to make decisions about accepting assistance; weighing out the benefits and drawbacks of current alcohol use; providing a menu options) that facilitate movement from precontemplation to contemplation would be indicated (DiClemente & Velasquez, 2002).

While the stages of change model can be useful in conceptualizing a person's readiness to change along a continuum, with implications for numerous populations and settings (e.g., to address substance use, partner violence exposure, health behaviors, and mental health), recent scholarship critiques the validity of some of its theoretical underpinnings (Institute of Medicine, 2001; Littell & Girvin, 2002). Based on a review of 87 studies that examined the stages of change with diverse target problems, Littell and Girvin (2002) conclude that this model is limited in two main ways. First, their review suggests that there is a lack of distinction between each of the discrete stages and that there is limited clarity regarding the relationship between readiness for change and the stages. Second, their review suggests that there is a lack of evidence to suggest that people move through the stages in a stepwise fashion. Little and Girvin propose that conceptualizing change along a continuum which may not reflect linear progression may be useful and that the model may have heuristic utility. However, they caution against intervention matched to stages and they argue that future research should further explore change processes across diverse problems and sociocultural contexts.

#### PUBLIC HEALTH—HARM REDUCTION APPROACH

Emerging out of the Netherlands in the 1980s, the harm reduction approach is relatively new in the substance abuse field and is sometimes seen as "at odds" with more traditional approaches (such as the 12-step model) that emphasize abstinence. A harm reduction philosophy, however, does not dismiss the fact that abstinence is often an ideal goal for many substance-using individuals (Marlatt, 1998). Additionally, prominent scholars in the addictions field argue that as a chronic health condition, "improvement rather than cure" is "the only realistic expectation for the treatment of addiction" (O'Brien & McLellan, 1996, p. 237). The approach recognizes, however, that many clients are not ready to pursue abstinence at the time they come into contact with treatment systems. Rather than arguing with these clients about appropriate goals, or worse, turning them away from treatment, harm reduction is a method of engaging clients as they are. It recognizes that the person who is currently using substances has strengths and it draws on these strengths to empower the client to reduce harms in his life and to achieve goals that are important to him. In many ways, a harm reduction approach is consonant with social work values. By meeting the client where he is, it acknowledges the inherent worth and dignity of the person, regardless of the substances she may use. Furthermore, it embodies the value of social justice by recognizing that all substance users, regardless of their motivation to abstain from using, deserve treatment services (Brocato & Wagner, 2003).

Harm reduction's public health approach has numerous key components. As described by the Harm Reduction Coalition (n.d.), harm reduction "does not attempt to minimize or ignore the real and tragic harm and danger associated with licit and illicit drug use"; however, it also "accepts, for better and for worse, that licit and illicit drug use is part of our world and chooses to work to minimize its harmful effects rather than simply ignore or condemn them" (<http://www.harmreduction.org>). Harm reduction strategies that aim to reduce harmful effects of drug use include direct practice intervention, environmental modifications, and public policy initiatives (Marlatt, 1998). Direct practice interventions

can involve the following strategies: motivational interviewing; education conducted with collaborative, participatory spirit; relapse prevention strategies informed by cognitive-behavioral approaches; and pharmacotherapy, such as methadone treatment (Hunt, 2003; Marlatt, 1998). Environmental modifications can involve making clean needles and condoms available; facilitating designated driver programs; facilitating access to health care and to safe, affordable housing; and preventing overdose with administration training and distribution of Narcan (Harm Reduction Coalition, n.d.; Marlatt, 1998). Public policy initiatives can involve advocacy to reduce barriers and facilitate access to services; reforming legal consequences for substance consumption; and addressing sentencing disparities (Marlatt, 1998). One such sentencing disparity is the 100 to 1 disparity for the federal mandatory minimum sentence for possession of crack and powder cocaine that disproportionately affects people who are African American (Hatsukami & Fischman, 1996). Under this policy, a person with a first-time offense of possession of 5 grams of crack cocaine would be mandated to a minimum sentence of 5 years; this sentence would require possession of 500 grams of cocaine hydrochloride (Hatsukami & Fischman, 1996). Addressing such disparities reflects public policy initiatives to reduce harm and to pursue social justice. Last, harm reduction values a range of positive outcomes that reflect reduced harm associated with drug use at multiple levels (e.g., individual, community, society) and it favors individualized approaches to reflect the unique experiences and interests of individuals and communities (Harm Reduction Coalition, n.d.; Hunt, 2003).

Research regarding harm reduction has focused heavily upon needle exchange and methadone treatment interventions (Hunt, 2003). In a review of 42 studies of syringe exchange programs, Gibson, Flynn, and Perales (2001) identify positive outcomes with 28 of them. The authors discuss methodological issues such as the design of the research, and selection and dilution biases which may have influenced the negative (2 studies) and null or mixed (14 studies) findings; however, based on their review, the authors conclude that "there is substantial evidence that syringe exchange programs are effective in preventing HIV risk behavior and HIV seroconversion among IDU [injection drug users]" (p. 1338). Methadone treatment has been researched for nearly 40 years; findings indicate positive effects on reductions in the use of heroin and HIV risk behaviors (Hunt, 2003). As described by NIDA (1999b), "patients stabilized on adequate, sustained dosages of methadone or LAAM can function normally" (p. 24). Last, while the research previously discussed supports the evidence base of motivational interviewing to assist people experiencing substance use problems, there is a lack of evidence to support motivational interviewing as an effective strategy for HIV risk reduction (Burke, Arkowitz, & Dunn, 2003; Hunt, 2003).

#### ADDITIONAL EVIDENCE-BASED APPROACHES

The prominent approaches discussed in this section are not exhaustive. They provide an introduction to various ways of thinking about and intervening to address substance use problems. Additional approaches that are described by NIDA (1999b) as scientifically based include the following: supportive-expressive psychotherapy; individualized drug counseling; a combination of behavioral and nicotine replacement therapies to assist people experiencing nicotine dependence; numerous behavioral strategies that incorporate vouchers to support abstinence from cocaine

and other drugs as well as housing-related outcomes; and the Matrix model which incorporates relapse prevention, group therapy, self-help, education about drugs, and family therapy to assist people with reduction of stimulant and other drug use. Much of the research regarding family-oriented intervention in the substance abuse field has focused on adolescents and the following models have a developing evidence base: multisystemic treatment, multidimensional family therapy, and brief strategic family therapy (Henggeler, Schoenwald, Borduin, Rowland, & Cunningham, 1998; NIDA, 1999b; Szapocznik & Williams, 2000). NIDA (1999b) also recognizes behavioral therapy as effective to assist adolescents with achieving and maintaining abstinence from drugs, as well as other outcomes (e.g., attendance at school or work and improved family relationships).

Among people experiencing co-occurring substance use and psychiatric disorders, integrated treatment that focuses on both conditions is recommended (NIDA, 1999b). Further information regarding evidence-based integrated treatment approaches, which tend to favor community-based, long-term interventions with individuals and their families, are reviewed and described in detail to facilitate practice implementation in a recent publication (Mueser, Nordsky, Drake, & Fox, 2003). Among people experiencing co-occurring substance use and posttraumatic stress disorders, specifically, an integrated treatment model with research support is Seeking Safety. This model, which is largely informed by cognitive-behavioral strategies and complemented with interpersonal and case management approaches, is also further described in ways that facilitate practice implementation in a recent publication by Najavits (2002).

#### INTERVENTION MODALITIES

Interventions vary not only according to the etiological models that inform them, but also in their functions, modalities and organizational structures. For example, interventions may vary according to focus (e.g., detoxification, long-term rehabilitation, aftercare), location (e.g., hospital, community), intensity (e.g., inpatient, residential, outpatient, self-help groups), identity of the helping system (e.g., substance abuse services, mental health center, child welfare, family and social support), client system (e.g., individual, group, family) and public or private funding sources (McNeece & DiNitto, 2005). Knowledge of various treatment modalities and locally available resources is particularly relevant for social workers in health-care settings who frequently facilitate referrals for additional specialized services. Detailed guidance for referring adolescent and adult clients to an appropriate level of care given their substance use characteristics, biopsychosocial conditions, and environmental context is provided by the American Society of Addiction Medicine's (2001) *Patient Placement Criteria for the Treatment of Substance-Related Disorders*.

#### SCREENING AND BRIEF INTERVENTION COORDINATION IN HEALTH-CARE SETTINGS

For health social workers to incorporate consideration of potential substance use problems into their clients' care, they must skillfully gather information about their clients' substance using behaviors. For a variety of reasons, many health and social service providers simply do not inquire, and thus, inadvertently overlook

possible substance use problems. The Institute of Medicine (1990) recommends that questions about substance use be included with routine lifestyle and behavioral questions, such as those about diet and exercise, of all persons who come into contact with health-care systems. The following section provides knowledge and tools necessary for detecting potential substance use problems. First, it discusses issues related to professional use of self when talking with clients about substance use behaviors. Second, it offers some basic considerations about gathering information. Finally, it presents information about established screening tools and protocols and how to consolidate information gathered to conduct brief interventions or to make referrals for other services as needed.

### SCREENING

Although screening and assessment are presented separately from interventions in this chapter, it is important to note that, just as in other types of social work practice, they are actually overlapping activities. More often than not, assessment continues during the intervention process. In fact, NIAAA (2004b) includes both screening and assessment activities as part of a brief intervention framework. Furthermore, the interpersonal experience of asking clients about their behaviors and providing feedback based on their answers can be a potent intervention in and of itself (Miller, 2000).

This chapter focuses more on screening than on assessment. In general, screening is a relatively brief process and is aimed at identifying individuals with potential substance use problems (Abbott & Wood, 2000; Donovan, 1999). When an individual is identified as being at risk, further assessment is required. The assessment process is more comprehensive in scope and aims to be definitive in diagnosing substance use disorders, assessing related health and psychosocial effects, and informing specialized services (Cooney, Zweben, & Fleming, 1995). This section presents information to incorporate substance use screening into a more general psychosocial assessment and to make appropriate referrals for further substance use assessment and intervention when necessary. Additional information regarding psychosocial assessment can be found in Chapter 8 in this *Handbook*.

Because of the stigma and shame often associated with substance use problems, the manner in which social workers ask about potential problems is critical. McCrady (1993) identified several provider characteristics that appear to be conducive to successful treatment with persons with alcohol problems. These characteristics are relevant for accurate screening as well. First, the clinician must be empathic and recognize that it is often embarrassing and difficult for clients to talk about their substance use. If they have struggled with substance use over time, it is likely that they have encountered criticism and disapproval from family, friends, and previous treatment providers. Additionally, it is important that clinicians have an appreciation for how difficult it can be to change substance-using behavior. Often clients have made multiple attempts at stopping their use of alcohol, tobacco, or other drugs only to relapse and feel as though they have failed, thus leading to greater demoralization. The ability to empathize both with the shame of substance use as well as the difficulty in changing substance-using behavior is critical.



Second, the clinician needs to be able to discriminate between the person and his or her substance-using behavior. McCrady (1993) noted that this can be a “delicate” balance. Clinicians first and foremost need to convey a sense of respect for the person, acknowledging her inherent dignity, value, and worth. At the same time, however, they should be careful not to dismiss or overlook the problematic substance using behavior.

Last, it is important to be mindful that recent research has not supported numerous myths that have influenced strategies to assist people experiencing substance use problems. For example, evidence does not support the following assertions: that there is such a thing as an “addictive personality”; that people with substance use problems have more enhanced defense mechanisms that are displayed as resistance or denial; or that aggressive confrontation facilitates change (CSAT, 1999b). Effective professional use of self can be facilitated by increasing one’s familiarity with emerging knowledge to support informed engagement, screening, assessment, and intervention.

Health social workers gather important information about clients’ substance use behaviors from a variety of sources. First and foremost they gather information from the clients themselves. Additionally, they may gather information from involved family and friends and other treatment providers. Finally, they may also gather information from existing medical/treatment records and from biological tests, such as toxicology screenings. The next section answers two important questions about the process of gathering information. First, what is the purpose of gathering this information? Second, what kinds of information should health social workers gather?

*Purpose of Gathering Information about Substance Use Behavior* It is important to understand the purpose of gathering information about clients’ substance use history and patterns. Clearly, strong associations exist between substance use and a variety of illnesses, health problems, and other social problems that may bring people into contact with health-care systems. Often, the identified health problem cannot be fully treated unless the associated substance use problem is also simultaneously addressed. Thus, screening for potential substance use problems is central to recommending and providing comprehensive treatment for clients’ identified health problems. For example, active use of alcohol and other substances may contraindicate certain pharmacotherapies and medical procedures. Specific information about the frequency and amount of use, as well as consequences of use, allows the health social worker to make appropriate recommendations and referrals.

*What Information to Gather* When screening for substance use problems, social workers may gather information that falls into several different categories: substances being used; frequency of use; amount of use; consequences of use; and circumstances in which one uses. Additionally, because of the genetic influence for substance dependence, social workers may want to ask about substance use in close family members (NIAAA, 2004b). Established tools, which are discussed next, may include questions from one or more of these categories. In general, questions that ask about consequences of alcohol and other drug use tend to be effective for detecting people who have substance use disorders; however, they may miss identifying people who are at risk for developing a

substance use disorder. Questions about frequency and amount are typically important for detecting persons at risk (CSAT, 1997).

Because it may be particularly difficult for clients to respond honestly about using illegal substances, it is generally helpful to begin with inquiring about alcohol use (Institute of Medicine, 1990) and then to discuss illegal drug use. As an exception, however, the CSAT Consensus Panel (1997) suggests that persons who are at high risk for illegal drug use be asked about alcohol and other drug use together. Questions about using other drugs may be less stigmatizing when paired with questions about using alcohol. Risk factors for illegal drug use include psychiatric illness, genetic predisposition, alcohol and drug using peers, familial conflict, and HIV positive status (CSAT, 1997).

NIAAA (2004b) recommends simply beginning by asking, "Do you drink alcohol?" Negative answers should be followed up with the question, "What made you decide not to drink?" (CSAT, 1997, p. 15). If the client has been a lifelong abstainer or reports abstinence for 5 years or more, the substance use screening, with a few exceptions discussed next, can be concluded. Regardless of what they report about drinking alcohol, adolescents should be asked about use of other drugs, particularly marijuana. Women who are pregnant or who have experienced a major life transition should be asked about prescription drug use and over-the-counter sleep aids (CSAT, 1997). Finally, all older adults (those age 60 and older) should also be asked about over-the-counter and prescription drug use (CSAT, 1998).

NIAAA (2004b) recommends that positive answers to "Do you drink alcohol?" should be followed with a question about frequency (e.g., "On average, how many days a week do you drink?") and amount (e.g., "On a day when you drink alcohol, how many drinks do you have?"). Furthermore, the recommendations indicate that it is useful to ask the client "What is the maximum number of drinks you consumed on any given occasion during the past month?" With this question in particular, standard drink measures should be clearly identified. One drink is equivalent to 12 ounces of beer or wine cooler; 8 to 9 ounces of malt liquor; 5 ounces of table wine; 3 to 4 ounces of fortified wine (such as sherry or port); 2 to 3 ounces of cordial, liqueur, or aperitif; and 1.5 ounces of spirits (NIAAA, 2004b).

With information about the frequency and amount of alcohol use, the social worker is able to determine if the client's alcohol consumption is within a safe range or is potentially problematic. In defining "at risk" alcohol use, NIAAA (2004b) states that criteria differ by age, gender, pregnancy/health/medication status, and family history of substance dependence. Consumption of alcohol according to the following conditions is considered "at risk":

- More than 14 drinks per week or more than 4 drinks on a given occasion by men
- More than 7 drinks per week or more than 3 drinks on a given occasion by women
- Any alcohol consumption by pregnant women
- More than 7 drinks per week or more than 1 drink on any given occasion by older adults
- Any alcohol consumption by children or adolescents

Additionally, problematic substance use may intersect with a variety of health and psychosocial problems. The presence of the following factors may suggest increased risk of substance use problems:

- Mental health problems
- The presence of infectious diseases such as HIV, hepatitis B and C, and tuberculosis
- Trauma exposure
- Involvement with peers who use drugs and alcohol
- Homelessness/housing instability
- Significant familial conflict or instability
- Familial history of substance use problems
- Vocational instability
- Legal problems (CSAT, 1997)

While the presence or absence of any of these risk factors cannot predict whether or not a person will experience substance use problems, their presence can cue the social worker to further consider possible risk (CSAT, 1997). Additionally, these health and psychosocial risk factors would likely be points of intervention for social workers in health-care settings as part of comprehensive biopsychosocial assessment and intervention.

#### ESTABLISHED TOOLS

Multiple measures have been developed to screen and assess for problems with substance use. These include structured interviews and self-administered questionnaires. It is essential that these tools demonstrate accuracy in their screening ability that is designated by the measure's sensitivity and specificity. Sensitivity refers to the measure's ability to identify all persons with the designated problem (i.e., to avoid false negatives). Specificity refers to the instrument's ability not to include people who do not have the designated problem (i.e., to avoid false positives; NIAAA, 2004b). For example, if a measure included the single question, "Do you drink alcohol?" and identified any person who answered positively as having an alcohol use disorder, it would have very high sensitivity and low specificity. On the other hand, a measure that identifies a person as having a problem with alcohol use by a positive response to the single question, "Have you ever blacked out or lost time when you were drinking alcohol?" would have low sensitivity and high specificity. The sensitivity and specificity of instruments can be altered by shifting their cut-off scores, changing their designated problem, and deleting or adding items. The discussion that follows illustrates some of these principles.

**CAGE** The CAGE is one of the most widely used short screening tools in the substance abuse field. Originally designed to detect alcohol dependence, it consists of four questions about aspects of alcohol use:

1. Have you ever felt that you should cut down on your drinking?
2. Have people annoyed you by criticizing your drinking?

3. Have you ever felt bad or guilty about your drinking?
4. Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (eye opener)?

A positive answer to two or more questions is considered clinically significant (Ewing, 1984). Research suggests that this measure has high levels of sensitivity and specificity for identifying persons with alcohol use disorders (Buchsbaum, Buchanan, Centor, Schnoll, & Lawton, 1991). Because it does not include questions about frequency or amount of alcohol use, however, it is likely to miss some persons who do not meet diagnostic criteria yet are at-risk drinkers (Adams, Barry, & Fleming, 1996). In an attempt to increase the CAGE's sensitivity for a wider range of substance use problems, both NIAAA (2004b) and CSAT (1997) recommend using the CAGE in conjunction with questions about frequency and amount of alcohol use. Furthermore, both agencies recommend that a positive answer to one question prompt further assessment.

The CAGE has also been modified to screen for other drugs in addition to alcohol. The CAGE-AID (CAGE Adapted to Include Drugs) consists of the original CAGE questions but rather than focusing solely on drinking, the CAGE-AID inquires about drinking or drug use with each of the questions previously identified. With the CAGE-AID, the questions should be preceded by the instruction: "When thinking about drug use, include illegal drug use and the use of prescription drugs other than as prescribed" (Brown, Leonard, Saunders, & Papasouliotis, 1998, p. 102). Because the CAGE-AID, like the CAGE, only inquires about negative consequences, CSAT (1997) recommends asking an additional question: "Have you used street drugs more than five times in your life?" (p. 17). A positive answer to this question or to any of the CAGE-AID questions suggests the need for further assessment.

The CAGE and CAGE-AID have been tested with older adults and shown to be effective in screening for both alcohol and other drug use problems among this population. Buchsbaum et al. (1992) used a score of two or greater on the CAGE to define problem drinking in a sample of medical outpatients over the age of 60 and found it to have reasonable sensitivity (.70) and very good specificity (.91). Another study examining the utility of the CAGE-AID for use with older adults demonstrated high sensitivity for detecting persons with alcohol or other drug use disorders (.91 and .92 respectively), but a low specificity of .48 (Hinkin et al., 2001). The authors noted that many older adults, regardless of whether they had a substance use disorder, answered positively to the question "have you ever felt you ought to cut down on your drinking or drug use?" By omitting this question, specificity was significantly increased to .69, though sensitivity decreased to .83. Taken together, these findings suggest that providers may want to make adjustments in how they use the CAGE depending on the population, setting, and goals.

*AUDIT* The Alcohol Use Disorders Identification Test (AUDIT) is a 10-item structured interview designed from a six-country, multicultural, collaborative project of the World Health Organization (WHO) to detect persons with alcohol use related problems (Saunders, Aasland, Amundsen, & Grant, 1993). The work group's initial intent was to develop a screening tool that detected persons with problems prior to the development of dependence or serious harm in order to pro-

vide early intervention. The measure covers three conceptual domains: level of consumption (items 1 to 3); dependence symptoms (items 4 to 6); and alcohol-related consequences (items 7 to 10). It is scored by summing the numbers of the answers to each question.

1. How often do you have a drink containing alcohol?
  - (0) Never
  - (1) Monthly or less
  - (2) Two to four times a month
  - (3) Two to three times a week
  - (4) Four or more times a week
2. How many drinks containing alcohol do you have on a typical day when you are drinking?
  - (0) 1 or 2
  - (1) 3 or 4
  - (2) 5 or 6
  - (3) 7 to 9
  - (4) 10 or more
3. How often do you have six or more drinks on one occasion?
  - (0) Never
  - (1) Less than monthly
  - (2) Monthly
  - (3) Weekly
  - (4) Daily or almost daily
4. How often during the last year have you found that you were not able to stop drinking once you had started?
  - (0) Never
  - (1) Less than monthly
  - (2) Monthly
  - (3) Weekly
  - (4) Daily or almost daily
5. How often during the last year have you failed to do what was normally expected from you because of drinking?
  - (0) Never
  - (1) Less than monthly
  - (2) Monthly
  - (3) Weekly
  - (4) Daily or almost daily
6. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?
  - (0) Never
  - (1) Less than monthly
  - (2) Monthly
  - (3) Weekly
  - (4) Daily or almost daily
7. How often during the last year have you had a feeling of guilt or remorse after drinking?
  - (0) Never
  - (1) Less than monthly

- (2) Monthly
  - (3) Weekly
  - (4) Daily or almost daily
8. How often during the last year have you been unable to remember what happened the night before because you had been drinking?
- (0) Never
  - (1) Less than monthly
  - (2) Monthly
  - (3) Weekly
  - (4) Daily or almost daily
9. Have you or someone else been injured as a result of your drinking?
- (0) No
  - (2) Yes, but not in the last year
  - (4) Yes, during the last year
10. Has a relative or friend, or a doctor or other health worker been concerned about your drinking or suggested you cut down?
- (0) No
  - (2) Yes, but not in the last year
  - (4) Yes, during the last year

Scores range from 0 to 40. In general, a score of 8 or greater points to the strong likelihood of problematic alcohol use (Saunders, Aasland, Babor, De La Fuente, & Grant, 1993).

Recent research suggests that, in general, the AUDIT has utility across gender and racial groups, although some differences in performance between groups have been found (Reinert & Allen, 2002). For example, Cherpitel (1998) found that, when used with a standard cut-off score of eight, the AUDIT was less sensitive for women than for men. Because of these findings, Reinert and Allen (2002) suggest that it may be appropriate to lower the cut-off score to five or six for women. The same authors also report little variation in the AUDIT's psychometric properties across racial groups. They caution, however, that a growing body of research indicates limited accuracy of the AUDIT among older adults.

*Additional Tools* Many other tools have been developed for screening and comprehensive assessment of substance use related problems. Although there are too many to describe here, a few are mentioned. The Michigan Alcoholism Screening Test (MAST) is a 25-item instrument designed to detect alcohol problems (Selzer, 1971). Two shorter versions are available: the 13-item Short MAST (SMAST; Selzer, Vinokur, & van Rooijen, 1975) and the 10-item Brief MAST (B-MAST; Pokorny, Miller, & Kaplan, 1972). The MAST-Geriatric Version (MAST-G; Blow et al., 1992) has been validated for use with older adults. Lastly, the Drug Abuse Screening Test (DAST; Skinner, 1982), was designed to identify problems related to the use of drugs other than alcohol.

#### FROM SCREENING TO BRIEF INTERVENTION

If the screening process indicates that a person may have a possible substance use problem, the social worker will then want to follow up with a brief intervention and, depending on the severity of the problem, make a referral for more compre-



hensive assessment and services. Brief interventions, which are discussed next, provide a means by which social workers talk with clients about risks related to their use and enhances their motivation to take positive steps toward addressing their substance use problems. Feedback about the screening results is the first step of an initial brief intervention. CSAT (1997, 1999a, 1999b) recommends that feedback be given promptly, in a direct and nonjudgmental manner, and framed in a way that conveys respect, relates to the client's medical health, and is delivered with cultural competence.

#### BRIEF INTERVENTIONS

Opportunities for addressing substance use problems frequently occur in non-substance abuse treatment settings. Health social workers and other professionals can be equipped to act on these opportunities through the use of brief interventions. Brief interventions are defined as "those practices that aim to investigate a potential problem and motivate an individual to begin to do something about his substance abuse, either by natural, client-directed means or by seeking additional treatment" (SAMSHA, 1999, p. 5). Brief interventions are informed by general guidelines and include a variety of strategies and techniques.

*General Goals and Guidelines* The general goal of all brief interventions is based on a philosophy of harm reduction: "to lower the likelihood of damage that could result from continued use of substances" (SAMHSA, 1999, p. 5). Goals specific to individuals depend on their aims, the characteristics of their use (e.g., substance of choice, severity of use, history of use), their readiness for change, and the setting in which the intervention is offered (CSAT, 1999a). While eliciting goals that are of interest to the client should guide the goal setting process, specific goals might include the following examples: participating in a more comprehensive assessment; identifying costs and benefits of substance use; recording amount of use over a given time period; decreasing amount of use over a given time period; declining an offer for a drink or other substance; attending an AA/NA meeting; expanding a supportive social network; and identifying positive activities that can be substituted for substance use (CSAT, 1999a). These are only a few examples. The social worker and client can creatively brainstorm to identify other goals appropriate for the particular circumstances of the client. Social workers should emphasize the positive quality of any goal that decreases the risk of harm resulting from substance use.

In an extensive review of 32 studies in 14 countries, the findings of Bien et al. (1993) provide substantial support for the effectiveness of brief interventions to assist people experiencing problematic alcohol use. In 11 out of 12 trials, brief intervention enhanced referrals and engagement in specialized services. In 7 out of 8 trials, brief interventions were effective in reducing alcohol use or problems associated with use in comparison to no intervention. Miller and Sanchez (1993) examined the brief intervention strategies employed in these outcome studies to determine common ingredients among the interventions. Six components of effective brief interventions were identified and are summarized by the now widely known and recommended FRAMES acronym: "Feedback, Responsibility, Advice, Menu, Empathy, and Self-efficacy" (Bien et al., 1993, p. 326; Britt et al., 2004; CSAT, 1999a; Miller & Sanchez, 1993).

First, providers give feedback to clients to inform them about the risks associated with their substance use; however, this feedback process should be interactive, with incremental provision of information and elicitation of the client's responses to it (CSAT, 1999a, 1999b). Effective brief interventions typically include structured screening, such as the NIAAA recommended protocol discussed above. Following this screening, clients receive information about the status of their substance use. In addition to educating clients about their general status, health social workers should also provide clients with information regarding the health interactions and consequences of their substance use. For example, active substance use contraindicates many medical interventions (e.g., organ transplants and particular medications).

Second, responsibility for change is placed with the client (CSAT, 1999a). It is important for the client to know that while the professional is concerned and interested in his welfare, ultimately it is the decision and responsibility of the client to make changes in his substance use behavior. Care must be taken so that the client does not feel alone in trying to change or blamed for his problems. Rather, social workers should recognize that this step is about self-determination and empowerment (CSAT, 1999b), which reflects the spirit of autonomy, a central component of motivational interviewing (Miller & Rollnick, 2002).

Third, the provider gives advice to the client to change his behavior (Bien et al., 1993; CSAT, 1999b). This advice will vary depending on the client and can range from suggesting a change in substance use behavior to providing relevant information about substance use (CSAT, 1999b). Key elements of giving advice in a way that is consistent with motivational interviewing include asking permission from the client to provide the advice (e.g., "Can I tell you what I've seen in the past in these situations?" CSAT, 1999b, p. 27), providing information in culturally relevant ways, and attending to the way in which the suggestions are made (Britt et al., 2004; CSAT, 1999b).

Fourth, a menu of various options to facilitate change is provided (Bien et al., 1993; CSAT, 1999b). Such options may include treatment services, self-help and other change strategies. Providing the client with information about the options and discussing his perspectives about them are central elements of assisting the client with making an informed decision about how he would like to proceed (CSAT, 1999b). Fifth, the social worker should use an empathic stance that conveys respect, caring, warmth, and reflective listening (Bien et al., 1993; CSAT, 1999b). Sixth, social workers should seek to enhance clients' sense of self-efficacy, that is, the belief that they can and will accomplish goals that they set for themselves (CSAT, 1999b). Conveying hope, optimism, and recognition of clients' strengths are meaningful ways in which to achieve this goal (Bien et al., 1993; CSAT, 1999b).

## CONCLUSION

Health social workers face many challenges in providing effective assistance to persons struggling with substance use problems. The knowledge base is expansive, the field is sometimes perceived as in flux, and substance use problems can seem impermeable to change. Additionally, such problems have a far-reaching presence across persons of diverse age, gender, sexual orientation, racial, cultural, and socioeconomic backgrounds. This chapter orients the provider to foundational information that is useful for offering hopeful and effective interventions with clients

experiencing substance use problems. Information about short-term psychoactive and long-term health effects of commonly used substances, along with current prevalence data, aims to equip health social workers with the ability to identify individuals who may be at risk for difficulties with the use of particular substances. Additionally, such information can assist with strengthening the developmental and cultural competence of services to reach affected groups. The overview of prominent approaches to conceptualizing and addressing substance use problems familiarizes the health social worker with intervention options that may be available or with treatment experiences that clients may have previously encountered. It is essential that social workers are aware of the existing evidence base for particular approaches, and when possible, refer clients to services that utilize evidence-based practice strategies. Finally, the chapter provides screening knowledge and tools, as well as a framework for brief intervention strategies. This information offers guidance so that the social worker may assist people experiencing substance use problems in ways that offer hope, reduce harm, enhance motivation, and strengthen efforts to pursue and sustain change.

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## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 13.1

What are the psychoactive and health effects of commonly used substances? How would you rank the risks associated with each of the substances? What is the basis for your ranking?

### LEARNING EXERCISE 13.2

What are some of the prominent approaches to conceptualizing substance use problems? How do the conceptual frameworks influence intervention strategies?

### LEARNING EXERCISE 13.3

What does research suggest about the effectiveness of the approaches discussed in this chapter? How might the research findings inform your direct practice with people experiencing substance use problems? What additional evidence can inform your direct practice in this area?

### LEARNING EXERCISE 13.4

What are key elements of screening for substance use problems?

### LEARNING EXERCISE 13.5

What does the acronym FRAMES represent? What might be strengths and challenges of applying this model in direct practice?

### LEARNING EXERCISE 13.6

What additional information would help strengthen your ability to effectively assist people experiencing substance use problems?

## LEARNING EXERCISE 13.7

In pairs, role play how might you draw on the FRAMES model in a brief intervention with Alex in the hypothetical situation that follows.

**Case Example 13.1**

Alex is a 25-year-old, heterosexual, Caucasian man of Italian American descent, who resides with his mother who is 60 years old. His brother, Carl, brought him to the community health clinic because he is concerned about his drinking, his use of cocaine, his overall health, and the worry their mother is experiencing about Alex. After seeing a primary care physician, Alex was referred to you. Your brief screening with Alex indicates that he has made numerous attempts to stop using cocaine and to reduce his drinking. He explains that these efforts “have not quite worked out,” but he feels he can address this issue on his own. He also feels angry with his brother for “making such a big deal about all of this,” but at the same time, he describes feeling guilty about his behavior when he drinks and uses cocaine. Alex states that he usually drinks a six-pack of beer 4 to 5 times a week, but recently, he has increased this amount and hasn’t “really kept track of it.” Alex describes that he uses cocaine less often since he lost his job a month ago and can’t afford it. Presently Alex does not have health insurance or steady income.

## SUGGESTED RESOURCES

Al-Anon and Alateen (<http://www.al-anon.alateen.org>)

Alcoholics Anonymous (AA; <http://www.aa.org>)

Alcoholism and Drug Addiction Counselor Information and Certification (<http://naadac.org/documents/index.php?CategoryID=1> and <http://naadac.org/documents/display.php?DocumentID=18>)

Double Trouble in Recovery (<http://www.doubletroubleinrecovery.org>)  
Based on a 12-step approach, this program assists people experiencing co-occurring substance use and mental health problems.

Harm Reduction Coalition (<http://www.harmreduction.org>)

Health Effects of Substance Use (<http://www.drugabuse.gov/consequences>)

International Harm Reduction Association (<http://www.ihra.net>)

Motivational Interviewing (<http://www.motivationalinterview.org>)

Narcotics Anonymous (NA; <http://www.na.org>)

National Clearinghouse for Alcohol and Drug Information (NCADI; <http://www.health.org>)

A clearinghouse of information and resources about alcohol and other drugs available from NIAAA, NIDA, and SAMHSA, resources include videos, posters, pamphlets, educational tools and kits, reports. Information geared toward a range of audiences (e.g., families, youth, health providers, educators, researchers) are available. Many of the resources are free.

National Institute on Alcoholism and Alcohol Abuse (NIAAA; <http://www.niaaa.nih.gov>)

This branch of the National Institutes of Health (NIH) researches the effects and treatment of problematic alcohol use.

National Institute on Drug Abuse (NIDA; <http://www.nida.nih.gov>)

This branch of the NIH researches the effects and treatment of drug abuse.

Substance Abuse and Mental Health Services Administration (SAMHSA; <http://www.samhsa.gov>)

This branch of the Department of Health and Human Services is charged with developing and disseminating effective prevention and treatment programs. SAMHSA includes both the Center for Substance Abuse Prevention (CSAP) and the Center for Substance Abuse Treatment (CSAT).

Substance Abuse Treatment for Gay, Lesbian, Bisexual and Transgender Individuals (<http://kap.samhsa.gov/products/manuals/pdfs/lgbt.pdf>)

Treatment Locator (NCADI; <http://dasis3.samhsa.gov>)

This resource locates substance abuse treatment providers sorted by geographic location, population, and type of treatment.

World Health Organization ([http://whqlibdoc.who.int/hq/1992/WHO\\_PSA\\_92.4.pdf](http://whqlibdoc.who.int/hq/1992/WHO_PSA_92.4.pdf))

This site provides guidelines for using the AUDIT in primary health care.

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PART III

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HEALTH SOCIAL WORK:  
SELECTED AREAS  
OF PRACTICE



## CHAPTER 14

# Social Work with Older Adults in Health-Care Settings

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**U**SING A BIOPSYCHOSOCIAL approach to understanding health and well-being, this chapter presents an introduction to issues relevant to social work with older adults in health-care settings. It focuses on knowledge needed by social workers to comprehensively assess the needs and resources of older persons, provides a review of the available empirical literature on various domains of assessment, and describes the nature of social work practice with older adults in a variety of health-care settings. The subject matter of this chapter overlaps to some degree with that of other chapters in this book, such as those addressing policy, disability, nephrology, oncology, chronic illness, end-of-life care, and pain management as they relate to work with older adults. This is meant to provide synergy and the reader is urged to treat the chapters as overlapping bodies of information rather than discrete and separate entities.

### CHAPTER OBJECTIVES

- Provide an overview of the demographic changes related to aging and their implications for social workers in health care.
- Describe the concept of comprehensive geriatric assessments and discuss the available empirical literature on their efficacy.
- Using a biopsychosocial approach, provide an overview of the domains of knowledge necessary to assess the needs and resources of older adults.
- Describe the nature of social work practice with older adults in selected health-care settings such as primary care, inpatient acute care, home health care, and nursing homes.
- Discuss the issues and challenges related to working with older individuals that are encountered by social workers in the current health-care environment.

## CHARACTERISTICS OF THE AGING POPULATION

The Administration on Aging (AoA, 2004) provides the following facts in "A profile of older Americans: 2003."

### Demographics

- Older adults, that is, persons 65 years or older numbered 35.6 million in 2002, representing 12.3% of the U.S. population—about one in every eight Americans.
- The older population itself is getting older and in 2001 persons reaching age 65 had an average life expectancy of an additional 18.1 years (19.4 years for females and 16.4 years for males).
- The older population is expected to burgeon between the years 2010 and 2030 when the "baby boom" generation reaches age 65. By 2030, there will be about 71.5 million older persons, more than twice their number in 2000, and will represent 20% of the population.
- The number of individuals 85 years and over is expected to more than double by 2030. Minority populations are projected to represent 26.4% of the elderly population in 2030, up from 17.2% in 2002.

### Health and Health Care

- Most older persons have at least one chronic condition and many have multiple conditions. Among the most frequently occurring conditions were: hypertension (49.2%), arthritic symptoms (36.1%), all types of heart disease (31.1%), any cancer (20.0%), sinusitis (15.1%), and diabetes (15.0%).
- Limitations on ability to perform specific activities of daily living (ADLs) because of chronic conditions increase with age. Among noninstitutionalized older persons, those 65 to 74 years old, 19.9% had difficulties with ADLs. In contrast, over half (52.5%) of those 85 years and older had difficulties with ADLs.
- In 2002, over 12.5 million persons aged 65 and older were discharged from hospitals. The rate of hospital discharge for persons aged 65 and older is more than three times the comparable rate for persons aged 45 to 64.
- The average length of hospital stay for persons aged 65 and older was 5.8 days; the comparable rate for persons aged 45 to 64 was 5.0 days. The average length of stay for older people has decreased almost 5 days since 1980.
- Older persons averaged more office visits with doctors in 2001: 6.2 for those aged 65 to 74 and 7.4 for persons over 75 while persons aged 45 to 65 averaged only 3.8 office visits during that year.
- Almost 97% of older persons reported that they did have a usual place to go for medical care and only 2.5% said that they failed to obtain needed medical care during the previous 12 months due to financial barriers.
- Older Americans spent 12.8% of their total expenditures on health, more than twice the proportion spent by all consumers (5.8%).

### IMPLICATIONS OF DEMOGRAPHIC CHANGES FOR SOCIAL WORK IN HEALTH CARE

Within the next decade, a larger proportion of individuals seen in all parts of the health-care system (primary care, specialty care, inpatient hospital stays, nursing home stays) will be older adults. Given the shortened length of stay in hospitals and the changing nature of nursing home stays (short stay, postacute care) there

will be a heavy emphasis on appropriate posthospital discharge planning and development of community-based care models to help maintain older adults in community settings. These community-based care models need to address physical, functional, psychological, and social needs of older adults and their families, and social workers will need to pay increasing attention to the development of culturally competent models of care to address the needs of the growing number of minority elders.

As noted by the Bureau of Labor Statistics (2005), "because hospitals are releasing patients earlier than in the past, social worker employment in home healthcare services is growing. However, the expanding senior population is an even larger factor. Employment opportunities for social workers with backgrounds in gerontology should be good in the growing numbers of assisted-living and senior-living communities. The expanding senior population will also spur demand for social workers in nursing homes, long-term care facilities, and hospices."

Although Medicare has enabled access to health care for the 65+ population, older adults have significantly higher out-of-pocket expenditures related to health care, especially for prescription drugs, as compared to other groups and older adults spend a greater proportion of their expenditures on health care (AoA, 2003). Thus, policy advocacy and resource development for health-care products and services will also remain important tasks for social workers in health-care settings.

## COMPREHENSIVE GERIATRIC ASSESSMENT

Comprehensive assessment of needs and resources has become a fundamental aspect of providing care to older persons. The principles of comprehensive geriatric assessments in health care originated in England in the 1930s in the work of Marjory Warren who created a specialized geriatric assessment unit in a "workhouse infirmary" which housed a large number of elderly patients who were neglected and bedridden. Through systematic assessments, Warren determined who might benefit by medical and rehabilitation efforts. She remobilized a majority of these patients and in many cases discharged them to their homes. These experiences led her to become a leading proponent of comprehensive assessment of elderly prior to their placement in a chronic hospital or nursing-home facilities (Wieland & Hirth, 2003).

Over time, the National Health Service in the United Kingdom established geriatric assessment units as a point of entry into the health-care system and these assessments were offered to all older patients through universal health coverage. Many other developed countries (e.g., Canada, Australia, Italy, the Netherlands, Norway) have followed the British model (Urdangarin, 2000). In the United States, however, the use of comprehensive geriatric assessment has been restricted to academic centers and Veterans Affairs hospitals (American Geriatrics Society, 1993).

The concept of a comprehensive geriatric assessment (CGA) in health-care settings such as primary care, inpatient care, and nursing home care is based on the assumption that older adults simultaneously experience problems in multiple domains—physical, social, and psychological, which results in many unmet health-care needs. These problems and needs require a more thorough assessment than what is possible in a routine diagnostic examination provided by the physician. The hallmark of a comprehensive geriatric assessment is that it is performed by a

multidisciplinary or interdisciplinary team, consisting primarily of physicians, nurses, and social workers, and can include specialists from fields such as occupational and physical therapy, nutrition, pharmacy, audiology, and psychology (Agostini, Baker, & Bogardus, 2001; Wieland & Hirth, 2003).

The American Geriatrics Society (1993) states that "routine CGA examines, at the very least, a patient's mobility, continence, mental status, nutrition, medications, and personal, family, and community resources. It involves all disciplines responsible for providing care, as well as the patient and family, in developing an appropriate care plan. Comprehensive geriatric assessment is an effective tool for teaching the integration of the biological, psychological, social, and environmental aspects of health care, while recognizing the geriatrician's special area of expertise."

Whereas a comprehensive geriatric assessment is very helpful in making a diagnosis and understanding a patient's needs, the value of a comprehensive assessment in improving patient outcomes is often limited because the assessment team does not have control over the implementation of the recommendations and treatment plan, which are usually initiated by a primary care physician. Researchers in the United States have noted that many of the recommendations made during the assessment were not followed either by the primary care physician or by the patient (Shah, Maly, Frank, Hirsch, & Reuben, 1997; Urdangarin, 2000) resulting in unmet needs and compromised health situations.

Because of the disconnection between the assessment and the actual treatment or care that is provided to the patient, in the United States there has been increasing recognition that needs assessment should be combined with the management of care. Thus, the geriatric evaluation and management (GEM) approach has been adopted as a basic component of clinical geriatric care by the Department of Veterans Affairs (Urdangarin, 2000). The Veterans Affairs (VA) system first established GEM units in inpatient hospital care and later in ambulatory care to identify, assess, and treat frail and disabled older veterans in the system who were at risk for institutionalization and failing to benefit from usual care (Wieland & Hirth, 2003). Early studies of the GEM approach within the VA system suggested that it was highly cost effective, leading to its adoption throughout the system and by the mid-1990s, over three-quarters of the 172 VA medical centers reported having a GEM program (Wieland & Hirth, 2003).

In GEM programs, patients receive most of their care from the GEM team. The team consists of the physician who provides medical care and generally supervises the team; the nurse who provides some medical care and education about the condition or disease, treatments and medications, the use of home health and emergency services; and the social worker who provides psychosocial counseling for the patient and caregiver, referral to appropriate financial, social, psychological, and community services, and appropriate discharge planning if the patient is hospitalized (Urdangarin, 2000).

Although the implementation of comprehensive geriatric assessment and evaluation has increased in other inpatient units and outpatient departments, it is not provided to older adults universally in the United States. Some of the barriers to providing this service have been the difficulty in obtaining adequate reimbursement for the service, the lack of trained geriatric physicians to run these units, and the difficulty in maintaining interdisciplinary teams (Wieland & Hirth, 2003). Another issue has been the mixed evidence on the effectiveness of these ap-



**Box 14.1**  
**Social Work in an Ambulatory Care Team in the  
Veterans Affairs System**

In the Veterans Affairs (VA) outpatient ambulatory care system, social workers are assigned to an ambulatory care team comprised of physician and nurse practitioner. Once a case is referred to the social worker, a psychosocial functional assessment is completed along with proposed plan for services to address the identified problem or deficits. The social worker provides psychosocial services to the older veteran, collaborating closely with other team members. In addition, the social worker may provide education and informational services, and refer clients to the services within and outside the VA system. Services range from helping to access transportation and medical care, planning for home health care, counseling and psychotherapy, supportive case management, and discharging planning.

proaches in influencing a variety of outcomes such as functional status, cognitive ability, affect, use of services, cost of care, satisfaction with care, and mortality.

The most commonly reported positive outcomes of CGA and GEM were a reduction in mortality, favorable effects on cognitive and physical functioning, increased likelihood of living at home, and decreased likelihood of hospitalization during follow-up (Urdangarin, 2000). Wieland and Hirth (2003) note that the attempt to move this field forward through research on CGA and GEM has been limited by the diversity of patients in the interventions, the differing nature of both interventions as well as “usual care” practices, the inherent complexity of geriatric evaluation and management, inconsistent measurement of outcomes, and the difficulty in replicating successful single-site studies. Thus, a multi-site controlled trial is needed to address some of these difficulties. Despite these issues, comprehensive geriatric assessment has become an accepted component of geriatric primary care and inpatient consultation services, especially with the spread of managed health-care programs. Box 14.1 describes the role of social workers in the ambulatory care system of the VA system.

According to R. L. Kane (2000a, p. 3), “the key to good assessment is using a strong conceptual model” that should not only identify specific client attributes of interest but also related factors such as the physical environment and informal support. Thus, using the biopsychosocial lens, various domains of assessment, their influence on the lives of older individuals, and the implications of their inclusion for social work practice are discussed below. Table 14.1 provides a list of commonly used tools that are used to assess patients and families in each of the domains. See Kane and Kane (2000) for details on the items and psychometric properties of the scales.

#### PHYSIOLOGICAL WELL BEING AND HEALTH

Assessment of an individual’s health status is the most basic feature of a comprehensive evaluation in health-care settings. As individuals age, the prevalence of chronic disease conditions increases significantly, with the most common health problems being arthritis, cardiovascular disease, cancer, and diabetes (AoA, 2004). Beyond the genetic or familial predispositions that contribute to developing these chronic conditions, all of these diseases or

**Table 14.1**  
Assessment Domains and Some Commonly Used Assessment Tools

Major Domains of Assessment	Some Commonly Used Assessment Tools
Physiological well being and health	<p>Medical Outcomes Study: Short Form-36 Health Survey (SF-36; Ware &amp; Sherbourne, 1992). Covers eight areas: (1) physical function, (2) role limitations due to physical problems, (3) social function, (4) pain, (5) general mental health, (6) role limitations due to emotional problems, (7) vitality, and (8) general health perceptions.</p> <p>Get Up and Go Test (Mathias et al., 1986) and Expanded Timed Get Up and Go (Wall et al., 2000). Widely used as a screen for risk for falls.</p> <p>Nutrition Risk Index (Wolinsky et al., 1990). Assesses problems with mechanics of food intake, prescribed dietary restrictions, morbid conditions affecting food intake, discomfort, and changes in diet.</p>
Psychological well being and mental health	<p>Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977; Turvey et al., 1998). Assesses depressed affect, positive affect, somatic/vegetative signs, and interpersonal distress. Available in shorter versions.</p> <p>CAGE questionnaire (Ewing, 1984). Assessment of alcohol problems.</p>
Cognitive capacity	<p>Mini Mental State Exam (MMSE; Folstein et al., 1975). Assesses immediate and delayed memory recall; orientation; calculation/working memory; visuospatial abilities; language.</p> <p>Global Deterioration Scale (GDS; Reisberg et al., 1982). Assesses the severity of dementia related to cognition, functional ability, and problem behaviors.</p>
Ability to perform various activities of daily living	<p>Katz Index of Independence in Activities of Daily Living (Katz et al., 1963). Measures performance in ADLs: dressing, bathing, eating, grooming, toileting, transferring from bed or chair, mobility, and continence.</p> <p>Older Americans Resources and Services-Instrumental Activities of Daily Living (OARS-IADL; Fillenbaum &amp; Smyer, 1981). Measures performance in IADLs: cooking, cleaning, shopping, money management, use of transportation, telephone, medication administration.</p>
Social functioning	<p>Social Support Questionnaire (Sarason et al., 1983). Measures objective and subjective aspects of support received: global, informational, perceived, structural, and provisional.</p> <p>Lubben's Social Network Scale (Lubben, 1988). Can be used as a screening tool for an older person's risk for isolation.</p>
Physical environment	<p>Elderly Resident Housing Assessment Program (ERHAP; Brent &amp; Brent, 1987). Assesses safety, functioning, comfort in various domains through interviews with homeowner, direct observation, and photographs by rater.</p>
Assessment of family caregivers	<p>Caregiver Strain Index (Robinson, 1983). Assesses physical, personal, family, and financial strain related to caregiving.</p> <p>Revised Memory and Problem Behavior Checklist (RMBPC; Teri et al., 1992). Assesses frequency of memory, mood, and problem behaviors in care of the older patient and how much these bother the caregiver.</p>
Economic resources	<p>Older Americans Resources and Services (OARS) Economic Resources (Fillenbaum &amp; Smyer, 1981). Assessment of income, pension, social security, health insurance, and other assets such as a house, cars, savings, and so on.</p>

**Table 14.1** *Continued*

Major Domains of Assessment	Some Commonly Used Assessment Tools
Values and preferences	<p>Values Assessment Protocol (Degenholtz et al., 1997). Assesses values and preferences of older persons in case-managed home care programs. Could be useful in developing care plans.</p> <p>Desire for Choice and Control in Nursing Homes (Kane et al., 1997). Assesses preferences for choice and control in everyday life in nursing homes.</p>
Spiritual assessment	<p>The Daily Spiritual Experience Scale (Underwood &amp; Teresi, 2002). The items attempt to measure experience rather than particular beliefs or behaviors; therefore, they are intended to transcend the boundaries of any particular religion.</p>

conditions influence and are influenced by what individuals do or don't do in their daily lives (Centers for Disease Control and Prevention, [CDC], 2004). Other common health measures that are important to assess are an older individual's overall health status, the presence of pain, nutritional status, risk for falling, incontinence, sleep, alcohol and drug use, dental or oral health, and sensory perception, especially vision and hearing (McInnis-Dittrich, 2002). These health conditions may significantly influence other domains such as lowering psychological well-being, limiting functional ability, and diminishing quality of life. For example, arthritis can be painful, limit mobility, and lead to depression. Similarly, complications from diabetes can result in a loss of limbs that requires modification of the home, access to assistive devices, and personal care assistance. Social workers are generally called on to help older individuals and their families address these issues.

One important problem associated with having multiple health conditions is "polypharmacy," that is, an individual may visit different doctors and receive prescriptions for different medications which may have significant interactions and side effects. Physicians may not be aware that the patient has seen other providers. Thus, a review of all medications should be a standard component of every geriatric evaluation (R. L. Kane, 2000b). Social workers need to be aware of the common medications prescribed for older adults and have some knowledge of side effects as well. Problems experienced with medications or with compliance can often be spotted in the context of home visits and conversations with family caregivers. Social workers in health-care settings should have some working knowledge of these issues in order to alert health-care providers, or encourage the patient and/or caregiver to discuss these issues with the physician or nurse. Another significant issue related to medication use is the cost of medications. Mojtabal and Olfson (2003) report that low-income Medicare beneficiaries with higher out-of-pocket spending for drugs were more likely to not adhere to prescribed medications because of their cost. Cost-related nonadherence with medication use was associated with poorer health outcomes in terms of worsening chronic conditions such as arthritis, heart disease, hypertension, and also depressive symptoms. Thus, for social workers, advocating for individuals to obtain prescribed medications has become an important feature of their practice in health-care settings. Social workers need to remain informed about local and national resources

(e.g., Medicare prescription plans, pharmaceutical company programs) as well as medication assistance programs that vary from state to state (see Chapter 5).

#### PSYCHOLOGICAL WELL-BEING AND MENTAL HEALTH

Although older adults experience many of the same mental disorders as other adults, the prevalence, nature, and course of each disorder may vary significantly (U.S. Department of Health and Human Services, 1999a). Depression, anxiety, and dementia are some of the pathological disorders that can develop in older age (McInnis-Dittrich, 2002). These problems are frequently underdiagnosed in large part due to several challenges that clinicians encounter when assessing the mental health of older persons. These challenges include comorbidity (the presence of other health conditions), wherein many symptoms of mood disorders (e.g., sleeplessness, fatigue) could be misattributed to health problems. Other challenges include stereotypes about aging where the belief that normal aging is associated with increased negative affect is likely to lead to a lack of attention to the symptoms of mood disorders (Grann, 2000). Family members may believe “senility” is a normal part of aging and delay seeking care for the older individual. Older adults themselves may be less willing to talk about their feelings, as different cohorts and cultures may view psychological symptoms very negatively, and instead focus on somatic complaints (see Chapter 9). For example, older individuals, especially those from Asian cultures, may be more willing to admit to sleep and memory problems than feeling sad or anxious (Kleinman, 2004). Finally, the overlap between the symptoms of dementia and depression makes it difficult to assess them separately.

Substance abuse, particularly the abuse of alcohol, prescription drugs, and over-the-counter medications, is another disorder that is underdiagnosed in the older adult population, often because decreased activity by an older adult is attributed to other age-related factors, so substance abuse is not seen as the cause of a disruption from work or social activities (Widlitz & Marin, 2002). Furthermore, clinicians are often unaware of an older person’s drinking problems because the topic is rarely discussed by the physician (R. L. Kane, 2000b). Specialized assessment tools such as the CAGE or the Michigan Alcoholism Screening Test (MAST-G) that specifically target symptoms relating to older persons are essential to screen for substance abuse. These symptoms include mood swings, loss of physical mobility, progressive isolation, unexplained accidents, and a decline in cognitive functioning. Left undiagnosed and untreated, substance abuse can decrease overall health as it is associated with immunodeficiency, arrhythmia, and increased risk for cancer, gastritis, and new seizure activity (Widlitz & Marin, 2002). See Chapter 13 in this *Handbook* for further information.

In the assessment of an older individual’s mental health, positive aspects of psychological well-being are often overlooked. That is, assessments of depression, stress, anxiety, and so on, generally do not address an individuals’ subjective well-being such as the presence of positive affect, hope, optimism, and life satisfaction. Folkman and Moskowitz (2000) suggest that positive affect in the context of chronic stress may help prevent worse outcomes such as clinical depression or adverse physiological consequences of stress. Hope is conceptualized as a future-oriented positive expectation that motivates an individual and provides a means of coping with uncertainty (Raleigh & Boehm, 1994). The lack of hope is predictive of suicidal thoughts among depressed older adults (Uncapher,

Gallagher-Thompson, Osgood, & Bonger, 1998), and the rate of completed suicide is the highest among individuals over 65 years of age (U.S. Department of Health and Human Services, 1999b; see Box 14.2). This fact, coupled with the decreased likelihood of older adults seeking mental health treatment, makes mental health assessment and intervention a significant issue for social workers in health-care settings. See Chapter 8 in this *Handbook* for further information.

#### COGNITIVE CAPACITY

Changes in cognitive capacity occur as people age. Two types of cognitive changes should be noted—the first has to do with small declines in memory, selective attention, information processing, and problem-solving ability that occur with normal aging, although the amount of change varies greatly (Siegler, Poon, Madden, & Welsh, 1996). The consequences of these cognitive changes may be a slower pace of learning and an increased need for repetition of new information (U.S. Department of Health and Human Services, 1999a). The second type of cognitive change is a progressive, irreversible, global deterioration in capacity that occurs as a result of illnesses such as Alzheimer's disease (AD), vascular dementia, and subcortical dementia. It is estimated that about 3% of men and women ages 65 to 74 have AD, and nearly half of those age 85 and older may have the disease (National Institute on Aging, 2004).

Another important issue is the determination of the competence of an individual with impaired cognitive capacity to make their own decisions regarding care. Usually this is accomplished by having either a family member or a social worker (if no family member is available) petition the court for guardianship of the patient's finances and/or person. The decision to grant guardianship is a legal determination made by the court but usually also involves a physician's and social worker's assessment of the clients' capacity for making decisions that do not cause harm to themselves or others (Cummings & Jackson, 2000).

As the dementia progresses, profound changes occur in memory, language, object recognition, and executive functioning, that is, the ability to plan, organize, sequence, and abstract. Behavioral symptoms such as agitation, hallucinations, and wandering are also common. These cognitive changes necessitate increasing supervision of the older individual leading to considerable strain and burden experienced by both formal and informal caregivers (Alzheimer's Association, 2004). Much of the social worker's effort is directed toward finding resources such as caregiver support groups, behavior management training, counseling, personal care services, respite, and alternative living arrangements (e.g., foster care, assisted-living facilities, nursing homes) to support the informal caregivers. Medications can also be helpful in managing some behavioral symptoms such as agitation and hallucinations. Social workers should encourage family members to discuss all symptoms and changes in behavior with the physician, the social worker, and the caregiver support group because many behavior management techniques can be learned from listening to the experiences of other caregivers.

#### FUNCTIONAL ABILITY

Functional ability is usually defined as an individual's ability to perform certain basic activities of daily living (ADLs) that refer to personal care (e.g., dressing,

**Box 14.2****Facts about Suicide among Older Adults**

- Suicide rates increase with age and are highest among individuals aged 65 years and over.
- Of the suicides in this age group, 85% were males. Caucasian males have the highest rates of completed suicide.
- As compared to younger suicide victims, older adults who complete suicide were more likely to have lived alone, be widowed, and have had a physical illness.
- About 70% of elderly suicide victims had visited their primary care provider in the month prior to their suicide attempt, representing a missed opportunity for intervention.
- Firearms were used in 73% of suicides committed by adults over the age of 65 in 2001 (CDC, 2004).
- In one study, only 58% of physicians asked their depressed and suicidal elderly patients about their access to firearms (Kaplan, Adamek, & Rhoades, 1998).

**The Public Health Approach to Suicide Prevention**  
(U. S. Department of Health and Human Services, 1999)

Whereas the clinical medical approach explores the history and health conditions that could lead to suicide in a single individual, the public health approach focuses on identifying and understanding patterns of suicide and suicidal behavior throughout a group or population. The public health approach defines the problem, identifies risk factors and causes of the problem, develops interventions evaluated for effectiveness, and implements such interventions widely in a variety of communities.

**The Elderly**

Most elderly suicide victims are seen by their primary care provider within a few weeks of their suicide and are experiencing a first episode of mild to moderate depression. Recognizing that clinical depression is a highly treatable illness, but treatment has not yet been adequately provided in primary care settings, a state with a large elderly population brought together a group of health professionals and community advocates. Together they devised and supported a pilot program to follow depression screening in the primary care setting with the addition of an on-site nurse or social worker specializing in depression services. These on-site specialists ensured that those elderly patients who screened positive for depression received depression treatment and follow up from the physician and assessed patient progress so that ongoing treatments could be adjusted to increase their effectiveness. Outcomes for patients in the pilot project were compared to those patients receiving usual treatment in comparable primary care settings. This evaluation provided information for fine tuning the program and extending the benefits to other primary care settings in the state.

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*Source:* "The Surgeon General's Call to Action to Prevent Suicide," by U.S. Department of Health and Human Services, 1999, available from <http://www.surgeongeneral.gov/library/calltoaction/default.htm>.

bathing, eating, grooming, toileting, getting in and out of bed or a chair, and urinary and bowel continence), and instrumental activities of daily living (IADLs) that refer to activities that need to be performed in order to live in a community setting (e.g., cooking, cleaning, shopping, money management, use of transportation, telephone, medication administration). Mobility, which addresses walking,



climbing stairs, balance, and transferring in and out of a chair or bed, is often included in the ADLs. The performance of these activities is usually assessed in terms of being independent, needing assistance (human help or mechanical devices), and being unable or completely dependent on human help to perform the various activities. The progression of disability in performing these activities predicts an individual's movement along the continuum of care ranging from independent living to assisted living (assistance could be informal, formal, or both) to nursing home care.

A variety of factors contribute to an individual's ability to perform ADLs and IADLs. Pearson (2000, p. 19) notes that "functional ability can be conceptualized as the dynamic interaction of an older adult's physiological status, the emotional or psychological environment, and the external or physical and social environment." For example, many of the health conditions discussed earlier could contribute to limitations in functional ability. Psychological issues such as depression, anxiety (including a fear of falling), and hopelessness may lead to a decreased motivation to perform these activities. Cognitive changes such as dementia also limit an individual's functional ability. Finally, the external physical environment (type of dwelling or neighborhood) as well as the social support available to an individual may promote or hinder one's ability to perform ADLs and necessitate a change in living conditions. For social workers, the implications are clear: An assessment of functional status requires an evaluation of all of the factors that may contribute to an individual's disability. Limitations in ADLs and IADLs are a prerequisite for eligibility for services in all publicly funded home and community-based services programs.

Another significant issue in the area of functional limitation is the ability to drive a motor vehicle. According to Straight and Jackson (1999), persons age 65 and older are relatively safe drivers. As a group they represent 14% of all licensed drivers but are involved in only 8% of police-reported crashes. The rate of crashes per mile driven is relatively constant for all adults age 25 to 69. The rate begins to rise at age 70, and increases rapidly at age 80. Thus, it is the oldest drivers who pose more risk to themselves and to public safety. A variety of age-related and other changes in vision, hearing, reaction time, and cognitive function can interfere with an individual's ability to drive. Yet, in the United States in particular, the ability to drive is one of the most significant components of the ability to remain independent. Thus, some communities have undertaken environmental modifications such as lengthening the time of traffic signals and increasing the size of lettering and visibility of street signs.

Organizations such as the Automobile Association of America (AAA) and the American Association of Retired Persons (AARP) offer a "Mature Driver Safety" program to retrain older drivers. Based on a study of older drivers, the Hartford Financial Services Group in partnership with the Massachusetts Institute of Technology (MIT) AgeLab developed a brochure that prepares family members on how to have a conversation with an older person about driving decisions (The Hartford, 2005). Older persons generally preferred to be approached by individual family members as opposed to those outside the family (such as a close friend or the police) when having conversations about their driving. Most married older adults preferred to hear first from a spouse, although over 18% of those who were married with a spouse in the household reported that they absolutely did not want to hear from their spouse about driving concerns. Doctors and adult children were also preferred

choices for conversations. In cases where older adults lived alone, doctors, followed by adult children, were most often selected (Coughlin, Mohyde, D'Ambrosio, & Gilbert, 2004). Social workers can be helpful in educating and engaging family members and physicians about addressing this issue with an older patient.

### SOCIAL FUNCTIONING

When assessing social function, it is important to remember the subjective and objective components to social functioning. Objective measures would include social support (support or help received), social networks (number of persons in the individual's social circle), social activities (attendance at social events, frequency of contact with others), and social roles (the number and type of roles performed). Subjective measures of social function ask individuals to report on their satisfaction with their social situation and their perception that support is available when needed. Individuals may vary considerably in objective measures of social function and yet express similar amounts of satisfaction. There is a large body of evidence that suggests that subjective evaluations of support are more strongly related to psychological well-being than objective indicators of social functioning, such as the frequency of contact with others (Krause, 1995). Different aspects of social functioning can be addressed depending on the goal of treatment or care planning. For example, social workers may focus on an increase in the frequency of contact with existing social networks (e.g., finding transportation to attend social or church activities) or an increase in social roles (e.g., finding employment or volunteer opportunities) depending on which aspects of social function are most salient to the older person.

Among older individuals, social integration, that is having social ties, roles, and activities, is associated with better health outcomes such as a lower risk of mortality, cardiovascular disease, cancer mortality, and functional decline (Unger et al., 1999). However, health also affects social functioning in that individuals who are confined to a bed or have severe mobility impairments are likely to disengage from social activities that involve leaving the home. Thus, as Levin (1994) points out, social functioning is both an outcome as well as a predictor of physical and psychological well-being.

Negative interaction or support is also an important area for assessment. Negative interaction typically occurs with individuals who have a close relationship with the older person (Antonucci, Sherman, & Vandewater, 1997), and can take the form of disagreements, emotional and financial abuse, and even physical abuse and neglect (discussed in the section on family and informal support).

One issue that overlaps social, physical, and psychological domains is the expression of sexuality and the experience of intimacy among older persons. (See Chapter 12 in this *Handbook* for more details.) In a review of the literature, Hooyman and Kiyak (2002) note that contrary to the misperceptions about the cessation of sexual activity as individuals grow older, sexual activity continued into older ages, and that sexual inactivity appeared to depend more on life circumstances rather than a decrease in interest or desire. For example, the influence of marital status and interpersonal relationships on sexual behavior is greater for women than for men (Mathias, Lubben, Atchison, & Schweitzer, 1997) whereas physical conditions resulting in sexual dysfunction appear to be the major difficulty influencing sexual activity for men (Wiley & Bortz, 1996). A psychosocial

assessment of factors that influence sexual activity in older adults should include an individual's past history of sexual activity, attitudes toward sexual activities and intimacy, availability of a partner, anxiety about sexual performance, opportunities for privacy, and attitudes of staff toward sexual activity in institutional settings (Hooyman & Kiyak, 2002). Given the rates of HIV and AIDS among older persons—10% of those with HIV are over age 50 and about 3% are over age 60 (Linsk, 2000), knowledge about HIV and the practice of risky behaviors should also be part of the assessment.

#### PHYSICAL ENVIRONMENT

As individuals age, we often see a widening in the gap between the demands of the environment and the individual's competence to address those demands. The aging process brings with it many physiological changes in sensory perception, gait, reaction time, and strength, all of which may compromise an individual's ability to negotiate the existing environment. For example, changes in vision and depth perception make it difficult to negotiate stairs, which may lead individuals to restrict their trips out of the house, leading to further dependence on assistance and increased social isolation. Inadequacies in the physical environment may also necessitate relocation from a house or residence that could negatively influence an individual's psychological well-being especially if the older person is opposed to the move. This is particularly true in the case of many nursing home admissions.

While independent homes are the most obvious targets of an assessment of the adequacy of the physical environment, Cutler (2000, p. 360) maintains that "all residential environments can be measured against the principles of universal design, wherein a residential setting should be adaptable, supportive, accessible, and safe." In 2000, about 78% of older adults (65 years and over) owned their home (U.S. Census Bureau, 2004) and about 89% of respondents aged 55 years and over strongly or somewhat agreed that they would like to remain in their current residence for as long as possible (AARP, 2000). Among older adults, falls are the leading cause of injury deaths and the most common cause of injuries and hospital admissions for trauma. Each year about 35% to 40% of adults 65 years and older fall at least once and about two-thirds to one-half of the falls occur in or around the home (CDC, 2001).

Thus, assessing the fit of the home environment with the capabilities of the individual is an important assessment domain and the prevention of falls is a critical area of intervention. Typical home assessments will examine the condition, adequacy, and accessibility of lighting, flooring, and carpeting including obstacles or potential hazards for falling; bath and toilet including need for assistive devices; kitchen; heating and cooling; access to home from outside; access to rooms within the home; and personal safety issues such as neighborhood conditions. Similar issues are also important when evaluating assisted-living or foster-care facilities.

#### ASSESSMENT OF FAMILY AND INFORMAL SUPPORT

Family members play an important role in organizing or providing for the care of an older adult. About two-thirds (64%) of the persons who live in the community and need long-term care rely solely on family and friends (i.e., informal support)

for help; 28% receive a combination of informal and formal care; and only 8% used formal care or paid help only (Liu, Manton, & Aragon, 2000). Family members of older adults most likely to be caregivers are adult daughters (27%), other female relatives (18%), sons (15%), wives (13%), husbands (10%), and others. About 30% of persons caring for elderly long-term care users were themselves aged 65 or older, and another 15% were between ages 45 and 54 (Spector, Fleishman, Pezzin, & Spillman, 2000).

The assessment of informal support generally focuses on the number and relationship of family helpers, amount and type of help provided, the expected permanence of family help, the strain or burden experienced by caregivers, and more recently on the positive aspects of caregiving (Gaugler, Kane, & Langlois, 2000; Pearson, 2000). Many caregivers have competing demands such as employment and caring for young children. With the declining functional ability that occurs with chronic illnesses and dementia, along with the need for increased vigilance, caregivers experience considerable strain that puts the older person at greater risk for entering a nursing home and also increases the likelihood of abuse or neglect. It is thus important to assess both objective and subjective components of caregiver strain to gain a better understanding of the needs of the caregiver. Objective components of burden refer to the disruption in finances, family life, and social relations whereas subjective components refer to the caregiver's appraisal of their situation as stressful (Gaugler et al., 2000).

There is some evidence of race or ethnic differences in the appraisal of strain due to caregiving, such as evidence that African American caregivers have a lower likelihood of viewing caregiving as stressful when compared to Caucasian caregivers (Gonzales, 1997). However, much of the research on race or ethnicity is confounded with socioeconomic status and little data are available on caregiver perspectives from different socioeconomic strata within racial and ethnic groups. In many long-term care programs, formal services are provided only when family members are not in a position to do so. Thus, it is important that social workers attend to both objective and subjective components of caregiver strain when developing a long-term care plan.

In the health-care system, the assessment of family support is often constrained by legal definitions of who is a family member. This creates significant structural and legal barriers for older gay and lesbian couples in various health-care settings. For example, partners may be denied access to medical records or visits to intensive care; in matters of medical decision making, health-care professionals may restrict themselves to dealing with family members rather than partners despite the fact that family members may know less about the preferences of the older patient than the partner; and staff may hold negative attitudes toward gay and lesbian couples (Hooyman & Kiyak, 2002). Social workers should be aware of their own values and practices related to this issue and act in concordance with the professional code of ethics to not discriminate against individuals on the basis of a variety of factors including sexual orientation (National Association of Social Workers, 2003).

Elder abuse often occurs when family members are overwhelmed with caregiving responsibilities, particularly if the care recipient and the care provider are living in the same household and there is a past history of family abuse. Additional risk factors for elder abuse include being over 75 years old, female, having physical and/or cognitive limitations, living in a lower socioeconomic household,

and care-giver vulnerability to problems such as substance, mental illness, or financial dependency on the care recipient (McInnis-Dittrich, 2002; National Center on Elder Abuse [NCEA], 2004). A survey of states by the NCEA in 2000 notes that social workers are mandated reporters of elder abuse in 30 states or territories in this country (NCEA, 2004). This is important in part because signs of elder abuse may be overlooked in health-care settings when bruises, bone fractures, or painful body symptoms might be attributed to changes due to normal aging, unexpected falls, or pain related to illness.

#### ECONOMIC RESOURCES

Typically, the assessment of economic resources (i.e., income, pension, health insurance, and other assets) is necessary to determine eligibility for publicly funded home and community based services. Almost every state operates a Medicaid waiver-funded home and community based services program that provides for home care services to older adults who are at risk of entering a nursing home. The actual assessment and eligibility criteria vary from state to state, but in general they include limitations in functional ability and an income at or near poverty (Centers for Medicare and Medicaid [CMS], 2004a). Those individuals whose incomes exceed the criteria are required to “spend down” their assets until they reach the eligibility level (CMS, 2004b). See Chapter 5 in this *Handbook* for additional information. Assessing income and assets can be a frustrating and time consuming activity due to the reluctance of older persons and their family members to divulge such information, often leading to an increased use of social work time and delays in the Medicaid application process (Diwan, 1999).

#### VALUES AND PREFERENCES

There is little systematic evaluation of the values and preferences of older adults in most health and long-term care settings (R. A. Kane, 2000). Kane outlines several areas in which some systematic ways of eliciting individual preferences are desirable, including:

- Preferences for end-of-life care that addresses whether individuals would want various procedures performed such as resuscitation, ventilator care, intubation, and hydration, and also whether they would like to designate a proxy decision maker in the event the older individual cannot make these decisions.
- Preferences about outcomes associated with alternative hospital discharge plans; for example, preferences related to particular types of home care services needed or the location of post hospital care.
- Preferences about housing arrangements such as those related to independent as well as various types of congregate living arrangements such as assisted-living facilities, small group homes, continuing care retirement communities, or nursing homes.
- Preferences for how routines of everyday life are conducted especially with ADLs and IADLs.
- Preferences related to religious practices.
- Preferences related to privacy, especially in congregate settings where individuals may share rooms and be observed by others when being helped with ADLs.

- Preferences related to safety versus freedom, for example, older adults may choose to live in situations that professionals consider less than adequate. R. A. Kane (2000) notes that while the right to take risks is a consumer-centered value, it is a difficult concept to articulate and measure because the trade offs that occur for choosing various levels of risk may be difficult to articulate.
- Preferences related to exercising control and choice over one's care.

Thus, in keeping with social work values that promote the principles of client self-determination and autonomy, assessment of values and preferences of older adults can help social work practitioners be more attentive to these issues when working with older adults in institutional settings that tend to minimize the opportunity for self-determination.

#### SPIRITUAL ASSESSMENT

A growing body of literature documents the positive link between religiosity, spirituality, participation in religious activities and health and psychological well-being among older adults (Koenig, 1990; Levin, 1994). Assessment of preferences for religious and spiritual activity is important because these factors are known to influence an individual's psychological and social functioning, ability to cope with stress, and overall quality of life. The actual domains of assessment may include religious affiliation, beliefs, commitment, participation in religious activities, and private daily experience (Olson & Kane, 2000). The salience of these domains to an individual (e.g., religious strictures for food, that is, kosher for observant Jews, halal for observant Muslims; or the availability of religious services) could significantly influence care plans for community-based care as well as for institutional long-term care arrangements.

#### ASSESSMENT VERSUS SCREENING

Although comprehensive assessment of older persons and their families is desirable, it is not feasible to assess individuals in depth in all possible areas. Typically, the content of an assessment is determined by its purpose and the setting in which it occurs. An abbreviated form of assessment is often used for the purposes of screening or case-finding, that is finding persons in need of social work intervention. Screening is usually done with a large group of people in order to identify individuals who may have difficulties or problems in certain areas of functioning. These individuals are then assessed in greater depth and often referred to specific disciplines for continuing care (Finch-Guthrie, 2000). For example, many health maintenance organizations (HMOs) screen all of their older patients by sending surveys at the time of enrollment. Individuals who meet certain "risk" criteria (e.g., those at risk for falling, breakdown of informal support, or those likely to be high users of emergency room services) are then referred to case managers who develop, implement, and monitor a care plan to address their particular risk factors. Screening, or case-finding, is also important in primary care settings where the needs of many older patients may be overlooked due to the lack of time or training to assess psychosocial needs of older patients with



chronic illness (Berkman et al., 1999). Another example of screening occurs in inpatient units where social workers screen high-risk individuals, or those who may require earlier intervention and intensive attention for the purpose of developing a viable discharge plan (Cummings & Jackson, 2000).

## SOCIAL WORK WITH OLDER ADULTS IN HEALTH-CARE SETTINGS

Social work practice with older adults occurs in a range of health-care settings: outpatient clinics, hospitals, emergency rooms, public health departments, home health-care agencies, agencies providing home and community-based services, and residential and rehabilitation facilities such as nursing homes and assisted living. Some essential social work practice skills that are needed to work with older adults in these settings are described in Table 14.2.

### PRIMARY HEALTH-CARE SETTINGS

The term *primary care* refers to the initial entry of the patient into the health-care system and implies a holistic approach to care focusing on health promotion, disease prevention, and integration of mental and physical health services (Cowles, 2003; Oktay, 1995). Primary health-care centers are considered important “one-stop” services because they can assist patients and families in navigating other health-care services and promote continuity of care and linkages between patient, family, and community (Donaldson, Yordy, Lohr, & Vaneselow, 1996). Most older patients in primary health-care settings have two or more comorbid chronic illnesses such as those described earlier in this chapter.

Generally, social workers come in contact with older persons through referral from physicians or nurse case managers or via high-risk screening methods. The social worker completes a psychosocial assessment to determine the strengths and service needs of the patient, develops a care plan in partnership with the patient and family, and seeks input from all of the health-care professionals involved in the delivery of care. The social worker’s level of collaboration with health-care professionals varies depending on the type of primary care setting

**Table 14.2**  
Essential Social Work Practice Skills in Health-Care Settings

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<i>Screening:</i> High-risk, service eligibility, special problems
<i>Assessment:</i> Problem identification, needs, strengths, resources (individual and community)
<i>Communication skills:</i> Verbal and nonverbal; interviewing (patient and family; special groups, other professionals and service providers)
<i>Interpersonal engagement skills:</i> Conveying values (autonomy, empathy, trust; clarifying roles; empowerment)
<i>Clinical skills:</i> Crisis intervention, counseling, and therapy (individual, family, and group)
<i>Group facilitation:</i> Support groups, psychoeducational groups
<i>Mediation/negotiation:</i> Advocacy, dispute resolution
<i>Documentation:</i> Health insurance, medical records, mandated assessments

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and availability of a geriatric consultation team. Social workers may advocate for access to identified gaps in services and resources within or outside the primary care setting on behalf of the older person to ensure successful implementation of the care plan. They also provide information on available resources in the community and refer older patients to community agencies that offer services such as housing, transportation, home health care, counseling/psychotherapy, durable medical equipment, and health insurance.

The goal is to facilitate comprehensive patient care that meets the needs of the patient. As direct service practitioners, they may provide emotional support and counseling to older persons to foster coping and adaptation to their illness, treatment, and prognosis. They also help identify and mobilize the social support system (family, friends, and significant others) in the community. In their evaluation of the Generalist Physician Initiative, funded by the Hartford Foundation, a program designed to enhance the care of older adults, F. Netting and Williams (2000) concluded that social workers were logical collaborators with primary care physicians in facilitating a holistic approach in provision of health care for older adults. Because provision of health care is rapidly shifting to ambulatory settings, social work experts envision a need for expanding the role of social workers in primary care settings to include more multidisciplinary and interdisciplinary team approaches, organizational networking, case management services, participation in medical ethics consultations, therapeutic and crisis interventions, and other supportive counseling and group work interventions (Berkman & Harootyan, 2003; Cowles, 2003; Netting, 1992).

#### INPATIENT HOSPITAL SETTINGS

Historically, the inpatient acute care setting has been the single largest employer of clinical social workers involved in health-care delivery (Ginsberg, 1995), although as noted by the Bureau of Labor Statistics (2005), as hospitals continue to limit the length of patient stays, the demand for social workers in hospitals will grow more slowly than in other areas. Social workers typically see older patients through referrals from physicians and nurses or through case-finding using high-risk screening methods. Characteristics of high-risk patients may include living alone, terminal or chronic illness, suicidal tendencies, mental health problems (Becker & Becker, 1986), and lack of supports (Berkman et al., 1999). Hospitalized older patients are referred to social workers for a wide range of issues and problems such as anxiety over being hospitalized; pre- or postsurgical concerns about procedures, treatment, recovery and discharge; lack of support and resources after discharge; family and patient consent on use of life-sustaining equipment; suspected abuse; and cognitive or functional impairments that require intervention. Acute health problems for which older persons may be admitted to the hospital include falls and fractures, physical impairment, iatrogenic illness, nutritional problems, or surgery.

Hospital social workers in inpatient settings are responsible for screening and case-finding, psychosocial assessment, discharge planning, post-discharge follow-up, out-reach, counseling (individual, group work), documentation and record keeping, and collaboration. Depending on the hospital, they may provide emergency services through on-call programs.

The psychosocial assessment evaluates the patient's level of functioning, service needs, social history, and availability of support if needed from family and

friends. The process of discharge planning and developing a post-hospitalization care plan involves coordinating input from the various members of a multidisciplinary team, and social workers coordinate this effort in their important role on the team as liaison for the patient and family (Cotti & Watt, 1989; Cowles, 2003; see Cummings & Jackson, 2000).

Social workers can help inform or educate older individuals about the seriousness of their illness, consequences if the illness is left unattended, resources available to assist in continuity of care, options for alternative care, legal rights, and so on, which can help patients to become effective consumers of services, and gain a sense of self-efficacy that is often lost when a person experiences losses in functioning and when dealing with large and complex health-care systems. Through referrals to community services and family conferences, social workers may engage in informing other formal and informal support networks to help the client after discharge or advocating for specialized services within or outside the hospital. This requires knowledge of the availability and eligibility requirements of various community resources. Social workers are also expected to have knowledge and skill in determining the method of reimbursement such as private or public insurance or out-of-pocket costs.

Frequently, social workers are involved in counseling older patients about adjustment to illness issues, and may provide crisis counseling to help the family and older person reestablish an emotional equilibrium, begin to understand the medical condition, prioritize tasks, and develop a short-term action plan (McInnis-Dittrich, 2002). Social workers may also develop support groups (such as bereavement, cancer, dementia, and high-risk health behaviors) to assist patients and their families with their losses and illness and undertake family counseling when needed. Facilitation of support groups for older patients in this setting requires skills such as relationship building, counseling, and communication skills (Ross, 1995).

The level of social work involvement in discharge planning may vary depending on hospital size, location, number of social workers employed, policies, protocols, and organizational culture. Generally, physicians refer patients to hospital social workers for concrete services such as assistance with instrumental activities of daily living, or social-environmental problems such as those involving financial needs, post-hospital care, and transportation rather than for primarily expressive problems involving attitudes, feelings, or behaviors related to health (Cowles & Lefcowitz, 1995). However, in a study by Holliman, Dziegielewski, and Datta (2001), social workers in the field perceived their role in discharge planning as requiring specific skills related to communication and assessment of social and financial issues and not just provision of concrete services.

#### HOME HEALTH-CARE SETTINGS

In 1999, about 8 million individuals in the United States received home health services from more than 20,000 providers (National Association of Home Care, 2001). Major source of funding for home health care is through Medicare and Medicaid, followed by private out-of-pocket payments. Certified Medicare home health-care providers have to meet the minimum federal standards of patient care and are expected to maintain an electronic Outcome and Assessment Information Set (OASIS) database. It consists of core elements of a clinical assessment

for all the adult home care patients served. The major components of the OASIS are living arrangements, supportive assistance, sensory status, skin condition, respiratory status, elimination, neuro/behavioral/emotional status, ADLs and IADLs, medications, medical equipment management, and emergent care (R. L. Kane, 2000c).

The federal government utilizes this information for cost reimbursements and on-going monitoring for measuring patient outcomes for purposes of outcome-based quality improvement. A physician has to refer an elderly person for home health-care services in order to receive Medicare and Medicaid reimbursement. Similarly, Medicare mandates that a social worker's services be covered, only if they are ordered by a physician. The goal of home health-care services is to reduce the length of inpatient hospital stays and delay of discharge or prevent nursing home placement or hospital readmission of an older person through the provision of a range of health and social services within the home setting.

Home health-care users are likely to be female, poor, live alone, and have functional limitations in activities of daily living. Medicare beneficiaries aged 85 and older represent 26% of the all home health users (Health Care Finance Administration, 1999). Most older persons receive home health care due to an acute episode of a chronic illness (e.g., diabetes, hypertension, or heart failure) and have psychosocial issues that compound their illnesses that require care from multiple professionals, including social workers (Lee & Gutheil, 2003).

Following hospital discharge, a homebound patient may require multiple services by a variety of health-care providers. Nurses and physical therapists may assist with medication and rehabilitation; home health aides may assist the patient with personal care activities such as bathing and transferring (i.e., getting in and out of bed or a chair), homemakers may assist with light housekeeping such as meal preparation, shopping, and laundry. In addition to coordinating these supportive services, home health social workers can arrange for community services, such as transportation and friendly visitor volunteers. They help the family and older person adjust to having providers enter the home and often provide supportive or therapeutic counseling services or arrange for similar services from other agencies in the community (Dziegielewski, 2004; Lee & Gutheil, 2003; McInnis-Dittrich, 2002).

A critical function of the social worker is to assess and facilitate the caregiver's involvement in the patient's recovery and rehabilitation. Social workers may help caregivers identify, secure, and utilize other community services, such as adult day health care, to meet the changing needs of the patient (Rossi, 1999). Social workers are frequently engaged in negotiating with health-care providers for specific services, service units, time-slots, requesting for specific staff, and so on, to match the patient's needs with services. The frequency of denial of requested services is greater in home health settings due to changes in cost reimbursement policies (conversion from a cost-based reimbursement system to a prospective payment system), and social workers feel ethically obligated to advocate for their patients (Kadushin & Egan, 2001).

#### NURSING HOME SETTINGS

The National Nursing Home Survey in 1999 noted 18,000 nursing homes operating in the United States with about 1.6 million residents, 90% of whom were aged

65 years and over (National Center for Health Statistics, 1999). Historically, nursing homes were viewed only as long-term care facilities. However, the past decade has seen greater use of nursing homes for short stays for rehabilitation and care after discharge from the hospital with a concomitant increase in the role of Medicare in financing nursing home care (Rhoades & Sommers, 2003). Seventy-two percent of nursing home residents are female, 57% are widowed, and about 75% of residents required assistance in three or more ADLs, including bathing, dressing, receiving help with toileting, and eating indicating a high prevalence of major functional limitations. Also, individuals over 75 years of age were frequently diagnosed with mental disorders (National Center for Health Statistics, 1999), generally dementia and other psychiatric conditions such as schizophrenia and mood disorders.

Depression is common among nursing home residents (Jakubiak & Callhan, 1995, 1996; Masand, 1995), especially in patients diagnosed with Alzheimer's disease, and is often attributed to co-existing conditions or simply to aging, and thus fails to receive appropriate intervention (Adamek, 2003). The most frequently received services by residents include nursing (96%), medicines (94%), medical (91%), personal care (90%), nutritional (73%), social services (72%), and equipment or assistive devices (53%) (National Center for Health Statistics, 1999).

Not-for-profit nursing facilities employ more full-time social workers than for-profit homes (Kruzich & Powell, 1995) with social workers employed as administrators, specialized unit directors (e.g., dementia care) or direct practitioners. Within the nursing home setting, social workers perform a variety of functions such as doing psychosocial assessments (Nathanson & Tirrito, 1998), working to resolve family conflicts with facility staff and administration (Iecovich, 2000; Vinton, Mazza, & Kim, 1998), and addressing problem behaviors of nursing home residents (Tirrito, 1996). In most nursing homes, social workers are responsible for conducting the pre-admission screenings to determine if patients have any major mental disorders (mental retardation, developmental disability, or related disorders) so that they can provide appropriate referrals and treatment (Cowles, 2003; Dziegielewski, 2004).

All Medicare and Medicaid certified nursing home facilities require a comprehensive assessment of residents within 14 days of admission. In response to public and professional concern about the quality of care in nursing homes across the country in the 1980s, Congress directed the Health Care Financing Administration (HCFA) to study how to improve nursing home regulation. HCFA contracted with the Institute of Medicine (IoM), which issued a report in 1986 titled "Improving the Quality of Care in Nursing Homes." Congress included many of the IoM recommendations from this report as part of the 1987 Omnibus Budget Reconciliation Act (OBRA). Based on the IoM report, OBRA 1987 regulations require the assessment of nursing home residents in 18 functional areas. The Minimum Data Set was developed as a recommended format for that comprehensive assessment (American Geriatrics Society, 2000). In most facilities, social workers complete the psychosocial assessment of the Minimum Data Set to develop the care plan for the resident (Cowles, 2003; Dziegielewski, 2004).

Among the most frequently cited sources of distress that older patients face in transitioning into nursing home settings are feelings of loss and abandonment; adjustment to new environments; fear and anxiety related to life changes, illness, and prognosis; and loss of privacy, independence, and family connection. Social

workers can help residents adjust to their environments by providing emotional support and initiating appropriate interventions (individual, family, and group) to enhance psychosocial functioning. They can also facilitate social integration within nursing homes through planned recreational activities in the nursing home. In conjunction with the provision of direct services to residents, involvement of family is especially critical during admission and discharge (Kruzich & Powell, 1995; Vourlekis, Gelfand, & Greene, 1992). Informal support networks can provide valuable assistance to older persons through their stays in nursing homes by providing support and monitoring the quality of care provided by the staff.

Because family members are considered an integral part of care plans, social workers may also want to provide meaningful services to them, for example, therapeutic care-giver support groups or educational groups on illness or end-of-life issues. In settings like nursing homes, where the patients and family members may be unable to negotiate the care of the person due to frailty, inability to make personal decisions, or bureaucracy, social workers can advocate on behalf the patient and empower families to voice their concerns and to negotiate the treatment needs and care of the elderly. They may also work with resident councils to improve the quality of care of facilities. In other situations, where there may be conflict between family members and nursing home staff, the social workers can mediate to help resolve the conflict and facilitate improved communication.

#### ISSUES AND CHALLENGES TO SOCIAL WORK WITH OLDER INDIVIDUALS IN THE CURRENT HEALTH-CARE ENVIRONMENT

Demographic trends make it clear that within the next decade older adults will represent a larger proportion of individuals seen in all parts of the health-care system (primary care, specialty care, inpatient hospital stays, nursing care). As the costs of health care continue to skyrocket, attempts to manage these costs have altered the context in which health care is delivered and has significantly influenced the practice of social work in a variety of health-care settings. The principal idea underlying managed care has been to control the costs of health care by decreasing “unnecessary utilization” of health-care services, which is accomplished through budget restrictions, case management and utilization review, incentives to providers for limiting services, and using the primary care provider as the gatekeeper for access to care (Berkman, 1996). Managed care, however, presents social workers with a dilemma of being a patient advocate while, to a certain extent, a gatekeeper of resources. For example, can social workers adequately assess the needs of patients and their families given prevailing time restraints? Can they attend to the preferences of the patient and the family given the institutional mandate to develop and implement a discharge plan that minimizes length of stay (Moody, 2004)?

Although Medicare has enabled access to health care for the population that is 65 and older, older adults have experienced significantly higher out-of-pocket expenditures related to health care through time, especially for prescription drugs, compared to other age groups and spend a greater proportion of their expenditures on health care (AoA, 2004). Thus, advocacy and resource development for health-care products and services will remain important tasks for social workers in health-care settings.



Given the shortening of inpatient stays in hospitals and the changing nature of nursing home stays (short stay, post-acute care), the development of community-based care models will be needed to help maintain older adults in community settings. However, the ability to maintain older individuals in the community depends on the availability and pulling-together of several community resources. In communities where resources are underdeveloped or where services are financially beyond the reach of clients, case management may simply become a referral service that fails to adequately address the needs of older adults and their families (Netting, 1992). Policy advocacy for supporting family caregivers will remain an important area of social work practice to support community-based care for older adults.

Finally, health promotion and disease prevention activities at the individual and community levels that help older persons maintain functional autonomy and physical and psychological well-being will be important areas of social work intervention.

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## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 14.1

Mr. and Mrs. C. are an older Caucasian couple who came to the attention of a hospital social worker after Mrs. C. had been hospitalized for dehydration. She was brought to the hospital based on the recommendation of her primary care physician who had found her to be quite confused and delirious during her visit to the doctor's office. Mrs. C. had been stable over the past few days, but her age (73) and her confusion had flagged her as an at-risk patient who would need additional attention to develop an adequate discharge plan. The social worker learned that the C.'s lived in their own home and their only son lived about 200 miles away from them. The C.'s lived modestly on their pension and social security. Mr. C. indicated that he wanted his wife discharged to their home because he was quite capable of looking after her. Mr. C. himself did not appear to have any observable limitations in his ability to carry out activities of daily living, although he did look tired. The social worker was not entirely convinced of Mr. C.'s ability to adequately care for his wife—she did after all have to be hospitalized due to her dehydration. According to the patient's chart, Mrs. C.'s confusion still seemed to persist, although she seemed quite lucid when talking to the social worker. The physician and the nursing staff wanted the social worker to develop a discharge plan fairly quickly. The hospital social worker decided that Mrs. C. should be discharged to her home in the care of her husband. However, she recommended that the physician order home health care for Mrs. C. because a nurse could monitor her condition and a social worker could do a more comprehensive assessment in the client's home. This way, at least someone could monitor this situation for several weeks.

Did the hospital social worker do everything she could have done with planning for the C.'s? What were some of the constraints or dilemmas experienced by the social worker?

## LEARNING EXERCISE 14.2

ABC Home health is the agency that is selected to provide in-home care to Mrs. C. The home health social worker visits the home once to make an assessment. The house seems a little cluttered and Mr. C. notes that he does all of the housework but because of the pain caused by his arthritis, he cannot really get things done quickly. The social worker suggests that they try to get some homemaker assistance. She gives Mr. C. the contact information for the local area agency on aging and also suggests that Mr. C. call his son to discuss long-term care plans since they would likely need more assistance as time went by. Mr. C. calls the area agency on aging for homemaker assistance but is put on a waiting list. One month later, Mr. C. trips on an area rug which results in a leg fracture and he ends up in the hospital.

How could this fall have been prevented? What are some of the resources in the community that could have been helpful to the C.'s? What are the options for Mrs. C. now? Research your community's resources to learn more about how you could help the C.'s.

## SUGGESTED RESOURCES

## WEB SITES

Administration on Aging (<http://www.aoa.gov>)

Provides information about programs, services, and opportunities for older adults and their caregivers. Also links to: Eldercare Locator <http://www.eldercare.gov> which furnishes information on state and local area agencies on aging as well as community-based service organizations that provide services to older adults and their care providers.

American Association of Retired Persons (AARP; <http://www.aarp.org>)

A national, nonprofit advocacy organization for adults age 50 and over. Main topic areas include: care and family, health and wellness, legislation and elections, money and work, policy and research, and travel and leisure. The information on the AARP web site is also available in Spanish.

Benefits Checkup (<http://www.benefitscheckup.org>)

An online service that allows individuals (age 55 and over) to check whether they may qualify for a variety of a program benefits. The service screens over 1,100 programs for federal, state, and local public and private benefits.

Care Planner (<http://www2.careplanner.org>)

Subtitled "A decision support tool for seniors, caregivers, family, friends, and professionals," this organization supplies information along with printable worksheets and checklists to assist elders and their care providers in decision making and care management.

Centers for Disease Control and Prevention (<http://www.cdc.gov>)

This is the official web site for the federal agency that monitors American's health and safety. Health and safety topics applicable to older adults include: disabilities, diseases and conditions, environmental health, health promotion,

and vaccines & immunizations. State and national health and safety data and statistics are also available on this web site.

Centers for Medicare and Medicaid (<http://www.cms.hhs.gov>)

The agency's official web site describes Medicare's and Medicaid's programs, benefits, and eligibility rules.

Family Caregiver Alliance (FCA; <http://www.caregiver.org>)

FCA is a national advocacy organization. The web site's topic areas include: public policy and research, caregiving information, fact sheets and publications, newsletters, online discussion and support groups (including specialized groups such as LGBT support groups), and news releases. The web site information is also available in Chinese and Spanish.

Massachusetts Institute of Technology—Age Lab (<http://web.mit.edu/agelab/index.shtml>)

The AgeLab was created to invent new ideas and creatively translate technologies into practical solutions that improve people's health and enable them to "do things" throughout the life span. The site provides descriptions of numerous projects that are in process.

Medicare Rights Center (<http://www.medicarerights.com>)

Subtitled "Your Guide Through The Medicare Maze," this national, nonprofit organization provides information on Medicare plan options and current policy changes.

Social Security Administration (<http://www.socialsecurity.gov>)

This official web site offers information on social security programs and policies. In addition, individuals can process on-line claims, estimate their future benefits, and apply for replacement social security cards.

Department of Veterans Affairs (VA; <http://www.va.gov>)

The VA's official web site supplies information on veteran's health benefits and services, vocational rehabilitation and employment services, pension benefits, and burial and memorial benefits.

Volunteers in Health Care (VIH; <http://www.volunteersinhealthcare.org/home.htm>)

VIH is a national resource center funded by the Robert Wood Johnson Foundation for organizations and clinicians caring for the uninsured. The web site contains useful information on prescription drug assistance programs at <http://www.rxassist.org>.

#### SUGGESTED READINGS

Beaulieu, E. M. (2002). *A guide for nursing home social workers*. New York: Springer. Provides a comprehensive overview of issues that social workers need to know and address in nursing homes.

Hooyman, N., & Kiyak, A. (2002). *Social gerontology: A multidisciplinary perspective* (6th ed.). Boston, MA: Allyn & Bacon. This text provides a review of the literature on various aspects of aging and discusses implications for a multidisciplinary audience in the allied health and mental health professions.

Kane, R. L., & Kane, R. A. (Eds.). (2000). *Assessing older persons: Measures, meanings, and practical applications*. New York: Oxford University Press. This edited book provides an excellent review of available assessment tools for each of the domains of assessment discussed in this chapter.

Knight, B. G. (1996). *Psychotherapy with older adults* (2nd ed.). Thousand Oaks, CA: Sage. Provides a practical account of the knowledge, technique, and skills that are necessary to work with older adults in a therapeutic relationship. Case examples illustrate the dynamics of the therapeutic task and issues covered in therapy and stress the human element in working with older adults.

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## CHAPTER 15

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# Social Work Practice and Disability Issues

REBECCA BRASHLER

**D**ISABILITY BRIDGES THE study of health care and the study of diversity within the social work curriculum. People with disabilities generally have a greater number of health-care encounters than do people without disabilities and therefore have a considerable stake in issues such as access to medical care, insurance, quality of care, and the delivery of health services (DeJong & Ian, 2001). Disability Studies is a distinct emerging field that embraces the study of humanities, social science, and the history of people with disabilities. It is analogous to other diversity topics such as Women's Studies, African American Studies, or Jewish Studies. For social workers, the study of disability often focuses on the psychology and the politics of difference—the stigma associated with those who fall outside the mainstream as well as the benefits found when differences are embraced and societal barriers are eliminated. This chapter provides a review of these issues for social workers who provide counseling to individuals with disabilities in a variety of settings.

### CHAPTER OBJECTIVES

- Discuss the challenges faced when attempting to define disability.
- Review disability models and discuss their assumptions as well as their power to influence our perspectives as social workers.
- Provide an overview of common challenges social workers encounter when working with clients who have disabilities.
- Explore societal values regarding difference and disability that influence both personal perspectives and clinical approaches.

### DEFINING DISABILITY

Disability may be viewed as a personal characteristic, much like blue eyes, brown skin, or curly hair—an identifying but not necessarily defining feature. Others

may view disability as a disease or an abnormality—something to be avoided at all costs, something that brings with it hardship, suffering, and stigma. Still others may view disability as a source of pride—an entrée into the rich world of disability culture and a disability community that celebrates difference while empowering people with disabilities to demand their rights. When discussing disability, examining our perspective becomes critical. This can be challenging, however, since our perspective is always changing—influenced by our life experiences, age, and health, as well as societal norms, historical context, and our own self-image as disabled or nondisabled persons.

To make matters even more complex, there is no universally accepted definition of disability. The *Oxford Concise Medical Dictionary* defines disability as “a loss or restriction of functional ability or activity as a result of impairment of the body or mind” (Concise Medical Dictionary, 2002).

The Americans with Disabilities Act (ADA) defines a person with a disability as a person who “meets at least one of the three criteria: (1) having a physical or mental impairment that substantially limits one’s ability to perform one or more major life activities; (2) having a record of such an impairment; or (3) being regarded as having such an impairment” (National Council of Disability, 1997, Appendix F).

While the Social Security Administration considers you disabled if “you cannot do work you did before and we decide that you cannot adjust to other work because of your medical conditions(s). Your disability also must last or be expected to last for at least a year or to result in death” (Social Security Publication No. 05-10029, 2003, p. 2).

The widely quoted World Health Organization’s (WHO) definition of disability in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) distinguishes among the three related concepts of “impairment,” “disability” and “handicap.” Impairments are defined as “disturbances of body structures or processes.” A disability “is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.” And a handicap is “the social disadvantage individuals experience as a result of impairment or disability” (WHO, 1980). This definition was subsequently revised by the World Health Organization’s ICIDH-2 Classification which places further emphasis on the role of environmental or social factors in “personal activity limitations” and “social participation restrictions.”

Because disability identification is so elusive, attempts to count the number of people with disabilities in our communities are “subject to methodological bias and the distortion of the cultural lens” (Fujiura & Rutkowski-Kmitta, 2001). The U.S. Census indicates that 19.3% of the population 5 years and over have some type of disability (U.S. Census Bureau, 2000). Often people with disabilities are referred to as the nation’s “largest minority” or as “a minority that we all, if we live long enough, join” (Shapiro, 1994). Some of us may never have a disability ourselves yet will spend a large portion of our lives caring for and loving a family member with a disability. Disability comes to people at different times; some of us are born with a disability while others acquire one through illness or accident. Many of us will spend most of our time as nondisabled individuals only to experience alterations in our functioning as we enter the final years of our lives.

Disabilities can be sorted by impairment type (e.g., mobility impairments, cognitive impairments, sensory impairments) or they can be viewed on a continuum

from mild to moderate to severe, depending on the limitations they bring. Some disabilities are invisible to outsiders while others are immediately obvious. Complex typologies have also been developed, such as John Rolland's, which classify disabilities according to onset, course, outcome, and incapacity (Rolland, 1994). While of interest to clinicians, most people with disabilities seem largely indifferent to these statistics, definitions, and classification schemes. What seems to matter most is whether people with disabilities are fully included in schools, communities, and workplaces and whether they are viewed by others as people with value. The perspective that others embrace dramatically shapes the lives of people with disabilities.

### HISTORICAL CONTEXT

In the early nineteenth century, many in the Western world viewed disease and disability in the same way that they viewed poverty and disaster, as "a visitation of a just God upon a frail and erring person . . . a direct consequence of undesirable personal or social behavior" (Trattner, 1974). It is not surprising, given this view, that people with disabilities were historically shunned, institutionalized, and feared. What may be surprising is how these same views, left unchallenged and fueled by Social Darwinism, led to the Eugenics Movement in the United States during the early twentieth century (Braddock, 2002; Pfeiffer, 1999). American physicians during this period routinely facilitated the deaths of babies with birth defects and sterilized institutionalized residents with intellectual disabilities so that their "inferior genes" would not weaken our society. The true horror of the Eugenics Movement became evident in Nazi Germany during the 1930s and 1940s where hundreds of thousands of disabled German citizens were murdered after being labeled "unworthy of life" (Lifton, 1986). This program of "euthanasia" carried out by physicians under the guise of medical treatment, is often seen as the prelude to the mass killings of Jews in concentration camps during World War II.

Throughout the twentieth century in the United States, people with disabilities, when not locked away in large, poorly funded institutions, were often exploited as curiosities—paraded before the public for amusement and profit in circuses and freak shows that remained popular well into the 1950s and 1960s (Thomson, 1996). Given this backdrop, the advent of religious and secular organizations that presented people with disabilities as objects of pity and deserving of charity seemed comparatively humane. However, the era of telethons and poster-children offered a view of people with disabilities only as victims of tragic circumstances. Telethons and other charity fund-raisers created sympathy by manipulating the fears of their viewers in order to get them to "open their wallets" (Shapiro, 1994, p. 13). The viewers' sense of vulnerability could be relieved by sending money that would fund a cure for the unfortunate children—the only acceptable solution—for rarely were images of disabled adults shared with the public.

Today, we find ourselves in innovative times as the disability rights movement replaces the charity movement and people with disabilities claim their right to equal opportunities and full participation in all aspects of society (Bickenbach, 2001). Through hard-fought legislative battles, the grass-roots independent living



movement, and individual efforts to change attitudes, the prevailing view of people with disabilities has changed dramatically in recent years. People with disabilities, previously seen as “the embodiment of misery and lost opportunity,” now claim pride in their identities, willingly embrace a disability subculture and force us to question our preconceived ideas of capacity and value (Trent, 2000). These changing views of disability challenge social workers and other mental health professionals to reevaluate their roles and reassess traditional thoughts about treatment.

## DISABILITY MODELS

Theoretical models are used to help us better understand complex concepts and are therefore tremendously helpful in examining disability. A number of models are used to understand the effects of disability on individuals and groups and therefore on how it is treated.

### THE MEDICAL MODEL

The medical model of treatment can be illustrated by following a person who wakes up with acute abdominal pain. The person may head for the emergency room where she becomes a “patient”—someone in need of care from an expert medical professional. The transformation from “person” to “patient” during hospital admissions was described by Goffman in his study of institutions as a “leaving off and a taking on, with the midpoint marked by physical nakedness” (Goffman, 1961, p. 18). The physician completes an assessment, usually consisting of a physical exam and history taking, sometimes augmented by further tests in order to determine the “problem” or “pathology.” The physician then arrives at a “diagnosis,” which in turn leads to a course of “treatment” or “intervention.” Often during the intervention phase, the patient is asked to give up a fair amount of autonomy and control to health-care professionals. This is easily seen in the patient hospitalized for an appendectomy, who is instructed on what to eat, what to wear, when to get out of bed, and when to interact with visitors. In the best scenario, the treatment leads to a “cure” or a resolution of the problem, returning the “patient” back into a person without pain or dysfunction. In the case of abdominal pain diagnosed as appendicitis and leading to an appendectomy, the medical model seems to provide a satisfactory process for delivering care.

However, for individuals with chronic illnesses and disabilities, the medical model holds some troubling challenges. First and foremost the diagnosis of a chronic or permanent condition—one not amenable to cure—seems to trap the individual in the “patient” or “sick” role forever. As a perpetual “patient,” people with disabilities may never be well and are forever stuck in a position of reduced status and power. Furthermore, because the intervention phase is prolonged for months or years, the person with a chronic illness or disability is asked to give up autonomy to the “expert” health-care professional for an undetermined period—a position that may foster feelings of dependency and helplessness. Also, the failure of the person with a chronic illness or disability to be cured—a failure to be “a good patient”—often elicits unexpected and negative reactions from their physicians and caregivers. Health-care professionals confronted by patients who

cannot be cured may become disheartened and retreat behind an impersonal technical approach (Halpern, 2001). Professionals may also abandon incurable patients in order to protect themselves from feelings of failure and vulnerability and move on to treat others who are more likely to have successful outcomes (Gans, 1983; Gunther, 1994).

The diagnostic phase of the medical model also holds some troubling risks for people with disabilities. Diagnostic labels and words used to describe people with disabilities have often served to stigmatize them. People with disabilities are “de-formed, dis-eased, dis-ordered, ab-normal, and most telling of all . . . in-valid” (Zola, 1982, p. 206). Diagnoses such as “imbecile,” “moron,” and “Mongoloid idiot” were historically used to describe people with cognitive impairments. The self-fulfilling prophecy and low expectations associated with some diagnoses encouraged institutionalization for many people who would later prove capable of living successfully in the community. It is critical to note that the desire for differential diagnoses schemes and classification systems for physical or mental disease has never been driven by patient needs. The goal of these diagnostic manuals is to “enable clinicians and investigators to diagnose, communicate about, study, and treat people with various [mental] disorders” (American Psychiatric Association, 1994). The *DSM* introduction, for example, cautions readers that it is not a “classification of people,” but a “classification of disorders that people have.” While this distinction is an important one, it offers no assurance that clinicians and others will not view the individual differently once their label or diagnosis has been determined. The labeling process appears to be inevitably stigmatizing and in the case of chronic illness and disability, the stigma it creates may last a lifetime.

In the medical model, disability resides within the individual. It assumes that there is something “wrong” with the person. People with disabilities are “deviant” or “abnormal.” They may be missing body parts, lacking in function, unable to perform typical tasks and incapable of going through life like their able-bodied peers. This model focuses exclusively on the pathology and some would argue reduces the person to a laundry list of ailments while ignoring their value and humanity.

#### REHABILITATION AND BIOPSYCHOSOCIAL MODELS

The field of rehabilitation medicine evolved in the mid-1900s and adopted a multidisciplinary team approach to the treatment of people with disabilities with physical therapists, occupational therapists, speech pathologists, social workers, vocational counselors, and psychologists joining physicians and nurses to treat people with disabilities (Albrecht, 1992). Rehabilitation professionals realized that the medical model did not necessarily fit the needs of their patients and began to ask if “in chronic illness and disability, is it the professional who treats the illness or is it the patient (or the patient and his family) who actually carries out the routine treatment day after day?” (Anderson, 1975, p. 19). The rehabilitation model of treatment acknowledges that the patient is not a passive recipient of care but an active member of his or her treatment team and that the goal of rehabilitation is not cure but restoration of the best possible physical and psychological functioning. Furthermore, in rehabilitation medicine there was a distinct shift from focusing solely on the individual with a disability to focusing on the

individual, the family, and the community in which that individual resided. Rehabilitation in this sense embraced the biopsychosocial model of health care (Engel, 1977).

The biopsychosocial model expanded thinking beyond the narrow confines of bodily pathology and greatly shifted the focus to psychological and family issues. However, this shift in focus sometimes led to a tendency to pathologize patients' psychological make-up along with their bodies. It is not difficult to find literature that promotes the belief that physical disability invariably inflicts horribly disruptive and negative psychological consequences and leads to a whole host of personality disorders. A review of the literature, for example, reveals that patients with arthritis:

have been said to have weak egos, to repress hostility, to be compliant and subservient, to be potentially psychotic, to be depressed, dependent, conscientious, masochistic, emotionally labile, compulsive, introverted, conservative, perfectionistic, moody, nervous, worried, tense, overconcerned about personal appearance, and prone to express psycho-pathology in physical symptoms. (Shontz, 1970, p. 112)

The mind-set among many mental health professionals for years seemed to be that pathological bodies led to pathological personalities—and they set out to analyze the “disabled personality” in spite of having limited research data to back up their assumptions. Far from freeing patients from the stigma of labels, early applications of the biopsychosocial model may have added to the stigma of disability by labeling patients first physically and then psychologically.

Relatives—particularly mothers—of individuals with disabilities also found themselves being labeled and diagnosed as the focus of treatment widened to encompass the entire family system. The classic example of this phenomenon may be Bruno Bettelheim's theory, later disputed, that autism was actually a psychological disturbance arising from cold and detached mothering (Bettelheim, 1967). Others wrote about “narcissistic mothers” of children with asthma who were unable to be “consistently giving,” or of the “overprotective mothers” of hemophiliacs whose denial and guilt feelings were “manifested in severe, undisguised anxiety” (Travis, 1976).

The biopsychosocial model leads one to think about the interactions between the person with a disability and person's family, community, and social system. It highlights the connection between biological and psychological functioning. It also challenges some underlying principles of traditional medical thinking, allowing people with disabilities to be seen as active participants in their care and to have legitimate goals and needs even in the absence of a cure. It suggests that people with disabilities are much more than their functional limitations but it remains at heart a medical paradigm—one that is prone to misinterpretation and not completely free from the dangers of labeling.

#### THE SOCIAL MODEL AND MINORITY GROUP PARADIGM

The social model of disability shifts the focus from the impairment within an individual or family system to the environment with which the individual interacts. Advocates for the social model challenge traditional beliefs that physical and

cognitive differences are inherently bad and generally lead to a lifetime of suffering. According to this model, “the culprit is not the biological, psychic, or cognitive equipment but the social, institutional, and physical world in which people with impairments must function—a world designed with the characteristics and needs of the nondisabled majority in mind” (Asch, 2001, p. 300).

Using the medical model approach, a child who uses a wheelchair and cannot enter a school with a flight of stairs at its entrance is seen as suffering from a “mobility impairment.” Furthermore, the medical model would classify her mobility impairment as having a neurological basis (spinal cord injury) with a predictive course (static), a traumatic onset (motor vehicle accident at the age of 5), and a distinct prognosis (permanent but not terminal). The child’s inability to walk creates her problem and limits her ability to go to class with “normal” children, leading to a whole host of social and psychological difficulties. Using the social model, however, the same child in that situation is seen as healthy and whole but socially excluded and unable to exercise her rights to a free public education by a system unwilling to accommodate her needs. The focus moves from the person to the environment and in the process it forces us to examine social norms, issues of discrimination, and political concerns.

It can be difficult to switch frameworks and think about disability as a purely socially constructed concept. We are taught to think about health and wellness as ideal states and to view all variation from the norm as undesirable. Anthropological studies can help dissect medical model assumptions. In her book, *Everyone Here Spoke Sign Language* (1985), Groce writes about hereditary deafness on Martha’s Vineyard in the eighteenth and nineteenth centuries. Because the island was populated by large numbers of individuals with hearing impairments, the general population was fluent in Island Sign Language, eliminating the typical communication barriers. Deaf individuals were often sent off-island to school and therefore received more extended formal education, making them more literate than their neighbors and generally financially secure. They were completely integrated into society to the point where oral historians had difficulty remembering who was deaf and who was not. In essence, the disability disappeared because it was no longer seen as a limitation or a significant characteristic. The study led Groce (1985) to conclude that if disability “is a question of definition, rather than a universal given, perhaps it can be redefined, and many of the cultural preconceptions summarized in the term ‘handicapped,’ as it is now used, eliminated” (p. 108).

The social model helps us recognize parallels between people with disabilities and people of other recognized minority groups defined by race, gender, sexual orientation, or nationality. Like other minority groups, people with disabilities are often judged solely by a single characteristic. They are segregated (in nursing homes and institutions), they receive separate and unequal education, and they have limited access to jobs, which in turn leaves them with less power and money, than those of majority status. People with disabilities have had to fight to protect their most basic civil rights and in this regard truly share the experiences of other oppressed groups.

Critics of the social model, however, argue that it ignores the real and often distressing aspects of living life with limitations and illness. It is difficult for some to view their disability as a “neutral” characteristic or based solely in society

when they are struggling to live with chronic pain, caring for a loved one who is minimally conscious, or attempting to adjust to the progressive loss of physical and cognitive abilities that accompany Amyotrophic Lateral Sclerosis (Lou Gehrig's disease) or Alzheimer's disease. It also may have limited utility for people who are newly diagnosed and are just beginning to learn about the changes (both good and bad) that disability may bring to their lives. The social and minority paradigm models seem to work best when discussing the experiences of adults who have had several years to grapple with their mobility and/or sensory impairments but may not resonate as clearly with people experiencing disability at different times or in other ways.

#### INTEGRATING MODELS FOR SOCIAL WORK PRACTICE

Undeniable tensions exist among these different models and whether one can truly find a synthesis between medical and social frameworks is not clear (Turner, 2001). For example, it is difficult to advocate for medical advances or searches for a cure, as Christopher Reeve did, without sometimes offending those working in the arena of disability rights. Some fear that:

Reeve, perhaps inadvertently, bolstered the case against disability rights by offering a story of the disability experience that concurred with those who insisted that what people with severe disabilities faced were personal, medical problems, that what they needed was compassion—and a cure. (Johnson, 2003, p. 129)

However, it may be equally closed-minded to think that everyone with a disability will or should approach their situation from the same perspective or that we should make no attempt to mitigate the medical conditions that lead to disability as we advocate for social changes (Kirschner, 2000). Some well-adjusted individuals will choose to celebrate their disabilities and view their disability as a "central element of their identity" while others who seem equally well-adjusted may choose to minimize their differences and shy away from the disability rights movement (Glastris, 1997). The challenge for many social workers, particularly those who practice in medical facilities, is to balance the skill set needed to negotiate their practice setting while remaining ever cognizant of the lessons learned from years of social oppression, institutional discrimination, and attitudinal barriers.

#### CLINICAL PRACTICE ISSUES AND THE ROLE OF THE SOCIAL WORKER

Social workers in many settings are called upon to provide support and counseling for individuals who are encountering disability for the first time.

#### INITIAL COUNSELING AND FRAMING THE DISABILITY

Whether counseling parents who have learned that their unborn child will have a congenital disability, meeting a child at a school who was recently diagnosed with

juvenile diabetes, seeing a patient in the ICU who has sustained a spinal cord injury and will not walk again, or treating a family in private practice whose grandmother is disabled from a stroke, the primary challenge is to frame the event in a way that will promote a positive adjustment.

It is important to recognize that social workers are rarely, if ever, capable of simply relaying facts and communicating a diagnosis without revealing their own bias. The professionals involved in “presenting” disability news to individuals must appreciate that the words they choose, the tone they adopt, their affect, their body language, and their message, intertwine to create a subtle but sometimes lasting influence. The parents of a child with Down syndrome might be told:

I’m afraid we have some very bad news about your child—he has Down syndrome. This is an incurable genetic disorder due to a mutation in one of his chromosomes. He has many of the characteristic physical features associated with this syndrome, including epicanthal folds, a sloping forehead, a flat nose, and short limbs. Children with this disorder are also moderate to severely mentally retarded and sometimes have other associated medical complications. We will need to consult with several specialists before you leave the hospital to make sure that appropriate care can be provided for him.

Alternatively, the parents could be told:

We just saw baby Elizabeth. She is quite beautiful and wonderfully alert! She looks perfectly healthy but we recommend that she see another physician because she has Down syndrome and may have some associated medical problems. Children with Down syndrome typically lead very normal lives, go to regular school, and are capable of developing very close relationships. However, she also may have some special learning needs and physical delays so it will be important that you have an opportunity to talk to other parents who have children with Down syndrome in order to fully understand some of the programs and services that can help Elizabeth.

While neither introduction to Down syndrome is ideal, complete, or without bias, the first clearly frames the disability as a tragedy due to a host of abnormalities and requiring a future of specialized medical care. The emphasis is on the child’s differences and the explanation focuses solely on medical concerns. The second presentation frames the disability as a manageable set of challenges that will be faced by a beautiful child and her loving parents. The emphasis is on the child’s relationship to others and the identified experts needed for consultation are other “normal” families who have experienced life with Down syndrome.

During the framing process, which can encompass multiple conversations, social workers and other professionals must appreciate that they carry preconceived ideas about what life with a disability is like. The literature on attitudes toward disability clearly indicates that health-care providers often harbor extremely negative views of disability, including beliefs that death is preferable to life with extensive disability and that incurable disability causes irremediable suffering. In fact, research studies have found quality of life to be only weakly correlated



with level of impairment and that people with disabilities repeatedly rate their quality of life higher than others would predict they might (Bach & Tilton, 1994; Craig, Hancock, & Dickson, 1994; Fuhrer, Rintala, Kare, Clearman, & Young, 1992; Gerhart, Koziol-McLain, Lowenstien, & Whiteneck, 1994; Longmore, 1995; Sprangers & Aronson, 1992). Given this knowledge, it is imperative that social workers who engage in initial counseling closely examine their own perceptions and make an effort to communicate the perceptions of others.

One of the most valuable commodities during the framing process is access to a nonjudgmental counselor who is willing to provide information based on "the views of a wide range of health professionals involved in caring for people affected by the condition, together with the views of individuals and families affected by the condition" (Marteau & Anionwu, 2000, p. 126). It seems critical that at some point during the framing process, people with newly defined disabilities have an opportunity to interact with others who actually live with similar conditions. Support groups, peer counselors, or access to first person narratives about life with disabilities can be invaluable when constructing a value-neutral frame. The overriding message must always be that although the individual now belongs to a specific diagnostic class, he or she remains a "distinct and idiosyncratic human"—one who will not by virtue of a single diagnosis share all the characteristics of others with the same genetic mutation, physical limitation, or chronic illness (Berube, 1996).

Providing adequate time and a safe environment during these sensitive counseling sessions is also vital. Too often, initial conversations are hurried and take place in hospital hallways or school classrooms. There is often a rush to send the family on to the next expert or to refer them immediately for additional examinations and further treatment. It may be the clinicians' own discomfort in the face of disability that leads to this kind of truncated interaction when what individuals need most is the "opportunity to ask their own questions in their own way, to go over difficult, often insoluble, problems in an unhurried manner and to feel supported" (Harper, 2000, p. 59). One mother's advice to professionals in similar situations should be heeded carefully, "do not disappear. Do not leave the room. Make eye contact. Look me in the eye and ask me what you can do to help me deal with this" (Berube, 1996, p. 38).

#### RESPONSES TO DISABILITY

Therapists over the years have searched for concrete models that would predict and explain the experience of people as they confront disability and adapt to changes in appearance or altered functioning. Various models of "adjustment" to disability can be found in the literature but it is important to recognize that there is limited empirical data in this area and no universally accepted "theory" regarding disability adjustment.

Stage models of adjustment to disability are derived from Elisabeth Kübler-Ross's work with terminally ill patients with cancer (Kübler-Ross, 1969). These models suggest that individuals confronted with a new diagnosis of disability experience predictable stages or reactions such as shock, denial, anger, bargaining, or depression and that the desired end-point is a final stage of adaptation or acceptance. The value of stage theories is that they can "de-pathologize" the process

of adjustment by emphasizing that even healthy and ultimately well-adjusted individuals may experience periods of disruption in functioning when first confronting a disability. However, in order to have any utility, stage theories cannot be taken literally and must account for individual differences. The adjustment process is rarely linear and individuals with disabilities have both good and bad days along their journey. Not everyone will pass through the stages in the same order; some individuals may skip a stage completely, while others will linger longer than expected in a particular stage without experiencing a negative outcome (Gunther, 1969; Livneh, 1991; Olkin, 1999).

Grief models compare reactions to disability with the process of bereavement following a death. Mourning is often defined as the "adaptation to loss" (Worden, 1991) and can have relevance to the loss of a limb, the loss of function, or the loss of the dream for a child without disabilities. The primary difference between bereavement and adaptation to disability is that death by its very nature is finite while disability is ongoing or chronic. The concept of "chronic sorrow" or periods of grief that resurface from time to time (often associated with key developmental milestones) acknowledges this distinction. While on the surface the idea of "chronic sorrow" may seem depressing and pessimistic, it does serve to caution professionals not to become impatient during the adjustment process, and not to think of prolonged adjustment periods as evidence of neurosis. It also challenges professionals "to abandon the simplistic and static concept of . . . acceptance"—at least acceptance that will be reached through a handful of therapy sessions (Olshansky, 1970). Others have pointed out that the losses associated with disability, particularly those that accompany disabilities like severe brain injury and late stage Alzheimer's disease are more "ambiguous" and complex than those that surround death (Boss, 2000). In these situations, the individual survives but has often lost the essence of the person he or she had previously been. There is a death of sorts, but one often devoid of any comforting rituals and one that is largely unrecognized by society.

Crisis Intervention models emphasize the temporary disruption in functioning and emotional stability that is created whenever a person experiences an event that is perceived to be a threat to one's life, the life of a loved one, or which has the potential to become overwhelming (Aguilera & Messick, 1978). This framework has some utility when thinking about disability because it values the "perception" of the person involved in the crisis. A young couple learning that their toddler has been diagnosed with cerebral palsy may indeed feel that they are in the midst of a crisis while a single parent who chooses to bring home a similarly disabled child from an adoption agency may view the event as joyful. A professional violinist who loses a finger in an accident may feel that she is facing a crisis of great magnitude while a machinist may view the same injury as minor and unimportant. A crisis can only be defined by the person—not by others who may have a different perspective of the same experience. Because crises are viewed as turning points or opportunities for growth, this framework also reminds the client and the therapist that people frequently emerge from crisis with improved coping skills and greater feelings of competence. The notion that people actually benefit from adversity is one that can be very reassuring to people experiencing disability challenges (Elliot, Kurylo, & Rivera, 2002; McMillan, 1999).

Regardless of which adjustment model frames one's work, it remains critical that social workers not become so distracted by the disability adjustment process

that they fall into the trap of blaming the disability for any and all difficulties an individual experiences. Individuals with disabilities experience marital problems, life-adjustment issues, child-rearing challenges, and emotional problems that may bring them to a therapist's office. Assuming that disability is the root cause of any of these difficulties is dangerous.

This assumption may be particularly lethal in situations where individuals with disabilities present with suicidal ideation and are treated less aggressively because of beliefs that anyone in their physical condition would rationally prefer to be dead. People with disabilities turn to suicide in response to the same triggers as do people without disabilities and "there is no evidence of a unique death-seeking dynamic associated with disability that . . . is somehow more rational than 'ordinary' suicide" (Gill, 2004, p. 185). In 1986, Elizabeth Bouvia, a woman in her 20s with cerebral palsy and arthritis, requested that a California hospital admit her and allow her to die by keeping her sedated while she stopped her gastric feedings. While nondisabled individuals with suicidal intentions are routinely hospitalized and treated for their emotional distress, the courts in this case ruled that Ms. Bouvia should be allowed to facilitate her death because her life with disabilities was regarded as "intolerable" (Asch, 2001). They were completely willing to overlook the fact that this young woman had lived successfully with her disability since birth but had recently experienced multiple losses, including the death of her brother, a miscarriage, a divorce, and withdrawal from her masters-level graduate school program in social work. The presence of a disability is often only one of many factors that will prompt an individual to question the value of life and/or exhibit signs of depression, hopelessness, and anxiety.

The most useful of adjustment perspectives are those that can account for the paradoxical feelings and ideas that most individuals have toward disability (Larson, 1998). They acknowledge that an individual can simultaneously hold seemingly contradictory thoughts about life with differences. Individuals do not really move through stages—they live in two or more stages at the same time. They do not experience distinct, easily defined periods of grieving—distress about losses may come and go in unpredictable patterns for years. Often, people with disabilities experience a series of crises rather than a single event followed by adjustment. One can be absolutely devastated about not being able to walk yet simultaneously hopeful about the future. One can truly love a child unconditionally yet simultaneously pray that she will be miraculously cured. One can bitterly grieve for the lost capacity to talk yet simultaneously be grateful to be alive. One can be angry about the barriers created by society yet simultaneously be joyful about newfound resourcefulness in the face of these barriers. One can completely dismiss a physician's prognosis as overly pessimistic yet simultaneously engage in prescribed therapies. Adaptation to disability is never simple, it is rarely black and white and, in this sense, it does not lend itself well to any single theory or model.

However, there are several critical points for clinicians to remember when assessing adjustment and thinking about structuring interventions:

- When confronted by disability, individuals are likely to encounter a period of disrupted functioning that in and of itself is not pathological or abnormal. Repeatedly normalizing the process may be the single most important service a social worker can provide.
- There is no right or wrong way for patients to approach disability adjustment.

- Each individual will perceive their disability differently and it is their perceptions, not ours, that are most relevant. Social workers must listen carefully to their patients' perceptions, inform them that they may be fluid, and expose them to other perspectives when appropriate.
- People's perceptions of their disability change over time and they often hold paradoxical views regarding disability.
- The adaptation process cannot be defined in terms of weeks or even years. It may ebb and flow throughout a person's lifetime. Just as individuals adjust to different stages of life, individuals adjust to different stages of life with a disability. Social workers should remain available well beyond the initial adjustment phase yet not associate this availability with the notion that our clients will never be psychologically well.
- Individuals may experience periods of depression and/or anxiety that require treatment at any point during their experience with disability. However, therapists cannot assume that these symptoms are caused solely by the disability, for they may be related to and interwoven with other life issues or be the result of frustration over societal barriers.
- There is no idealized state of final adaptation or acceptance—just as there is no idealized state of adjustment to life without a disability.

#### ADVOCACY

Most social workers provide not only counseling, but concrete case management services to clients with disabilities. Counseling and advocacy efforts are ideally provided in an integrated fashion rather than being packaged as discrete functions. Counseling an individual experiencing the recent onset of a disability that prevents a return to work without providing information and advocacy around income maintenance would be fruitless just as assisting an elderly person with a nursing home placement without addressing the issues of losses associated with aging and illness would be irresponsible. Throughout the United States, there are confusing arrays of fragmented financial, legal, educational, medical, and family services available to people with disabilities, many of which have complex application and eligibility requirements. Social workers in private practice, schools, and medical settings must educate themselves about the community resources available to their clients in order to assist them in negotiating the overwhelming maze of disability services that are available.

Disability can bring devastating financial burdens in three areas: (1) hospital/medical expenses, (2) loss of income or earning potential for the individual and his or her family caregiver, and (3) additional community/living expenses. Medicare, Medicaid, Managed Care, Indemnity, Worker's Compensation, Veteran's Benefits, and other forms of health insurance may cover medical expenses related to disability but often people are unfamiliar with their coverage, uncertain how to apply for coverage, and unaware of what types of medical care may not be paid for under their policies. In cases of catastrophic injuries, fears about financial ruin may be very real. For the uninsured and underinsured in our country, concerns about access to quality health care remain a certainty. For many, managing the overwhelming amount of paperwork required in filing a claim or navigating the bureaucracy of a large managed care company is more than they

can handle while in the midst of a medical crisis. Social workers assistance in this area is invaluable.

Income maintenance may be available from Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), the Veteran's Administration, Crime Victims Compensation, Private Disability Insurance, and Worker's Compensation. Again, these programs are complex and services are sometimes difficult to secure. Individuals may also encounter challenges in returning to work with a disability related to employer biases, disincentives built into the system, and inflexible benefits. Knowing both entitlement eligibility and legal protections is important for social workers in this area.

Community living expenses includes the cost of transportation, affordable/accessible housing, and attendant care services. Advocating for better transportation, housing, and attendant care consumes many local disability rights groups who appreciate that access to these basic services frequently mean the difference between being able to live freely in the community and having to live in an institution or nursing home. The politics that surrounds community living programs are complex and there remains a bias toward the institutionalization of people with disabilities in our current government programs. Even when it may cost less to care for a person with disabilities in the community, they may end up in a nursing home because they cannot piece together the support systems needed to allow for independent living. Attendants are difficult to find and keep because the job often pays less than other nonskilled jobs in the community and often does not include health care or other benefits. Family members willing to provide care in their homes often do so at the expense of their own careers and while risking their own health. They remain an invisible source of free labor that goes unrecognized and unaccounted for by traditional economic measures (Gould, 2004).

The right to a free, appropriate, public education for children regardless of the type or extent of their disability has been secured in the United States through passage of Public Law 94-142 (1975), later amended and renamed the Individuals with Disabilities Act (IDEA) in 1990. Before this law it was estimated that "at least 1 million children in the United States were being excluded from public schools because of their disabilities" (Switzer, 2003, p. 61). With this law, parents became participants in the planning for their children's education through the use of Individual Education Programs (IEPs) and schools were mandated to place children in the "least restrictive environment." However, these government regulations also led to a complex system of registration, case study evaluations, multidisciplinary conferences, placement protocols, and procedural safeguards. Parents often feel the need for an advocate to help them through the process, particularly if there are disagreements about their child's needs. Controversies still surround the move from no education, to separate schools, to mainstreaming in regular schools with separate classrooms and finally to full inclusion. Social workers can assist parents and children in their quest to secure the most appropriate and inclusive educational program available in their community.

Advocating with clients who have disabilities, whether they face discrimination in the workplace, difficulties accessing health care, or problems researching available community services is a critical role for most social workers. However, during this process, social workers must remain sensitive to the very real power differential that invariably exists between the professional and the client seeking services—particularly when the client is a member of a vulnerable and oppressed

group. Too often social service professionals who work with vulnerable groups are seen as extensions of the bureaucracies that employ them and/or gatekeepers who must be manipulated in order to receive needed services. This has been particularly true for many people with disabilities. Our patients are not “cases” and they do not need to be “managed.” They need information and support at times but, “help is useful only when it leads to empowerment” (Charlton, 1998, p. 5). True empowerment for people with disabilities, as with other minority groups, will be realized only when they reach positions of status in hospitals, universities, legislative bodies, and governmental agencies in meaningful numbers. Making sure that people with disabilities represent themselves and assume a primary role in shaping the services they require must be social workers’ ultimate goal whenever we act as advocates.

### FINDING MEANING

The search for meaning is a journey than can take many years. It is a universal process that every person engages in, but for people with disabilities it may have some added poignancy and importance. Many mental health professionals have noted the need to shift our focus from examining the parameters of patients’ physical conditions or analyzing clients’ psychological make-up to helping them clarify their values in an effort to create positive meaning. Trieschmann (1999) writes:

I have become increasingly dissatisfied with the conceptual models of traditional western medicine and psychology because they do not offer me comfortable viewpoints or strategies that are really helpful in teaching people to find happiness. When people do find happiness, it derives from a re-evaluation of what is important in their lives, usually accompanied by a deepening of their spirituality, and usually accomplished by themselves without help from professionals. (p. 32)

The work of Victor Frankl, a psychiatrist who developed a therapy model he called “Logotherapy,” is particularly helpful when thinking about the process of finding meaning. Frankl (1984) wrote extensively about his experiences in a concentration camp and how survival became dependent on finding acceptable meaning for an unacceptable atrocity. He wrote, if “one cannot change a situation that causes his suffering, he can still choose his attitude” (p. 148). Frankl and others emphasize that the meaning people create must be uniquely theirs based on their own life experiences, religion, culture, family structure, worldviews, and belief systems. Health-care professionals can facilitate this search for meaning but it will be different for each individual.

First person narratives from people living with disability illustrate how varied their individual meanings can be, yet they all seem to reflect changing perspectives, a reassessment of values, or a process of “sifting out the trivial from the important” (Wright, 1983, p. 191).

One father takes comfort in the randomness of the universe:

I’ve come to believe that there’s no design for tragedy nor a design whereby the sins of the past return to punish the sinner . . . this means that there’s no method to the madness and sadness found here on Earth. Life is as random and unpredictable as



the shape of the next snowflake, and we all must take our chances if we are to stick. (Seerman, 1995, p. 89)

While others find meaning in religious terms:

I have a higher power, my God, who is with me always, even though I may not feel that presence all the time. I know that I can make it; I know that I can keep up hope; I know that even if things do not turn out as they should, I am not alone . . . what more could a person want? (Kahlback, 2001)

Another father writes about the essence of humanity:

Peering into the crib of a child with disability in the predawn moonlight can bring tears of truly unconditional love, love that will not be based on the report card performance, scores as a star quarterback or excellent performance as a trial lawyer. This love is for who the person is, for their qualities, their trial and for the inner strength they must develop to take their place. (Kappes, 1995, p. 25)

A writer with a facial difference due to cancer surgery struggles to tease out the difference between internal and external images. She once thought:

I was my face, I was ugliness—. . . the one immediately recognizable place to point to when asked what was wrong with my life. (Grealy, 1994, p. 7)

But she later writes:

I experienced a moment of the freedom I'd been practicing for behind my Halloween mask all those years ago. As a child I had expected my liberation to come from getting a new face to put on, but now I saw it came from shedding something, shedding my image. (p. 222)

A mother of an autistic son who lives and works on a university campus writes:

to have an autistic child is to learn to love difference, the humanity that runs far deeper than the success and achievement we are all taught to value. . . . I was forced to confront my deepest prejudices. . . . Living all my adult life in an academic environment, I had never been forced to consider that intellect is not the same as merit, it is not the same as virtue. It is a gift of nature as surely as any other. (McDonnell, 1997, p. 324)

A man with a spinal cord injury finds meaning by shifting his focus from the negative to the positive and says:

before I was paralyzed, there were ten thousand things I could do: ten thousand things I was capable of doing. Now there are nine thousand. I can dwell on the one thousand, or concentrate on the nine thousand I have left. And of course the joke is that none of us in our lifetime is going to do more than two or three thousand of these things in any event. (Corbet, 1980, p. 32)

An important social work role is to assist people in formulating a meaning that works for them, that brings them to a place where the disability becomes understood and therefore less frightening. American society places a premium on youth, athleticism, independence, power, wealth, beauty, and achievement. Helping people look beyond these ubiquitous values and treasure the spirit that they and their loved ones bring to our world—a spirit uniquely theirs that transcends the mundane issues of how one walks or talks or eats or looks or thinks—can be tremendously rewarding.

### DISABILITY AND ETHICS

Some of the most pressing ethical issues of our times involve disability on some level—physician assisted suicide, stem cell research, genetic engineering, health-care resource allocation, and end-of-life care are just a few examples. Examining one landmark case in detail can help illustrate how the disability perspective can alter our thinking about ethical dilemmas and may lead us to different conclusions.

In 1990, Kenneth Bergstedt was a 31-year-old mentally competent man who had sustained a spinal cord injury at the age of 10 in a swimming accident. He had lived with quadriplegia and had required ventilator support for 21 years. Kenneth resided with his father, who was his primary caregiver, in their family home in Nevada and Kenneth's mother had died from cancer several years earlier. Kenneth's father was facing some serious health problems of his own and was beginning to worry about what would happen to Kenneth if he died. In response to this concern, an attorney filed a petition in the Nevada courts on behalf of Kenneth and his father that would allow the removal of Kenneth's respirator by someone who could also administer a sedative and thereby relieve any pain that would otherwise accompany his death. Kenneth's petition also asked the court for a declaration "absolving him of suicide" in the removal of his life support system (McKay v. Bergstedt, 1990).

Most analyses of the Bergstedt case weigh the competing interests of the individual (his right to privacy, his right to self-determination, and his right to refuse medical treatment) against the interests of the state (in preserving life, preventing suicide, and protecting the integrity of the medical profession; Shapiro et al., 2003). The Nevada courts eventually decided that Kenneth's interests outweighed those of the state—although the final opinion was actually rendered some time after Kenneth's death. For many, protecting the rights of people with disabilities to control their medical care, including the withdrawal of life-sustaining treatment, appears to be an ethically sound position, one that is centered on the principle of autonomy.

However, if we examine Kenneth's request from the perspective of a clinician, cognizant of social model concerns, and informed by an understanding of adjustment issues and community resource limitations, several issues come to light. First, Kenneth appeared to be extremely socially isolated—having no significant contact with others who had experienced life with disabilities. In spite of having access to a portable respirator, he rarely left his home, and it appeared that it was difficult for him to speak on the telephone (Johnson, 1990). He may not have known of anyone who lived successfully on respiratory support and may not have been able to imagine that many people with high spinal cord injuries actually

hold down rewarding jobs, enjoy satisfying intimate relationships, and live on their own with attendant care services. It is possible that Kenneth was living within a very negative disability frame.

Second, one can assume that Kenneth was devastated by this father's failing health and frightened about what would happen when the last remaining caregiver he had ever known would die. Third, the people whom Kenneth trusted most—his father and the advocates who helped them file the petition—reinforced the belief that death was the best option given his situation. Kenneth did not want to live in a nursing home or another institution and there seemed to be no other choice.

Addressing the kind of social isolation Kenneth faced may be the easiest of therapeutic interventions, yet one that is often overlooked. By widening Kenneth's world through participation in support groups, access to peer counselors, and exposure to other social, recreational, and vocational activities, social workers could have attempted to introduce him to different ways of thinking about disability that would have challenged his notions about his capacity to enjoy life. It is known that people's perceptions about their disability change over time given the opportunity to experience their disability in different contexts. The first intervention might have been to give Kenneth the opportunity to view his disability and his place in the world from a new vantage point prior to making any conclusions about his wishes.

Second, the emotional pain this man must have been experiencing in anticipation of his father's death was certainly overwhelming. Clearly, Mr. Bergstedt was facing a significant life crisis. This crisis was heightened by his disability, but the underlying issue should not be ignored. Kenneth should have had the opportunity to receive counseling to address his anticipated loss and reassurance that bereavement services would be available at the time of his father's death. One could argue that it was his father's imminent death that led him to consider ending his life—not his disability—which had not changed substantially in 21 years.

Third, Kenneth needed some help in generating different options besides life in an institution and death. It may be that the possibility of life in a group living situation or independent living situation was not fully explored or aggressively pursued. Helping the family look into viable options and advocating for Mr. Bergstedt's right to receive community services that are rarely easy to access was another critical service that seemed to be lacking in this case. With these interventions, this man might have been able to construct a very different meaning for his disability—one that preserved his right to self-determination but did not lead him to view death as his best option. Without having information about other living options, one could argue that Mr. Bergstedt could not truly make an informed decision about his future.

Another troubling aspect of this case is that it was difficult to separate the views of Kenneth from those of his father and attorney. Although the court was swayed by the argument that Kenneth ought to have the right to self-determination and that we should respect his autonomy, there is no written record of Kenneth's own views nor did he ever make any public statements to the press. While there is no reason to doubt that Kenneth's father and attorney were motivated by the best of intentions, their advocacy on behalf of Kenneth appeared to be the focus of the case, and one must question whether this advocacy was taking place in the absence of efforts to empower Kenneth to speak for himself.

What we find from this analysis is that Kenneth Bergstedt was woefully isolated, emotionally distraught and lacking in good social services/support systems. But this is true of many other vulnerable individuals we treat, such as minority children living in the inner city, single mothers who are being abused by their boyfriends, or newly immigrated refugees. What seems to set the person with a disability apart from these other groups, is a willingness of the part of medical, social, and legal professionals to see death as a solution when we would never suggest to these other individuals that they might want to consider ending their lives rather than trying to cope with the challenges of poverty, abuse, racial differences, national standing, and displacement.

### SUGGESTED LEARNING EXERCISE

This learning exercise helps students explore their personal values related to people with disabilities and facilitate an open discussion of societal ideals.

#### LEARNING EXERCISE 15.1

Students are told that they comprise the board of directors of a small community hospital. Their community has been hit with a new illness that is 100% fatal—usually within a few hours. The only successful treatment is an injection of a new drug that has just been developed and cures the patient almost immediately. Unfortunately, the drug is in short supply and difficult decisions have to be made regarding which patients will be treated and which patients will be left to die from the infection. The hospital currently houses 10 patients who have the infection and are in dire need of treatment. The hospital has just received a shipment of 5 doses of the medication. The “board members” must decide which of the patients, based only on the profiles that follow, will get the injection:

1. A 65-year-old nun who has spent her entire life in a secluded convent and has devoted herself to a life of prayer and poverty.
2. A 44-year-old African American, single, foster mother who has adopted five hard-to-place disabled children and is raising them on her own.
3. A 24-year-old male model who was recently voted one of the 10 most beautiful people in the United States. He is single and has just been cast in his first film.
4. A 5-year-old Hispanic American boy who is blind, deaf, and mentally retarded. He is well adjusted and lives with his mother, grandmother, and six siblings in a loving and secure home.
5. A 23-year-old woman who is working on her MSW and is engaged to be married. She sustained a spinal cord injury in a car accident 10 years ago. She uses a wheelchair for mobility and is independent in self-care.
6. A 77-year-old Nobel Prize winning researcher who is working on a cure for arthritis and has made several important breakthroughs in recent months.
7. A 10-year-old Caucasian boy who likes to play soccer and video games. He lives in the suburbs with his parents and his sister in an upper-middle-class home. He has learning disabilities and sometimes struggles with impulse control/anger management.

8. A 50-year-old accomplished concert pianist. He is moody, temperamental, and a self-described loner. Never married, he has few friends and lives for his music.
9. A 40-year-old beloved coach of the U.S. Women's Olympic Softball team which is preparing to compete in the next Olympics in 18 months.
10. A 21-year-old African American teen currently incarcerated on drug charges. He is due to be paroled in 6 months. While in jail, he completed his GED and started an innovative program to help teens stay out of gangs.

Following the exercise, the group should list the deciding factors that drove their choices. Is age more important than lifestyle? Is intellectual capacity more important than artistic ability? Did patients without obvious disabilities fair better than others? Is past behavior more critical than future potential? What value do we place on the patient's capacity to relate to others? Assuming that the board of directors will have their choices scrutinized by the community at large, will any of their decisions meet with community disagreement or outrage and why?

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## CHAPTER 16

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# Nephrology Social Work

TERI ARTHUR BROWNE

**E**ND STAGE RENAL Disease (ESRD) is a chronic condition that requires life-long renal replacement therapy via hemodialysis, peritoneal dialysis, or kidney transplant. ESRD is a significant American public health issue. It is also an important practice focus for health social work because it provides the only Medicare mandate for MSW service provision for a disease or treatment category. This chapter provides an overview of psychosocial issues related to ESRD and a discussion of the role of the nephrology social worker in various arenas.

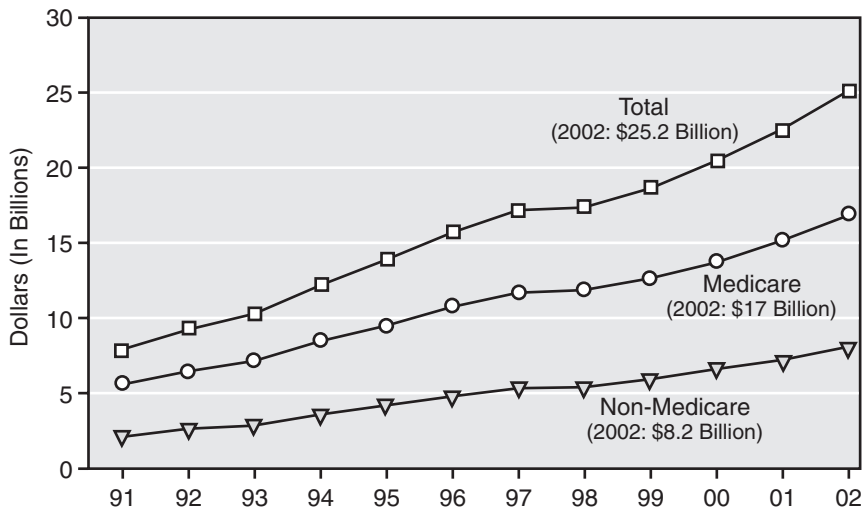
### CHAPTER OBJECTIVES

- Explore psychosocial aspects of renal failure and its treatment regimes.
- Identify roles and responsibilities of nephrology social workers.
- Explore nephrology social work assessment and intervention recommendations.
- Examine the history of nephrology social work in dialysis and transplantation.
- Define professional issues of nephrology social workers.

### END STAGE RENAL DISEASE AS A PUBLIC HEALTH ISSUE

ESRD is a significant and growing American public health issue, as evidenced by the following findings from the U.S. Renal Data System Annual Data Report (2004; see Figure 16.1):

- In 2002, 431,284 U.S. residents had ESRD (308,910 on dialysis; 122,374 with a kidney transplant). It is projected that by 2030 the number of ESRD patients will increase to 2.24 million.
- The total spending for ESRD care in 2002 was \$25.2 billion, with expenditures expected to double by 2012.



**Figure 16.1** ESRD Expenditures 1991–2002. Adapted from *Annual Data Report* by the U. S. Renal Data System, 2004, Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases.

- ESRD care represents a significant proportion of federal health-care costs, comprising 6.7% of the Medicare budget in 2002 (a 41% increase within a decade).
- Medicare contributions to the ESRD program rose from \$5.8 billion in 1991 to \$17 billion in 2002. Non-Medicare expenditures for ESRD care from Medicaid, private insurers and state kidney programs rose from \$2.2 billion in 1991 to \$8.2 billion in 2002.

ESRD is a chronic illness that results in kidney failure and necessitates renal replacement therapy via dialysis or kidney transplantation. When an individual's kidneys fail, waste products and fluids accumulate in his body, urine output decreases (and may cease entirely), and red blood cell production diminishes. ESRD may develop suddenly or over many years; without treatment an ESRD patient will die. ESRD has many causes, with diabetes and hypertension being the two greatest. Other causes of ESRD include: lupus, gout, chemotherapy, cancer, substance use, and kidney diseases such as glomerulonephritis, nephritis, and polycystic kidney disease.

The average 2002 cost for dialysis was \$63,000 per patient per year; the cost for transplantation was approximately \$100,000 for the year in which the transplant was received and \$15,700 per year after the transplant (U.S. Renal Data System, 2004). Two types of dialysis currently are available: hemodialysis and peritoneal dialysis. Dialysis is increasingly being provided by large for-profit national dialysis chains usually on an outpatient basis. Transplants are provided in hospitals.

Hemodialysis is a medical treatment in which a patient is connected to a dialysis machine via tubing joined to an external catheter in the patient's chest or needles that are inserted into a permanent vascular access (called a fistula or graft, which is usually in the patient's arm), which is attached to tubing that

leads to the machine. The hemodialysis machine consists of tubing, solutions, monitors, and a filtering device called a dialyzer that removes excess fluid from the patient and cleanses her blood prior to its return to the body through tubing connected to the catheter or access. Hemodialysis usually is performed three times a week, for at least three hours per treatment in an outpatient dialysis clinic by nurses and patient care technicians. Hemodialysis patients see their health-care team while receiving treatments. The hemodialysis regime can vary, and home, daily, and overnight dialysis are available patient treatment options.

Peritoneal dialysis is conducted by patients themselves. A catheter is surgically implanted in the patient that protrudes from her abdomen and is used to attach tubing to containers of dialysate fluid, which is drained into the patient's abdomen. Using the patient's peritoneal membrane surrounding the abdominal cavity, the fluid filters her blood and attracts excess fluids and is drained and re-filled periodically. Peritoneal dialysis is done daily, either several times throughout the day or overnight via a machine. Peritoneal dialysis patients see their health-care team during visits to the clinic.

Kidney transplantation is a surgical procedure in which a donor kidney is placed in the ESRD patient's body. The donor kidney can come from a deceased (also known as cadaveric) or a living donor. To get a transplant, an ESRD patient must undergo extensive evaluation and testing. If a living donor cannot be located, the patient is placed on a waiting list for a cadaveric kidney. If a patient does have a living donor, he may be scheduled for surgery. A person whose kidneys are healthy can function with only one kidney, making a living donation an increasingly popular form of transplantation. Although it usually occurs between patients and donors who have a relationship with one another, altruistic donations from donors who do not know transplant recipients are becoming more common. Transplantation is considered a form of ESRD treatment, not a cure, because the patient must take immunosuppressant medications for the life of the kidney to ensure that his body does not reject the donor kidney. Transplants may fail, requiring a patient to return to dialysis. In an ESRD patient's lifetime, he may experience all three forms of ESRD treatment.

Kidney transplantation is the most cost-effective treatment for ESRD and provides patients with enhanced physical and mental health, especially when compared to dialysis (Becker et al., 2000). An objective of Healthy People 2010 is to increase the number of dialysis patients who get kidney transplants. Transplants may not be possible, however, in situations where patients are not medically suited for transplant surgery or in which they prefer another form of treatment.

Acute dialysis was first done in the 1940s, the first kidney transplant was performed in 1951, and chronic outpatient dialysis was first available in the early 1960s. In 1965, there were only 200 dialysis patients in the world; prior to 1972, hemodialysis machines were scarce and dialysis was largely paid for by patients or with donated funds (Fox & Swazey, 1979). Selection committees chose individuals for dialysis and many ESRD patients were prohibited from having dialysis due to a lack of funding and scarcity of treatment venues. Selection committees were comprised of lay individuals who chose dialysis patients based on their perceived "social worth," with preference given to family breadwinners and community leaders (Jonsen, 2000). On October 30, 1972, the national ESRD program, Public Law 92-601, was passed after significant lobbying by patients, their families, and the community in response to the rationing of dialysis care (Fox &

Swazey, 1979). This law provides Medicare coverage of dialysis or kidney transplantation for all ESRD patients regardless of age. This coverage is unique, because ESRD is the only disease category that guarantees Medicare eligibility (with sufficient work history of the patient or his spouse/parent).

### DEMOGRAPHICS OF RENAL PATIENTS

The demographics of the renal patient population have changed dramatically since the start of widespread ESRD care in the United States. The majority of dialysis patients used to be younger heads of families. Today, individuals 65 years and older comprise the fastest increasing population among ESRD patients (Kutner, 1994). Older adults with ESRD have more comorbidities, greater psychosocial issues and needs, and more physical problems than do younger adults with the condition (Chen, Wu, Wang, & Jaw, 2003).

End Stage Renal Disease affects certain groups in the United States disproportionately; African Americans, American Indians, and Alaskan Natives are more likely to develop renal failure than are White Americans. Disparity in kidney transplantation exists, with White American males more likely to receive a kidney transplant than any other demographic group in the United States. African American ESRD patients are much less likely than White Americans to be referred for renal transplant, placed on a waiting list for a kidney, or to receive a kidney transplant (U.S. Renal Data System, 2004). Reasons for this disparity include a lack of preventive care, patient preference, socioeconomic disadvantage, and medical reasons. Further research on ESRD disparity is needed.

### PSYCHOSOCIAL ASPECTS

Eighty-nine percent of ESRD patients report experiencing significant lifestyle changes from the disease (Kaitelidou et al., 2005). The chronicity of End Stage Renal Disease and the intrusiveness of its required treatment provide renal patients with multiple disease-related and treatment-related psychosocial stressors that affect their everyday lives (Devins et al., 1990). Illness intrusiveness related to ESRD is defined as "the extent to which the illness and/or its treatment interfere with important facets of a patient's life" (Landsman, 1975, p. 328). Researchers have found that psychosocial issues negatively impact health outcomes of patients and diminish patient quality of life (Auslander, Dobrof, & Epstein, 2001; Burrows-Hudson, 1995; Kimmel et al., 1998). Social workers can help patients ameliorate psychosocial barriers to ESRD care such as:

- Adjustment and coping to the illness and treatment regime(s)
- Medical complications and problems
- Issues related to pain, palliative care, and end-of-life care
- Social role adjustment: familial, social, and vocational
- Concrete needs: financial loss, insurance problems, and prescription coverage
- Diminished quality of life
- Body image issues
- Numerous losses such as financial security, health, libido, strength, independence, mobility, schedule flexibility, sleep, appetite, freedom with diet and fluid



## DISEASE-RELATED PSYCHOSOCIAL ASPECTS

ESRD may impair sense of taste, diminish appetite, and cause bone disease that can require surgery and impair a person's ability to walk. A build up of toxins in the blood may cause patients to be anemic and uremic. Uremia and anemia lead to symptomology such as confusion, lethargy, and sleep problems that have psychosocial sequelae. Anemia is common among ESRD patients and impairs activities of daily living, diminishes energy, and consequently can affect quality of life (Gerson et al., 2004). ESRD patients have a compromised nutritional status, and a subsequent low blood albumin level also decreases patient quality of life (Frank, Auslander, & Weissgarten, 2003).

Moreover, ESRD usually occurs along with chronic illnesses such as hypertension and diabetes. These illnesses bring their own psychosocial issues that require ESRD patients to frequently access health services from a number of community sources (Merighi & Ehlbrecht, 2004c).

ESRD patients often require complex medication regimes due to kidney failure as well as other health conditions. Medications and blood transfusions may be needed during dialysis to address anemia and iron deficiency. Dialysis patients often must take several phosphorous-binding tablets with every meal as well as numerous other medications related to ESRD and its side effects such as cramping, and restless leg syndrome. Transplant patients may, in fact, have to take dozens of pills a day to manage their transplant and prevent rejection of the organ.

The toll of these disease-related stressors is great. Some researchers have found ESRD patients to be significantly more likely than persons in the general population to commit suicide (Kurella, Kimmel, Young, & Chertow, 2005). Others have noted that ESRD results in anxiety and depression. Auslander et al. (2001) found that 52% of ESRD patients had significant anxiety; Wuerth and colleagues (2001) found that 49% of patients were depressed. Depression in ESRD patients is a significant issue because of the following reasons:

- Kimmel, Peterson, Weihs and their fellow researchers (2000) determined that ESRD patients who are depressed are more likely to have poor nutritional outcomes and have a higher mortality rate. Koo et al. (2003) have also found that depression leads to malnutrition. Patients who are depressed are not likely to eat properly. Depression is linked to higher mortality rates (Hedayati et al., 2004). In addition, DeOreo (1997) found that depressed patients were less likely to adhere to their recommended treatment regimes than nondepressed patients and were more likely to have a higher level of morbidity and mortality.
- Paniagua, Amato, Vonesh, Guo, and Mujais (2005) found that ESRD patients who are depressed are more likely to be hospitalized.

Depression can also diminish patients' quality of life (Frank et al., 2003; Mollaoglu, 2004). This is relevant to public policy and is a public health concern because DeOreo (1997) and Mapes et al. (2004) have shown that a low quality of life in ESRD patients is significantly related to a higher hospitalization rate, greater morbidity, and higher mortality.

ESRD patients have a lower functional status than the population as a whole and are likely to need assistance with activities of daily living (Kimmel, 2000).

ESRD patients often have insomnia and sleeping problems (Valdez, 1997). They may also have body image issues related to their dialysis access and medication side effects (Beer, 1995). Vascular accesses for hemodialysis can become quite large and visible on patients' arms. Peritoneal accesses and catheters used for hemodialysis are surgically implanted and protrude from the patient's body. Medications, especially transplant immunosuppressant drugs, can cause weight gain or other changes in a patient's physical appearance.

Sexual functioning may be diminished due to ESRD, another major source of concern for patients (Wu et al., 2001). ESRD female patients have decreased rates of fertility because the disease impairs reproductive endocrine functioning. This impaired endocrine functioning results in numerous complications of pregnancy, and ESRD patients are unlikely to have a successful pregnancy (Holley & Reddy, 2003).

Poor adjustment to ESRD may be exacerbated by what Landsman (1975) refers to as "the marginal man syndrome." Most ESRD patients may appear "healthy" despite being chronically ill. Others may therefore have unrealistic expectations of their abilities, and expect more of them than is appropriate. Friends, neighbors, and coworkers may not understand why patients cannot participate in a pizza party due to the renal diet or other social functions due to the dialysis schedule. Landsman (1975) describes the necessity of coping with the "concept of perpetual treatment without cure . . . suspended in a state of limbo between the world of the sick and the world of the well, belonging to neither, yet a part of both . . . (questioning), am I sick or am I well?" (p. 268).

Restless legs syndrome, in which patients have persistent tremors in their extremities, is common in ESRD patients (Takaki et al., 2003). Acute and chronic pain is very common among ESRD patients and can impair quality of life (Devins et al., 1990). Pain can result from surgeries, cramping, needle sticks, neuropathy, and bone disease. Iacono (2003, 2004) found that 60% of dialysis patients have chronic pain, and that 66% of these patients were using prescription medication for pain. Lori Hartwell (2002), an ESRD patient and advocate, describes her experiences with pain as follows:

During my many medical procedures, I've had to endure hundreds of needle pricks. When I was younger, I would never complain about the number of sticks the nurses made. Consequently, they repeatedly told me what I good patient I was. In reality, those needles hurt! I wanted to cry and scream at the person who kept poking me. Most often I was silent and tried to be as accommodating as possible. (p. 8)

Palliative care and end-of-life issues are prevalent in ESRD. The life expectancy of patients is 75% lower than similar individuals without ESRD (Moss, 2005). Discontinuing dialysis is a recognized treatment choice and patients may opt to stop their treatment, which will lead to death. Many ESRD patients have psychosocial problems and concerns prior to their death, including significant pain in the last week of their life (Cohen, Germain, Woods, Mirot, & Burleson, 2005).

Finally, there are particular disease-related challenges for children suffering from ESRD. Pediatric ESRD patients and their families face unique psychosocial stressors. Infants born with ESRD require frequent hospitalization and medical visits. Their development is impaired and they may need supplemental nourishment or a feeding tube. Parents of pediatric ESRD patients are more likely to have anxiety, depression, and coping problems than parents of well children

(Fukunishi & Honda, 1995). This is in part because ESRD alters normal infant care. Infants with ESRD may not produce urine, for instance, which can be anxiety-provoking for parents (Brady & Lawry, 2000).

Children and adolescents with ESRD may be concerned especially about body image related to dialysis accesses (Fielding et al., 1985). Along with body image issues, they may have a difficult time adjusting to the ESRD regime of treatment and a special diet. Kurtin, Landgraf, and Abetz (1994) found that 59% of ESRD adolescents have poor adherence to medical regimes.

ESRD has significant psychosocial ramifications for patients' families as well (see Box 16.1). Dialysis patients' partners have problems coping with the illness and its treatment regimes (White & Greyner, 1999). MacDonald (1995) found that families of ESRD patients have problems adjusting to the impact of the illness on their lifestyle. Other authors have noted spouses' and partners' increased levels of stress and problems with managing role reversal and the need to assume more responsibilities than usual due to ESRD (Gudes, 1995; Pelletier-Hibbert & Sohi, 2001). The family must also cope with the possible financial burden of ESRD. Because of the time needed to care for the patient and transport her to treatments, a spouse or child may need to limit his work hours. Kaitelidou et al. (2005) found that 51% of ESRD family members reported absences from work related to the patient's illness.

ESRD may present patients and families with a loss of income, which is another very important concern of patients and their families (Wu et al., 2001). One study found that only 13% of ESRD patients were able to resume employment after starting dialysis (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000). Sixty percent of a sample of hemodialysis patients in Greece had to change professions or retire due to ESRD (Kaitelidou et al., 2005). Thus, it may be particularly important for renal social workers to consider the employment options of their patients. Maintaining employment and being active after a diagnosis of ESRD can be beneficial. Working patients are less depressed than their unemployed counterparts (Chen, Wu, Wang, & Jaw, 2003). Patients with a good rehabilitation status who stay active through employment or other activities also may have a better quality of life (Mollaoglu, 2004).

#### TREATMENT-RELATED PSYCHOSOCIAL ASPECTS

The treatment regimes related to ESRD can have serious psychosocial ramifications. Dialysis patients are required to assume strict diets due to their inability to process food products with high levels of potassium and phosphorous, and a need for sodium restrictions. Nonadherence to the standard renal diet can have significant consequences because potassium levels outside the range considered appropriate can lead to heart failure. High phosphorous levels can lead to permanent bone disease and calcification of the heart. Dialysis patients therefore are placed on diets that severely limit foods such as bananas, melons, dried fruit, tomatoes, oranges, potatoes, nuts, dairy and cola products, and sodium. Patients may also require a high protein diet due to their low albumin levels. Efforts toward optimal diet often are hampered by patients' impaired appetite and a diminished sense of taste.

Because of their inability to effectively produce urine, patients have very strict fluid restrictions, as little as 48 ounces per day. Otherwise, excess liquid will build

### Box 16.1 An ESRD Case Example

Dan is a 17-year-old peritoneal dialysis patient. The nephrology social worker had been working with Dan and his father, Chris, for over a year to improve his adherence to the renal diet and medication regime in order to have him physically prepared for kidney transplantation surgery and recovery. Dan didn't take his phosphorus binding medication with his meals, which indicated a lack of potential commitment to take his immunosuppressive medications posttransplant. If Dan failed to take these medications as prescribed, his kidney transplant would be at serious risk of failure. Dan's father and the social worker met several times about this matter with little success. Chris was emotionally debilitated due to two jobs and sole custody of his three children, and had little energy to follow through with the constant monitoring that Dan required.

Because Dan was the oldest child and Chris was often working or asleep, Dan had been the primary caregiver of his siblings since he was 7 years old. The combination of an overwhelming age-inappropriate sense of responsibility and the normal growth and development of adolescence was not mixing well. Chris had come to rely on him a great deal and found Dan's illness to be a major interference in their routine. He brought Dan to the appointments but remained disengaged and angry; Dan and his father were in open conflict much of the time. The social worker intervened on a number of clinic visits to reduce the conflict between the two.

The social worker was able to gain Dan and his father's agreement to attend one of the groups she held to educate and support kids and their parents as they prepared for transplant. Fortunately, one of her other challenging patients, Jeff, also attended that group with his mother. Jeff, a 15-year-old, had struggled with his own adherence issues. With social work counseling and education, Jeff had been able to manage his medications and a year ago received a successful transplant. As the group progressed, it was clear that Dan found the group "lame" and wanted to leave. Jeff confronted Dan directly, one teen to another. Jeff's mother, Denise, offered to bring Dan lunch every day at school to make sure he took his phosphorus binders with his meals. Chris cried as Denise told them that she truly understood what he was dealing with and how overwhelmed she often felt trying to care for Jeff. The social worker was able to direct the discussion to facing challenges with the benefit of a support system.

School grades improved and both Dan and his father began to come out of their self-imposed isolation. They kept appointments on time and eagerly reported on things they were doing to have fun. A couple of group sessions later Dan, Chris, Jeff, and Denise arrived together. They had had an early supper in the cafeteria, where Denise asked Dan about his medications. Rather than the surly responses he was famous for, he laughed and produced his pills. It was clear that the four had connected and felt they could help each other within the support group, as well as outside the hospital milieu. Within the year, Dan's phosphorous level was within range and he was emotionally ready for his transplant. His level of responsibility, as demonstrated by his adherence with the treatment plan, was an accomplishment that he reveled in and has brought back to the group on a routine basis.

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Prepared by Sandra Coorough (Phoenix Children's Hospital Kids Kidney Center).

up and cause patients' extremities to swell and their lungs to fill with fluid. Extreme weight gains between dialysis treatments can lead to high blood pressure and discomfort during hemodialysis, and removal of excessive fluid results in severe cramping and low blood pressure. Dry mouth and thirst are common among dialysis patients. Peritoneal dialysis patients have much less restrictive dietary and

**Box 16.2****A Day in the Life of a Hemodialysis Patient**

Florence is a 65-year-old patient who attends dialysis every Monday, Wednesday, and Friday. Her treatment begins at 5:00 in the morning, so she must awaken at 3:30 in the morning to begin the 25-mile journey to her dialysis unit. Because she is diabetic, Florence must eat breakfast before leaving her home. She must get to the dialysis unit by 4:45 in the morning so that she can weigh herself (so that the treatment team will know how much fluid to take off her during hemodialysis), have her blood pressure taken, set up the pillow and blanket she will use during her treatment, tune the television that is above her dialysis chair to her favorite morning news channel, and greet her fellow patients before the technician puts the needles in her forearm that connect her to the machine. During her four-hour treatment, her vital signs will be taken, her medications will be given, and she likely will be visited by her physician, nurses, dietitian, and social worker. After dialysis, Florence sometimes has problems with excessive bleeding or low blood pressure, so she may have to wait for her problems to stabilize to go home. Florence takes the local senior citizen van to her home (because the van does not operate before 9:00 in the morning, Florence must pay her neighbor to bring her) and often must wait over 30 minutes for the van to arrive at the dialysis center. Many times the van does not take Florence home directly, because other people are there for travel to doctor appointments or shopping. Because of this, Florence usually does not get home from dialysis until noon. This means that it has been almost eight hours since she initially left her house.

fluid intake restrictions and transplant patients normally are not required to follow renal diets or limit their fluids.

Nonadherence to ESRD treatment regimes can have serious ramifications for patients. Missed treatments and high fluid weight gains between treatments are associated with increased mortality in dialysis patients (Saran et al., 2003). Failing to take transplant immunosuppressant medications leads to transplant rejection (Russell & Ashbaugh, 2004). Many dialysis patients may not adhere to medical recommendations about diet, prescriptions, or fluid restrictions (Friend, Hatchett, Schneider, & Wadhwa, 1997). A study of hemodialysis patients found that:

- 27 to 31% of patients missed one dialysis treatment per month.
- 35 to 41% of patients signed off of dialysis early and did not receive their full treatment.
- 76 to 85% patients had problems following their recommended diet.
- 75% of patients who were coping poorly were likely to miss treatments.
- 50% of patients who were coping poorly did not follow their recommended fluid restrictions (Dobrof et al., 2000).

The ESRD treatment regime is both very intrusive and unrelenting (see Box 16.2). Patients may find it difficult to travel, because dialysis must be done while they are away from home. It can be difficult to access dialysis treatment services while traveling in rural areas, areas in which the number of patients exceeds treatment possibilities, or in areas experiencing staff shortages. Payment can be challenging for dialysis patients who are traveling. Some private insurers refuse to pay for out-of-network procedures, Medicaid coverage is specific to the state in which

the patient resides, and dialysis in territories outside the United States is not covered by Medicare and most insurers. Hemodialysis usually takes between four and six hours, including transportation, pre- and posttreatment procedures, and attention to complications, three times per week.

Common side effects of hemodialysis include cramping, nausea, and vomiting. A serious complication of peritoneal dialysis is an infection called peritonitis, which is painful and occasionally fatal. Transplantation requires significant workup, frequent postsurgical visits, and numerous daily immunosuppressant medications. Transplantation is a serious surgery and may lead to complications. Long-term immunosuppressant usage may cause serious negative physical outcomes.

### RAMIFICATIONS OF PSYCHOSOCIAL ISSUES

Many psychosocial factors can negatively impact patients' nutritional status and albumin management (Vourlekis & Rivera-Mizzoni, 1997). Barriers to a quality diet may include a patient's education and literacy level because she may not comprehend the diet instructions. Insurance may not allow a patient to obtain recommended nutritional supplements. Social support availability is another psychosocial attribute related to poor diet in ESRD patients because they may need assistance to purchase groceries and prepare meals. A patient may also have a decreased appetite due to depression or anxiety. These factors are very important for social workers to address because a poor nutritional status has been clearly linked to death in ESRD patients (Lowrie & Lew, 1990).

ESRD patients with psychosocial problems who are less cognizant of the illness and its treatment are more likely to have high fluid gains and missed treatments, which lead to poor health outcomes. Patients with poor psychological status are less likely to be adherent to treatment regimes and to have more hospitalizations and higher rates of mortality (DeOreo, 1997). ESRD patients who feel they are less in control of their illness tend to cope less effectively and have a lower quality of life (Mapes et al., 2004).

Patients are likely to experience several different treatment regimes during the course of the disease, including unsuccessful kidney transplants. As they cope with numerous losses, repeated lifestyle adjustments, and difficult transitions between transplant and dialysis, these changes can lead to the compounding effect of the burden of ESRD (Levine, 1999). One patient describes her experience as follows:

I lived through dialysis treatments, three transplants, and two rejections. Each transplant brought renewed hope; each rejection would send me reeling. It took me years to learn how to manage the feelings that came along with the constant diagnoses, the seemingly endless stream of bad news. (Hartwell, 2002, p. 7)

### SOCIAL WORK INTERVENTION

The significant psychosocial issues faced by ESRD patients and their families require social work intervention, referred to as "nephrology social work" or "renal social work." ESRD is the only disease category or treatment regime with a pub-



lic policy inclusion for master's level social workers on health teams. Medicare regulations mandate that a master's level social worker be on staff in every dialysis center and kidney transplant program (Federal Register, 1976). These social workers focus on "improving the patient's ability to adjust to and cope with chronic illness and the health-care system's ability to meet the needs of the patient" (McKinley & Callahan, 1998, p. 123).

Social workers are included on renal medical teams, which also include nephrologists (kidney doctors), nurses, dietitians, and patient-care technicians. Teams may also include transplant surgeons and pharmacists. The inclusion of a number of specialists reflects the complexity of the needs and issues renal patients face, and has been linked empirically with optimal service delivery (Goldstein, Yassa, Dacouris, & McFarlane, 2004). For example, Lindber et al. (2005) found that a team approach to patient education about vascular accesses, that included a social worker, was more successful than a single-disciplinary approach. A report on morbidity and mortality of dialysis by the National Institutes of Health (1993, p. 1) states: "the social and psychological welfare and the quality of life of the dialysis patient are favorably influenced by the . . . involvement of a multidisciplinary team."

Nephrology social work interventions tend to be valued by patients. Siegal, Witten, and Lundin's 1994 survey of ESRD patients found that 90% of respondents "believed that access to a nephrology social worker was important" (p. 33) and that patients relied on nephrology social workers to assist them with coping, adjustment, and rehabilitation. Dialysis patients have ranked a "helpful social worker" as being more important to them than nephrologists or nurses by Rubin et al. (1997). One study reported that 70% of patients said that social workers gave the most useful information about treatment modalities compared to nurses and physicians (Holley, Barrington, Kohn, & Hayes, 1991). These researchers also found that patients thought that social workers were twice as helpful as nephrologists in helping them to choose between hemodialysis and peritoneal dialysis for treatment.

#### NEPHROLOGY SOCIAL WORK TASKS

Social workers can help renal patients with their psychosocial needs in a variety of ways in collaboration with the renal health team. The activities conducted by nephrology social workers may include assessment, counseling, education, crisis intervention, end-of-life care, case management, rehabilitation assistance, and patient advocacy. Social workers also intervene at the community level.

*Assessment* Comprehensive individual psychosocial assessment of ESRD patients is central to the achievement of optimal patient outcomes (Fox & Swazey, 1979). Nephrology social workers conduct an assessment of a patient's psychosocial status to identify her strengths, needs, and the areas for social work intervention. Social work assessments are completed for every dialysis and transplant patient and take into account a patient's social, psychological, financial, cultural, and environmental needs. Appendix 16.1 provides an example of a nephrology social work assessment tool.

A unique attribute of ESRD social work care is that it is provided on a chronic, rather than episodic, basis. Nephrology social workers are fortunate to work in

settings that allow them to develop long-term relationships with patients. Long-term relationships provide them the opportunity to evaluate the effectiveness of services and reassessment of clients' needs through time.

Social workers also assess transplant donors. Living donor kidney transplants, including donations from strangers, have become increasingly popular in the United States. Social workers assess donor and recipients to gauge any normative pressures on the donor that may influence their decisions to donate, as well as their motivations for donating and their ability to make informed consent. This is important because kidney donation requires significant surgery and recovery. If an individual feels pressured to donate his kidney, a social worker may recommend that he not be a donor pending further assessment. Social workers investigate the nature of relationships between donors and recipients, as well as the psychosocial and mental health statuses and developmental and substance use histories in order to make a recommendation to the transplant team regarding surgery (Leo, Smith, & Mori, 2003).

Nephrology social workers use various standardized assessment tools with demonstrated validity and reliability, including those to measure depression and quality of life (e.g., Quality of Life Questionnaire for Dialysis Patients; Promoting Excellence in End-of-Life Care, 2002; the Kidney Disease Quality of Life instrument; the SF-36; and the CHOICE Health Experience Questionnaire, Wu et al., 2001).

*Counseling and Education* Nephrology social workers provide emotional support, encouragement, and counseling to patients and members of their support networks. ESRD patients and their families may have difficulty adjusting to the illness and treatment regimes. Social workers can help them cope through individual, family, and group counseling as well as through support groups.

Social workers can provide counseling and education to decrease patient depression. Depression is a serious issue that often is experienced by ESRD patients. Chen, Wu, Wang, and Jaw (2003, p. 124) recommend, "a good psychosocial support program should be incorporated into the treatment of patients with chronic renal failure to reduce the possibility and severity of depression." In an empirical study, Beder (1999) found that nephrology social work counseling and cognitive behavioral education interventions significantly lower patient depression. In her experimental study, Cabness (2005) found that a cognitive behavioral education group led by social workers is significantly linked to lower depression. Johnstone and LeSage (1998) found that 76% of depressed dialysis patients indicate that they prefer to seek counseling from the nephrology social worker on their treatment team, rather than pursue care from an outside mental health practitioner.

Nephrology social workers help patients deal with emotional concerns that stem from the numerous losses associated with ESRD. These include failed vascular accesses and transplants, schedule and dietary restrictions, the death of fellow patients, decreased activity levels, and employment and professional losses. Kidney transplant patients also require social work assistance when coping with anxiety and frustration over being on a transplant waiting list because it can take several years to get a kidney transplant. Transplant patients may need help with guilt about accepting a cadaveric organ. They may also have concerns about re-

ceiving a kidney from a living donor because the donor is placed at risk because of the surgery.

Through patient education and other interventions, nephrology social workers are successful in improving patient's adherence to the ESRD treatment regime (see Box 16.3). For example, Rita-An Kiely and her social work colleagues counseled patients on the importance of coming for all hemodialysis treatments, tracked attendance, and provided ongoing encouragement for adhering to the treatment regime. As a result of this social work education and counseling, there was a 50% decrease in missed hemodialysis treatments (Medical Education Institute, 2004). Auslander and Buchs (2002), and Root (2005) have shown that social work counseling and education led to reduced fluid weight gains in patients. Johnstone and Halshaw (2003) found that social work education and encouragement were associated with a 47% improvement in fluid restriction adherence.

Beder, Mason, Johnstone, Callahan, and LeSage (2003) conducted an experimental research study to determine the effect of cognitive behavioral social work services. They found that patient education and counseling by nephrology social workers was significantly associated with increased medication compliance. This study also determined that such interventions improved patients' blood pressure. Sikon (2000) discovered that social work counseling can reduce patients' anxiety level. Several researchers have determined that nephrology social work counseling significantly improves ESRD patient quality of life (Chang, Winsett, Gaber, & Hathaway, 2004; Frank, 2003; Johnstone, 2003).

*Crisis Intervention* Nephrology social workers provide crisis intervention services in dialysis and transplant units. A patient may act inappropriately during

**Box 16.3**  
**Outcomes-Oriented Nephrology**  
**Social Practice**

Nephrology social workers at Fresenius Medical Care in San Diego, CA have created an exemplar of outcomes-oriented dialysis social work intervention. They also provide "wellness programs" for patients with ESRD. Similar to programs offered to cancer patients, wellness programming for the patient with ESRD focuses on three areas: First, these programs highlight the key role of the patient as part of the renal team and invite them to actively participate in their care. Second, the programs focus on imparting life skills that help patients learn to manage the complex medical regime in order to improve survival and quality of life. Finally, the programs, often featured as wellness classes, launch patients out with a sense of empowerment over their own medical destiny. The perception of control and self-efficacy that improve with these programs, combined with the additional social support that the classes offer, are seen as the key change agents to their improved outcomes. This group of social workers also conducts numerous research projects related to various psychosocial interventions and are frequent contributors to renal publications and presentations.

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hemodialysis, yelling at staff or patients, threatening violence, or trying to pull the needles out of his arm. Social workers also resolve crises with peritoneal dialysis and transplant patients. Social workers often effectively mediate conflicts in dialysis settings (Johnstone, Seamon, Halshaw, Molinair, & Longknife, 1997). Merighi and Ehlebracht (2004a) found that more than 75% of nephrology social workers mediate conflicts.

*End-of-Life Care* Social work has an important role in the palliative and end-of-life care of ESRD patients. Social workers provide end-of-life information to patients and their families (Promoting Excellence in End-of-Life Care, 2002). Yusack (1999) found that patient education provided by social workers about advance directives led to a 51% increase in the use of such documents. Terminally ill ESRD patients and their families said that they would like more emotional support and other interventions from social workers and requested that social workers make contact with their families after they died (Woods et al., 1999).

The National Program Office of the Robert Wood Johnson Foundation created an ESRD workgroup entitled "Promoting Excellence in End-of-Life Care" in 2002. It recommends that nephrology social workers:

- Provide education to ESRD patients and their families on palliative and end-of-life care.
- Create palliative care programs that include attention to pain and symptom management, advance care planning, and psychosocial and spiritual support.
- Advocate for the adoption of patient self-determination policies.
- Create peer-mentoring initiatives and bereavement programs.

*Case Management* Renal social workers provide information to patients and their families about resources and information that are unknown to the family (McKinley & Callahan, 1998). They routinely provide case management services including information, referrals, and linkages to local, state, and federal agencies and programs.

*Rehabilitation Assistance* Social workers help patients maximize their rehabilitation status. This includes assessing barriers to patient goals of rehabilitation, providing patients with education and encouragement, and providing case management with local or state vocational rehabilitation agencies. Social workers can also encourage patients who are unable to work, or not interested in working to be involved in other activities, such as volunteering and exercise. In a literature review about nephrology social work and rehabilitation, Romano (1981) outlines different roles for social workers related to rehabilitation:

- *Enabler/facilitator*: Social workers can encourage patients to be as active as possible with work, social activities, and exercise.
- *Educator/advocate*: Social workers can educate patients and their families about vocational rehabilitation resources available for ESRD patients. They can also educate schools, workplace settings, and vocational rehabilitation

agencies about the needs of ESRD patients and advocate for patients within these settings (Raiz, 1999).

- *Administrator:* Social workers can develop and oversee programs that offer rehabilitation opportunities for ESRD patients, as well as conduct relevant research. There are many social workers involved as board members and advisors for the national organization Life Options that provides the ESRD community with information about rehabilitation.

*Team Collaboration* Nephrology social workers collaborate with the renal team in providing patient care. They participate in quality assurance programs and team care planning, and train other health-care professionals on the topic of psychosocial issues.

*Advocacy* Social workers advocate for their patients within their clinics as well as with community agencies (see Box 16.4). For example, a social worker can explain to the nurse manager that a patient's hemodialysis schedule can't be changed because the patient would like to attend a computer class in the afternoons. A transplant team may hesitate to transplant a patient with a history of substance use; a social worker can advocate for this patient and explain that her 4 years of sobriety and her 3 years of demonstrated adherence to a dialysis regime merits her consideration for transplant. Social workers also advocate for patients on a systems level, with various organizations and governmental agencies. Arthur, Zalemski, Giermek, and Lamb (2000) found that nonrenal medical professionals such as home care or nursing home-care providers, are unfamiliar with the psychosocial issues associated with ESRD. Renal social workers can help patients navigate complex systems of service provision, educate nonrenal community care providers on the unique issues related to ESRD care, and advocate for patients with community providers not familiar with their special needs.

*Community Level ESRD Social Work Intervention* Nephrology social workers are committed to social reform and influencing policy and programs affecting renal patients. Arizona dialysis social worker Kay Smith organized weekly garage sales to raise money for patients and persistently lobbied for dialysis services for illegal immigrants. She was temporarily suspended from her job at a for-profit dialysis center because of these activities. Ms. Smith was named the 2003 "Social Worker of the Year" by the National Association of Social Workers (NASW). Her award noted "she made an outstanding difference in areas of advocacy for clients, social policy, social work practice, program development, administration, and research, while demonstrating outstanding leadership and contributing to a positive image for the profession" (NASW, 2003). Social worker Steve Bogatz (2000) successfully advocated with a managed care organization to secure payment of a kidney transplant for a patient.

Social workers are also employed in macrolevel services to the ESRD community (see Box 16.5). They may be clinical managers of treatment facilities, social work directors of dialysis corporations, regional social work coordinators, academic researchers, members of boards of directors of community agencies, or independent consultants to ESRD organizations. Nephrology social workers are employed by nondirect patient care organizations including the Centers for Medicare and

**Box 16.4****Social Workers as Advocates: Changing Health Policy**

In 1982, Arizona Medicaid coverage for organ transplantation was limited to kidney transplants only. There were many poor and working poor individuals enrolled in Medicaid who needed heart, liver, and bone marrow transplants but Medicaid would not provide coverage for those life-saving treatments. By the late 1980s and early 1990s, Medicaid patients eligible for Medicaid based on federal entitlement such as Supplemental Security Income (SSI) or Aid to Families with Dependent Children (AFDC) were covered for life-saving organ transplants. But those working poor individuals not federally entitled but eligible based on low income and high medical costs or "spend down" were still not covered for life-saving transplants, even though they were enrolled in Medicaid. It was not uncommon for patients to become disabled and receive SSI for the first 6 months of disability and be eligible for Medicaid coverage of their transplant only to lose SSI and that coverage once they began receiving Social Security Disability Income (SSDI). Patients receiving SSDI then had to wait 2 years before becoming eligible for Medicare that would cover their life-saving transplant. Many did not live that long. In 1985, the social workers from the Arizona transplant hospitals were able to document that in the previous several years over 50 people enrolled in Medicaid had died as a result of this policy.

In November 1994, transplant social workers joined with support group leaders to form a coalition to lobby the Arizona State Legislature and the governor to change the Medicaid policy that denied heart, liver, and bone marrow transplants to the working poor enrolled in Medicaid (Thomas, 1999). The coalition met regularly and invitations were sent to every transplant support group in Arizona, administrators from the transplant programs, the State Organ Procurement Organization, the Coalition on Donation, the Health Departments from the major metropolitan counties, the State Health and Medicaid Departments, the National Kidney Foundation, the American Liver Foundation, the American Association of Kidney Patients, the lobbyists from the transplant hospitals, the American Hospital Association, the Legislative Liaisons (lobbyists) from the counties, and individuals denied transplants by Medicaid and their families. The social workers from the transplant centers functioned as community organizers.

Rothman's (1968) principles of social work practice were utilized: locality development, social planning, and social action. Locality development occurred in developing the coalition of concerned "stakeholders." The social planning principle was important because the coalition was able to document that Medicaid was paying more to provide medical services to individuals dying than it would have to provide a heart, liver, or bone marrow transplant. For example, one woman who received extensive media coverage died needing a bone marrow transplant that would have cost \$130,000 but instead Medicaid paid over \$800,000 to provide services while she died. The coalition identified three alternative funding sources; (1) additional federal funds, (2) unused Medicaid funds in the annual budget, and (3) revenue from a new tobacco tax. The Social Action phase included the development of a policy brief or "white paper" that documented how Medicaid "discriminated" against the working poor in its transplant policy, contacting the media, and training coalition members and others on the legislative process and how to engage the legislature.

The legislature and Medicaid were slow to respond to the coalition and many of the coalition members were in urgent need of a transplant. Utilizing a tactic from Alinsky (1971), "the threat is usually more terrifying than the thing itself," the



coalition threatened media coverage every time a Medicaid patient died that had been denied a transplant. As noted, the media had previously reported on several individuals that had died after Medicaid denied coverage for the transplant. This proved to be very effective in getting the legislature's attention. The coalition increased its direct lobbying of the legislature, the governor and the media.

In March 1995, 5 months after organizing the coalition, the Arizona State Legislature passed emergency legislation authorizing the immediate appropriation of \$8.2 million from the tobacco tax to pay for 63 heart, liver, and bone marrow transplants for the working poor. The governor personally came to the floor of the state senate to sign the bill into law. In October 1995, the coalition persuaded the governor to call the legislature into special session when an additional \$2.7 million from the tobacco tax was appropriated to fund 17 heart-lung and lung transplants. In 1996, the legislature expanded the state renal medication program from \$100,000 per year to \$250,000 per year. In 1997, an additional \$100,000 was added to the renal medication program for a total of \$350,000 per year. In 1998, legislation was passed that created a new \$200,000 per year nonrenal medication program for heart, liver, and lung transplant patients. One unexpected outcome of this process was the development of a policy that allowed transplant candidates on waiting lists to remain on the lists if they lost their Medicaid eligibility and have Medicaid become a payer when the transplant eventually occurred. As of 2004, over 120 working poor individuals have been transplanted with an average cost to the state of approximately \$5 million annually and over \$4 million of state appropriations have helped needy transplant recipients with the costs of their medications. Transplant social workers continue to be involved in community organizing activities.

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Medicaid, the National Kidney Foundation (national and regional offices), the American Kidney Fund, the American Association of Kidney Patients, the ESRD Networks, and the Missouri Kidney Program.

### THE PROFESSIONALIZATION OF NEPHROLOGY SOCIAL WORKERS

Social workers are very involved in providing effective intervention with ESRD patients. However, there are professional challenges that may face nephrology social workers, and they may be assigned tasks inappropriately by their employers. Tasks that are clerical in nature or involve admissions, billing, and determining insurance coverage prevent nephrology social workers from performing the clinical tasks central to their mission (Callahan, Witten, & Johnstone, 1997). Russo (2002) found that all of the nephrology social workers that he surveyed felt that transportation was not an appropriate task for them, yet 53% of respondents were responsible for making transportation arrangements for patients. Russo found that 46% of the nephrology social workers in his survey were responsible for making dialysis transient arrangements (which involved copying and sending patient records to out-of-town units), yet only 20% were able to do patient education. In the Promoting Excellence in End-of-Life Care's 2002 report, *End-Stage Renal Disease Workgroup Recommendations to the Field*, they recommend that dialy-

**Box 16.5****Social Work and the End Stage Renal Disease Networks**

The ESRD Network system was established by law in 1972 to promote the efficient and equitable distribution of quality medical care to persons with End Stage Renal Disease. The 18 ESRD Networks, operating as contractors to the Centers for Medicare and Medicaid Services (CMS), manage a computerized patient registry system, assure quality of care through continuous quality improvement methodology and data analysis, provide community education, process patient beneficiary complaints, and provide regulatory guidance for providers. The mission of ESRD Network Patient Services professionals is to provide a patient-centered perspective in the design and implementation of ESRD Network programs, and to meet the needs of ESRD patients by assuring quality of care through communication, education, and conflict resolution.

Full-time positions of Patient Services Coordinators (PSC) became mandated by CMS at each Network in 2003. It is required that PSCs be Masters-prepared social workers or equally qualified individuals (experienced nephrology nurses or counselors). Most of the Networks utilize social workers for the position, who are responsible for addressing challenging patient situations. This effort creates a strong social work perspective in the Network system and allows facility social workers a contact for assistance. This has enabled Network organizations to be viewed by many as a resource far beyond regulatory concerns. A challenging patient is defined as an individual who is nonadherent to their treatment regimen, can be verbally abusive, physically threatening, or physically violent. In some instances, staff response is not appropriate and exacerbates the situation. All PSCs, regardless of discipline, assume a proactive role in the prevention, facilitation, and resolution of difficult patient and/or facility situations. This role may include implementing educational programs that will assist facility staff in handling difficult situations, and be an advocate for individual patient rights and/or rights of all patients at a facility, depending on the situation presented.

Although regional differences due to geography, cultural concerns, and density of population create Network-specific PSC tasks, the overall purpose is the same. Some of these tasks include visits to facilities to meet with patients, staff, and administrators for the purposes of patient education, staff training, and responding to grievances, attending regional conferences as a participant or presenter, and creating Network-wide patient newsletters. Some Networks have a Patient Advisory Committee (PAC) consisting of patients who volunteer their time to help improve the quality of care in their facilities. The Network PSC usually coordinates the PAC.

Most PSCs intake grievances at the Network level and seek resolution through interactions with the facility or follow-through with appropriate agency referrals while maintaining a database that is used to track trends. Network Vocational Rehabilitation efforts to assist facilities to encourage patients to return to work are under most PSC's purview as are efforts to encourage patient exercise programs. Some PSCs communicate Network policies, concerns, and goals to other professional organizations, such as the National Kidney Foundation, Kidney and Urology Foundation of America, American Kidney Fund, American Association of Kidney Patients, The Society for Social Work Leadership in Health Care, and the national and local Councils of Nephrology Social Workers, among others.

In this environment, PSCs respond to patient needs with an expanded view of quality of care, embracing psychosocial as well as medical concerns. The social

work perspective has enhanced the awareness of patient needs in national discussions on quality of care issues for renal patients. These discussions have had impact in meetings with CMS officials and in developing Network policies that support patient health and address quality-of-life concerns.

ESRD Network resources and newsletters can be accessed through their web sites. Links to all Networks can be found at the Forum of ESRD Networks web site, [www.esrdnetworks.org](http://www.esrdnetworks.org). In addition, publications by Network PSCs (E. Anderson, B. K. Campbell, M. Meir, K. Niccum, D. Perez, M. L. Pederson, R. Russo, R. Valdez) have added to social work literature, as well as that of other disciplines, via numerous articles in nephrology publications and journals.

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Prepared by Rick Russo (ESRD Network of New York).

sis units discontinue using master's level social workers for clerical tasks to ensure that they will have sufficient time to provide clinical services to their patients and their families. The 2005 Department of Health and Human Services' proposed conditions for coverage of ESRD facilities recognize this issue as follows: "we recognize that dialysis patients also need other essential services including transportation and information on Medicare benefits, eligibility for Medicaid, housing, and medications, but these tasks should be handled by other facility staff in order for the MSW to participate fully with the patient's interdisciplinary teams so that optimal outcomes of care may be achieved" (Federal Register, 2005, p. 6222).

Merighi and Ehlebracht (2004a, 2004b, 2005), in a survey of 809 randomly sampled dialysis social workers in the United States, found that:

- 94% of social workers did clerical tasks, and that 87% of those respondents considered these tasks to be outside the scope of their social work training.
- 61% of social workers were solely responsible for arranging patient transportation.
- 57% of social workers were responsible for making travel arrangements for patients who were transient, taking 9% of their time.
- 26% of social workers were responsible for initial insurance verification.
- 43% of social workers tracked Medicare coordination periods.
- 44% of social workers were primarily responsible for completing admission packets.
- 18% of social workers were involved in collecting fees from patients. Respondents noted that this could significantly diminish therapeutic relationships and decrease trust.
- Respondents spent 38% of their time on insurance, billing, and clerical tasks versus 25% of their time spent counseling and assessing patients.
- Only 34% of the social workers thought that they had enough time to sufficiently address patient psychosocial needs.

The study also noted that as nephrology social workers increased their involvement in insurance and billing, their job satisfaction decreased. This was true particularly for social workers who collected fees from patients. Nephrology social work job satisfaction was correlated positively with the amount of time spent in

counseling and patient education and negatively with insurance-related, clerical tasks. Nephrology social workers who spent more time on insurance, billing, and clerical activities reported increased emotional exhaustion. Those who spent more time doing counseling and patient education reported less emotional exhaustion. The authors posited that providing education and direct counseling to patients and family members were more congruent with the professional training and education of master's level social workers, and thus more satisfying for them.

Another professional concern for nephrology social workers is high patient caseloads. Some dialysis social workers may be responsible for up to 200 patients and may cover more than one unit or an extensive geographic region. Transplant social workers can be responsible for hundreds of patients. Large nephrology social work caseloads have been linked to decreased patient satisfaction and less successful patient rehabilitation outcomes (Callahan, Moncrief, Wittman, & Maceda, 1998). Social workers report that high caseloads prevent them from providing adequate nephrology clinical services, most notably counseling (Merighi, & Ehlebracht, 2002, 2005).

The Council of Nephrology Social Workers (CNSW; 2002) recommends an acuity-based social worker to patient ratio that takes into consideration the psychosocial risks of patients and recommends a maximum of 75 patients per full-time dialysis social worker. The state of Texas mandates a load of 75 to 100 patients per full-time social worker. Nevada likewise has a mandated ratio of one full-time social worker per 100 dialysis patients. However in Merighi and Ehlebracht's (2004c) national survey of social workers, they found that only 13% of full-time dialysis social workers had caseloads of 75 or fewer, 40% had caseloads of 76 to 100 patients, and 47% had caseloads of more than 100 patients. As of 2005, no social work ratios had been mandated by federal authorities.

In a recent study, nephrology social workers reported that large caseloads hindered their ability to provide clinical interventions (Bogatz et al., 2005). Social work respondents in this study reported caseloads as high as 170 patients and 72% had a median caseload of 125 patients. The researchers found that 68% of social workers did not have enough time to do casework or counseling, 62% did not have enough time to do patient education, and 36% said that they spent excessive time doing clerical, insurance, and billing tasks. One participant in their study stated: "the combination of a more complex caseload and greater number of patients to cover make it impossible to adhere to the federal guidelines as written. I believe our patients are being denied access to quality social work services" (p. 59).

### THE COUNCIL OF NEPHROLOGY SOCIAL WORKERS

The CNSW, a professional council affiliated with the National Kidney Foundation (NKF), is the largest organization of nephrology social workers in the world. The organization's goals are to: (1) develop and promote patient and public education; (2) support and promote the profession and education of renal social work; (3) impact regulatory and legislative issues; (4) ensure that qualified social workers are employed in ESRD settings; and (5) provide ongoing support and education to renal patients. In 2005, more than 800 members belonged to the organization, the majority of whom were from the United States. More than 55 local CNSW chapters are located around the country, all of which

are overseen by the national organization. Nephrology social workers may belong to other professional organizations, including:

- The Society for Transplant Social Workers, which was founded in 1986 and is active in the United States and Canada.
- The European Dialysis and Transplant Nurses Association, which has a social work component.
- The Kidney Foundation of Canada, which includes a nephrology social work organization.

The CNSW became a national entity and an advisory board to the National Kidney Foundation in April 1973. Prior to this time, nephrology social workers had met regionally to discuss common issues and concerns. Early CNSW activities included providing input on the ESRD federal regulations and lobbying for the inclusion of MSWs on renal teams. Since then, CNSW has developed a number of professional resources, including an annual training program for nephrology social workers as well as publications such as "Standards of Practice for Nephrology Social Work" and "Continuous Quality Improvement for Nephrology Social Workers." The CNSW partners with the other National Kidney Foundation professional councils, such as the Council of Renal Nutrition and the Council of Nephrology Nurses and Technicians, on various projects and to publish a quarterly professional newsletter. Since 1981, the CNSW has provided funding for research projects initiated by nephrology social workers. In 2005, the organization provided \$20,000 annually for nephrology social work research.

Addressing the professional challenges discussed here and providing outcomes-oriented nephrology social work care is a major emphasis of CNSW. In 1995, CNSW collaborated with the National Association of Social Workers (NASW) to create the "NASW/CNSW Clinical Indicators for Social Work and Psychosocial Services in Nephrology Settings," a set of guidelines for measuring social work outcomes. In 1999, CNSW began a series of 18 training sessions entitled "Refocusing Nephrology Social Work: An Outcomes Training Program," which consist of live presentations, regional continuing education trainings via videotape, and Internet-based professional education programs on the following topics:

- Understanding and Assessing for Depression in the ESRD Patient
- Understanding Psychosocial Predictors of Treatment Outcome
- Conducting a Comprehensive Clinical Assessment
- Assessment and Management of the Patient with Altered Mental Status
- Providing Protective Services
- Treating Depression
- Delivering, Scoring and Interpreting Biopsychosocial Instruments to Enhance Assessment, Monitor Treatment Outcomes, and Guide Continuing Interventions
- Providing Case Management Services
- Assessment of Cultural Barriers and Design for Effective Care Plans
- End-of-Life Issues
- Patient Education
- Developing Individualized Plans for Rehabilitation

- Multidisciplinary Team Collaboration and Teaching
- Marital and Family Counseling to Enhance Patient Adaptation to Illness
- Conducting Interventions to Improve Adherence
- Facilitating Support, Psychoeducational, and Brief Therapy Groups
- Continuous Quality Improvement

A major CNSW emphasis is legislative advocacy. CNSW is an active member of the National Consortium of Health Care Social Work Organizations and works with the NKF to lobby for improvement in health insurance coverage for ESRD patients as well as to extend Medicare coverage for transplant recipients to include immunosuppressive medications. Another focus of CNSW is professional advocacy, and the organization has created a number of documents to clarify the role of a nephrology social worker, such as "Definition of Qualified ESRD Social Work Staff," "Quality and Accessibility of Social Work Services to Dialysis Patients," "Maintaining the Qualified Social Worker in End-Stage Renal Disease Settings," and "The Role of the Nephrology Social Worker in Optimizing Treatment Outcomes for End-Stage Renal Disease Patients." In 2002, CNSW released the first edition of its publication entitled "Professional Advocacy for the Nephrology Social Worker." The Council has three very active e-mail listservs, one each for general membership, regional chapter chairpersons, and pediatric social workers. These Internet resources allow members quick access to their colleagues.

In February of 2005, Medicare released the first proposed conditions of coverage for transplant and dialysis facilities in 30 years. These regulations, which will specify the care provided in all ESRD facilities in the United States, are to be finalized by 2008. The CNSW organized its members to provide a response to these conditions, advocating for attention to ESRD psychosocial issues and appropriate utilization of MSWs on renal teams.

## CONCLUSION

ESRD is a significant public health concern with serious biopsychosocial ramifications. Nephrology social work interventions have demonstrated effectiveness in addressing the psychosocial barriers to optimal ESRD patient care. Nephrology social workers practice in micro- and macro-level settings and work with patients of all ages and backgrounds. This chapter presents information that can guide social work practice in nephrology, as well as inform all health social workers about ESRD and its psychosocial issues.

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## SUGGESTED LEARNING EXERCISE

Divide the students into six groups. Within these groups, half of the group will take the role of a nephrology social worker and complete the relevant portions of a social work assessment by asking the other half of the group (who will role-play one of the patient scenarios that follow, improvising details as they wish) questions from the assessment tool in the appendix of this chapter. Each group will report back to the class about the unique psychosocial issues identified in the



role-play. If time allows, the student groups can utilize the assessment tool to create an intervention plan for the hypothetical patient.

#### CASE EXAMPLE 16.1

Edward is a 46-year-old White American male with diabetes who just started dialysis. He did not know that his kidneys were failing and was shocked to be admitted to the hospital with ESRD after going to the emergency room because he was short of breath. After spending a week in the hospital, he started dialysis at an outpatient hemodialysis clinic three times per week. He is married with two small children, and had been working full time as a construction worker. He is concerned about how the dialysis schedule will work around his job duties, and is also very upset that he may not even be able to return to his physically demanding job because he is so weak. He has a close family, and lives in the same town as his parents and siblings.

#### CASE EXAMPLE 16.2

Eric is a 32-year-old Asian male who has been on peritoneal dialysis for 1 year. He is interested in a kidney transplant and went to the hospital for an evaluation by the transplant social worker. His family has already been tested as possible living donors for the transplant, however no one is a good blood match and he must go on the transplant waiting list for a cadaveric kidney. He is concerned about the waiting time for a kidney, as some of his friends from the dialysis clinic have been waiting for a kidney for more than 4 years. His dialysis unit reported to the transplant clinic that Eric has not adhered entirely to his dialysis regime, as he does not always do all of his peritoneal exchanges three times per day. This concerns the unit because they are unsure if Eric would take all of his immunosuppressant medications if he got a transplant, putting him at risk for rejecting a transplanted kidney.

#### CASE EXAMPLE 16.3

Brian is a 61-year-old African American male who has been on hemodialysis for 2 years. He would like a kidney transplant, and his family has convinced him that he should get a kidney from his eldest daughter who is a perfect candidate for donation. He is concerned about jeopardizing his daughter's health by the surgery, and is afraid that he may be too old to get a transplant.

#### CASE EXAMPLE 16.4

Lauren is a 27-year-old White American female who returned to dialysis after a kidney transplant failed after 8 years. She is married with a 3-year-old child. She has high blood pressure, and has been having problems with her husband because of her low libido resulting from her antihypertensive medications. She was very upset that she has to come back to dialysis and is most concerned about arranging childcare for her daughter around her dialysis schedule. She is also very concerned that her doctor told her that she should not try to get pregnant again.

## CASE EXAMPLE 16.5

Tina is a 28-year-old Hispanic American female who came to the transplant center for a social work assessment in preparation for donating a kidney to her brother Tomas. She lives in a different state than Tomas and has three small children. Out of her siblings and parents, she is the only one who matches Tomas for a kidney donation. The family reports that this match is a “miracle.” Tina is ambivalent about transplantation, however, because she is concerned about travel expenses and child-care issue related to the workup, surgery, and recovery period. She also is not very close to Tomas and feels pressured by her family to donate her kidney to her brother.

## CASE EXAMPLE 16.6

Dorene is a 43-year-old African American female. She found out that a fellow church member, Matthew, needs a kidney for a transplant, and would like to be evaluated as a donor because she feels it is her “calling.” Although she does not know Matthew well, she heard about his illness at church and how he has a long wait for a kidney transplant because he has a very common blood type. She does not know anything about kidney transplantation, and her family thinks that she is crazy for wanting to donate a kidney to a stranger. Dorene, however, heard on television about a nephrologist who donated a kidney to one of her patients, and also saw the *Oprah* show where a woman was praised when she gave a coworker a kidney. She is adamant about being tested as a kidney donor for Matthew.

## SUGGESTED RESOURCES

## NEPHROLOGY SOCIAL WORK

- Canadian Association of Nephrology Social Workers ([www.cansw.org](http://www.cansw.org))
- National Kidney Foundation ([www.kidney.org/professionals/CNSW/index.cfm](http://www.kidney.org/professionals/CNSW/index.cfm))
- The Society of Transplant Social Workers ([www.transplantsocialworker.org/index.cfm](http://www.transplantsocialworker.org/index.cfm))

## KIDNEY DISEASE, PSYCHOSOCIAL ISSUES, AND TREATMENT OPTIONS

- American Association of Kidney Patients ([www.aakp.org](http://www.aakp.org))
- American Kidney Fund ([www.akfinc.org](http://www.akfinc.org))
- American Society of Nephrology ([www.asn-online.org](http://www.asn-online.org))
- American Society of Pediatric Nephrology ([www.aspneph.com](http://www.aspneph.com))
- American Society of Transplant Surgeons ([www.ast.org](http://www.ast.org))
- Centers for Medicare and Medicaid Services ([www.cms.gov/providers/esrd.asp](http://www.cms.gov/providers/esrd.asp))
- Healthy People 2010 ([www.healthypeople.gov/Document/HTML/Volume1/04CKD.htm](http://www.healthypeople.gov/Document/HTML/Volume1/04CKD.htm))
- Home Dialysis Central ([www.homedialysis.org](http://www.homedialysis.org))
- IKidney.com ([www.ikidney.com/iKidney/home.htm](http://www.ikidney.com/iKidney/home.htm))

Institute on Rehabilitation Issues ([www.rcep6.org/IRI\\_Publications.htm#27th](http://www.rcep6.org/IRI_Publications.htm#27th)) (www.niddk.nih.gov)

Kidney and Urology Foundation of America, Inc. ([www.kidneyurology.org](http://www.kidneyurology.org))

Kidney Directions: For Research in Polycystic Kidney Disease ([www.kidneydirections.com](http://www.kidneydirections.com))

Kidney School ([www.kidneyschool.org](http://www.kidneyschool.org))

Life Options ([www.lifeoptions.org](http://www.lifeoptions.org))

National Kidney Foundation ([www.kidney.org](http://www.kidney.org))

The Nephron Information Center ([www.nephron.com](http://www.nephron.com))

NephroOnline ([www.nephronline.com](http://www.nephronline.com))

NephroWorld: The Whole World of Nephrology ([www.nephroworld.com](http://www.nephroworld.com))

PKD Foundation: For Research in Polycystic Kidney Disease ([www.pkdcure.org/home.html](http://www.pkdcure.org/home.html))

Promoting Excellence in End of Life Care ([www.promotingexcellence.org/esrd/index.html](http://www.promotingexcellence.org/esrd/index.html))

Renalnet: Kidney Information Clearinghouse ([www.renalnet.org/renalnet/renalnet.cfm](http://www.renalnet.org/renalnet/renalnet.cfm))

RenalWeb: Vortex Web Site of the Dialysis World ([www.renalweb.com](http://www.renalweb.com))

United Network of Organ Sharing ([www.unos.org](http://www.unos.org))

United States Renal Data System ([www.usrds.org](http://www.usrds.org))

#### INTERNATIONAL NEPHROLOGY

International Society for Hemodialysis ([www.ishd.net](http://www.ishd.net))

International Society of Nephrology ([www.isn-online.org](http://www.isn-online.org))

International Society of Peritoneal Dialysis ([www.ispd.org](http://www.ispd.org))

The Kidney Foundation of Canada ([www.kidney.ca](http://www.kidney.ca))

Kidney Health Australia ([www.kidney.org.au](http://www.kidney.org.au))

National Kidney Research Fund ([www.nkrf.org.uk](http://www.nkrf.org.uk))

U.K. National Kidney Federation ([www.kidney.org.uk](http://www.kidney.org.uk))

World Kidney Fund ([www.worldkidneyfund.org](http://www.worldkidneyfund.org))

#### APPENDIX 16.1: NEPHROLOGY SOCIAL WORK ASSESSMENT TOOL<sup>1</sup>

The following areas are recommended for assessment to determine the strengths and barriers relevant to ESRD patient adaptation:

- I. Developmental history
  - A. Ethnic/cultural background
  - B. Primary/other language

<sup>1</sup>Source: ESRD Network of Texas (2002), Social Services Practice Recommendations. Reprinted with permission.

- C. Communication barriers
  - D. Role of religion in coping with illness
  - E. Family of origin
  - F. Quality of relationships with family members
  - G. Significant childhood illness
  - H. If pediatric, mother's pregnancy and delivery of patient, place of birth
    - I. If pediatric, explore age at which patient did the following: reached for familiar objects, sat and stood unsupported, walked alone, spoke words and short sentences, fed self with spoon, dressed self, developed bladder and bowel control
    - J. If pediatric, feeding and diet history
  - K. If pediatric, activity history including any problems associated with sleeping, walking, speaking, hearing, toilet habits, dressing, discipline
  - L. If pediatric, behavior history exploring problems such as excessive worries or fears, thumb sucking, temper tantrums, overactivity, underactivity, nightmares, nail biting, fighting, lying, shyness, distractibility, clumsiness, head banging, and so on.
  - M. If pediatric, parental history, including age, health status, psychiatric history, substance use, family roles, patient's and siblings' relationships with parents, history of parenting problems, issues of separation from family, patient's birth order, relationships with extended family, and level of support
- II. Educational history
- A. Identification of patient's current ability to learn
  - B. Identification of patient's ability to understand information relevant to treatment plan
  - C. Last grade level completed
  - D. Vocational training
  - E. Current learning barriers
  - F. Educational goals (if applicable)
  - G. Patient's perception of ability to achieve
  - H. If pediatric, preschool history
    - I. If pediatric, has an Individualized Educational Plan been developed
    - J. If pediatric, patient's/family's perception of patient's ability to achieve future educational and vocational goals
- III. Rehabilitation status and goals
- A. Functional status
    1. Functional status including ability to perform activities of daily living
    2. Amount of personal care assistance needed
    3. Assistive devices used
    4. Exercise (type and frequency)
    5. Degree of motivation to improve functional status
    6. If pediatric, participation in sports
    7. If pediatric, perception of physical limitations by patient/family
    8. Functional rehabilitation agency involvement
  - B. Employment
    1. Employment history
    2. Transferability of skills

3. If employed, present position (work hours, job satisfaction, supervisor's name, employer understanding and willingness to accommodate treatment needs)
4. Salary, benefits
5. Agency involved in helping patient maintain employment
6. Patient's motivation and perception of ability to return to work
7. Patient's perception of barriers (physical, emotional, architectural)
- C. Homemaker
  1. Perception of ability to perform preillness household and family functions
  2. Patients perception of barriers to performing responsibilities
  3. Agency involvement in skill rebuilding
- D. Volunteer
  1. Organization
  2. Hours/days
  3. Motivation and perception of ability to maintain preillness activity level
  4. Patient's perception of barriers to volunteerism
- E. Retired
  1. Motivation and perception of ability to maintain preillness interests
  2. Level of activity and patient's perception of barriers to active retirement
- IV. Financial Status
  - A. Economic status of household
  - B. Source of income
  - C. Eligibility for state and federal benefits
  - D. Real or perceived effects of illness on family's standard of living
  - E. Insurance and eligibility for Medicare, Medicaid, state kidney program
  - F. Eligibility for pharmaceutical company assistance programs
  - G. Financial agencies working with patient
- V. Living situation/peer relations/social issues/support system
  - A. Present marital status
  - B. Name of significant other/spouse
  - C. History, strength and duration of relationship with significant other/spouse
  - D. If marriage terminated, reason
  - E. Current living situation
  - F. Adequacy of housing
  - G. Management of household tasks
  - H. Number and location of children
  - I. Number and location of siblings
  - J. Status of relationship with significant friends and neighbors
  - K. Patient's perceptions of reactions of significant others to his or her illness
  - L. If pediatric, psychosocial versus chronological age
  - M. If pediatric, ability to interact and form relationships with peers
- VI. Medical history/adaptation to illness/mental health issues
  - A. Cause of renal failure and other diagnoses
  - B. Time since ESRD diagnosis
  - C. Surgical history

- D. Previous ESRD treatments and duration
  - E. Adaptation to illness (including appearance and body image concerns)
  - F. Patient's perceptions of physical limitations due to health
  - G. Patient's description of his or her emotional state
  - H. Previous treatment for mental health issues
    - I. Family/support network involvement
    - J. Patient's perception of adherence to diet, medications, and treatment prescription
  - K. If pediatric, previous childhood illnesses
  - L. If pediatric, difficulties taking medications
  - M. If pediatric, name and phone number of pediatrician
- VII. Suitability for treatment modalities
- A. Familiarity with different renal replacement therapies
  - B. Reasons for choice of treatment, if made
  - C. Success of previous treatment modality, if applicable
  - D. Assessment of patient's suitability for home training, in-center treatment, or transplantation
    - 1. Medical and psychological factors influencing decision, contraindications
    - 2. Patient's perception of barriers
    - 3. Support system
    - 4. Environmental resources, particularly for home dialysis
      - i. Adequacy of space
      - ii. Electrical power
      - iii. Plumbing facilities
      - iv. Resources available to make modifications for home dialysis
    - 5. Distance from treatment facility
    - 6. Resources for treatment
    - 7. Patient's/family's understanding of risks/benefits
    - 8. Factors that influence decision to consider treatment option
    - 9. Availability of live donor if applicable and patient/family/potential donor's feelings/concerns about transplantation
    - 10. Availability of transportation
- VIII. Clinical assessment/impressions
- A. Review of psychosocial barriers to achieving NKF's Dialysis Outcomes Quality Initiative recommendations
  - B. Quality of life measurement
  - C. Decision-making capability
  - D. Reality testing
  - E. Cognitive functioning
  - F. Intellectual ability
  - G. Independence/dependence
  - H. Insight
    - I. Major defense mechanisms
    - J. Style of coping with stress
  - K. Ability to make use of support systems/community resources
  - L. *DSM* diagnostic impression (when appropriate)
  - M. Patient level of acceptance of intervention



- N. Background or social situation which may enhance or deter staff's ability to effectively treat patient
- O. If pediatric, parents could also be assessed using the above criteria
- IX. Recommendations
  - A. Suggestions for staff to work with the patient to enhance overall adherence to medical recommendations and adaptation to illness
  - B. Rationale regarding specific treatment modality
- X. Plan
  - A. Treatment goals and appropriate social work interventions including:
    1. Education intervention to assist patient/family understanding of illness/treatment, modality selection, rights/responsibilities at facility
    2. Psychosocial counseling/intervention to assist patient/family in adapting to illness, patient's adherence to prescribed treatment regimen
    3. Rehabilitation interventions including encouragement of exercise/fitness, referral for physical, vocational, and/or psychosocial rehabilitation
    4. Interventions to provide information about/arrange needed services, that is, financial assistance, personal care, peer support, transportation

#### APPENDIX 16.2: HIGH-RISK CATEGORIES FOR THE RENAL TRANSPLANT CANDIDATE

The following can be used in conjunction with the psychosocial assessment to further assess the patient's suitability for transplant:

- I. Behaviors
  - A. Past rejection due to noncompliance
  - B. Current or past abuse of substances (alcohol, drugs)
  - C. Healthy behaviors (physically active, nutrition)
  - D. Difficulty in keeping appointments or following medical instructions
- II. Psychosocial issues
  - A. Lack of support system or caregivers
  - B. Non-English speaking/cultural impact of medical intervention
  - C. Current prisoner or legal charges
  - D. Unhealthy or vulnerable environment or surroundings
- III. Psychological
  - A. Past or current psychiatric diagnosis (*DSM IV*)
  - B. Developmental disorder/mental retardation
  - C. Prior history of coping
  - D. Coping with disease and treatment
  - E. Appropriateness of affect
  - F. Cognitive capacity
- IV. Economic
  - A. Lack of insurance
  - B. Loss of disability if gainful activity resumed
  - C. Undocumented alien

- D. Transportation/accommodations
- E. Limited financial coverage for medications posttransplant
- V. Ethical indications
  - A. Cadaver list versus live donor
  - B. Relationship to live donor
  - C. Time period on “wait list”

### APPENDIX 16.3: TRANSPLANT DONOR EVALUATION SUGGESTIONS

In addition to obtaining a thorough psychosocial history, the following questions should also be considered when interviewing a potential kidney donor:

- I. Initial decision
  - A. Who told you about the need for a donor?
  - B. What was your initial reaction?
  - C. How were you asked to donate and by whom?
  - D. How difficult was it for you to decide to donate?
- II. Knowledge about donation
  - A. What were you told or what did you find out about the risks of donation to yourself?
  - B. Did you receive adequate information from the transplant center (including teaching materials, discussions with surgeons, staff, videos, etc.)?
  - C. Have you ever spoken to someone who was a donor? Have you ever spoken to someone who was a recipient? What was their experience?
  - D. Are you aware that the recipient can be maintained on dialysis or is eligible for a cadaveric transplant?
- III. Relationship with recipient
  - A. How would you describe/characterize your relationship with the recipient?
  - B. What do you think recipient feels about your donating?
  - C. What have you discussed with recipient so far about donation? Do you feel there are any unaddressed or unresolved issues you’d like to bring up?
  - D. Do you think the relationship with the recipient will change after surgery? If yes, why?
- IV. Relationship with other significant others
  - A. Do you have concerns about the impact of deciding to donate may have on your family?
  - B. How has your spouse, significant other, parents, siblings, doctor, and so on, reacted to your decision to donate?
- V. Lifestyle Changes
  - A. Do you have any personal concerns that could interfere with your donating a kidney?
  - B. Can you think of any upcoming events in your life that might conflict or prevent your donating a kidney?

- C. Are you employed in a job that could interfere with your decision to donate?
  - D. Do you have any concerns/questions related to the financial impact of donation?
- VI. Review
- A. Common feeling donors may experience pre, during, and post hospitalization
  - B. Transplant experiences from others
  - C. Recovery and healing time
  - D. Preparedness and assistance needed after discharge
  - E. Kidney related support groups, networks, Internet sites
  - F. Social work, surgeon, and team availability for the donor and family
  - G. Offer further personal or family interventions as appropriate

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## CHAPTER 17

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# Oncology Social Work

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**O**NCOLOGY SOCIAL WORK is a specialization within social work practice that addresses the needs of people affected by cancer. The conceptual foundations for this work are found in psycho-oncology, the field of study and practice that addresses the psychological, social, behavioral, and spiritual impact of cancer on individuals, families, and communities. The field of psycho-oncology is transdisciplinary, yet through research, education, and building awareness in the medical community, social workers have been vital in the struggle to give voice to the concerns of people affected by cancer. This chapter introduces the foundations of psycho-oncology and social work's unique efforts to integrate psychosocial elements into a holistic model of oncology care.

### CHAPTER OBJECTIVES

- Introduce basic cancer etiology, treatment methods, and terminology.
- Introduce social workers to the history and conceptual foundation of psycho-oncology (also referred to as psychosocial oncology).
- Present an overview of the psychosocial, behavioral, and spiritual impact of cancer on individuals, families, and communities.
- Address the impact of cancer at varied stages of the life cycle.
- Teach basic psycho-oncology skills focused on adult, child, and family assessment.
- Provide social workers with an overview of resources available for professional development as well as client education and support.

### INTRODUCTION TO ONCOLOGY SOCIAL WORK

Psycho-oncology is the field of study and practice that addresses the unique psychological, social, and spiritual needs of individuals, families, and communities affected by cancer. Social workers with specialized knowledge in psycho-oncology are familiar with the challenges specific to varied types of cancer diagnosis and are

skillful at delivering interventions that address the adaptive and psychosocial needs of clients during the different stages of illness development. These stages include diagnosis, treatment decisions and initiation, coping with treatment side effects, termination of treatment, survivorship, recurrence or metastasis, and terminal illness.

Traditionally, social workers with special knowledge of psycho-oncology performed mostly clinical functions in health-care and community settings (Christ, 1983). The ecological, or systems, perspective provides a unique frame for social work in oncology since it allows social workers to address macrolevel policy and organizational issues while also attending to the impact of these issues at the micro-, or individual and family level. In addition to these functions, social workers in oncology develop and implement research projects guided by the principles of psycho-oncology and are active in professional development and training.

Significant changes in the treatment of cancer and in health care in general have complicated the work of social workers in oncology settings. This is particularly salient in hospital settings where crisis intervention, patient advocacy, and discharge planning are common activities for social workers. Technological advances in treatment options coupled with the shift toward greater patient autonomy in treatment decision making places additional strain on individuals and families. In addition, in recent decades, cancer has transitioned from a terminal to a chronic illness, meaning client needs are shifting to incorporate long-term effects of cancer and treatment, with an emphasis on quality-of-life issues, and fears of recurrence. These developments in cancer care have pushed social workers to develop innovative interventions to meet the needs of their clients (see Box 17.1).

While transdisciplinary teams, of which social workers are an integral part, in oncology settings are increasingly common, several major obstacles have stalled social workers and other practitioners more attuned to addressing psychosocial needs from becoming an integrated part of cancer treatment. First, the medical

### **Box 17.1**

#### **Association of Oncology Social Workers Scope of Practice**

The scope of practice in oncology social work as identified in the Association of Oncology Social Work (AOSW) Standards of Practice (1998) includes:

- Services to cancer survivors, families, and caregivers through clinical practice providing comprehensive psychosocial services and programs through all phases of the cancer experience.
- Services to institutions and agencies to increase their knowledge of the psychosocial, social, cultural and spiritual factors that impact coping with cancer and its effects, and to insure provision of quality psychosocial programs and care.
- Services to the community through education, consultation, research and volunteering to utilize, promote or strengthen the community services, programs, and resources available to meet the needs of cancer survivors.
- Services to the profession to support the appropriate orientation, supervision and evaluation of clinical social workers in oncology; participate in and promote student training and professional education in oncology social work; and advance knowledge through clinical and other research.

Source:<http://www.aosw.org/mission/scope.html>.

community's historically narrow focus on treating biological disease to provide a cure has failed to validate or even include efforts to improve patients' quality of life. More recently, attention to quality-of-life concerns are starting to be attended to as standard practice. However, psychological distress associated with adjusting to a medical illness still carries a social stigma, which itself can represent an obstacle to individuals and families pursuit of clinical care. Limited funding and a lack of clinically validated psychosocial measures to assess psychological and social phenomena put additional pressures on the growing number of researchers working to produce a body of literature about psycho-oncology (Holland, 1998). Fortunately, much of this has changed in the past few decades and social workers have developed a much broader and more specialized understanding of cancer's impact on individuals and families.

### THE HISTORY OF PSYCHO-ONCOLOGY

Understanding individual, family, and community responses to cancer requires an understanding of cultural, social, and historical factors that impact the meaning given to cancer and the quality of available treatments. Given the state of medical education and technology at the turn of the twentieth century a definitive diagnosis of cancer was difficult to make and the disease was almost always terminal. Little was known about cancer or its etiology, leading to widespread fear of contagion and the resulting stigmatization (Sontag, 2001). People who did have cancer were often faced with uncontrolled pain and debilitation due to a lack of adequate analgesics, foul-smelling tumors due to a lack of hygienic measures, and loss of attractiveness and self-esteem (Holland, 1998). Due to severe stigma, a cancer diagnosis was rarely announced, even to the patient, whose obituaries often alluded to a "persistent illness." With limited formal medical options, home remedies were abundant and included folk remedies, homeopathy, and chiropractic approaches.

The introduction of anesthesia opened the door to surgical interventions, which had the potential to be curative if they were initiated early enough. Surgical treatment was augmented in the 1920s with the discovery of radiation and its palliative use in conjunction with surgery. During this time, psychiatric units made an initial appearance in hospitals, signifying the first joining of physical and psychological treatment in the same facility. Also, the American Society for Cancer Control, precursor to the American Cancer Society ([www.cancer.org](http://www.cancer.org)), was formed and adopted as its mission public education for cancer detection. They developed public advertisements and encouraged physicians to fight their pessimism about cancer treatments. In the 1940s, the society trained volunteers, mostly cancer survivors, to serve in a visitor program that provided counseling and information to people preparing for treatment or to patients adjusting to major treatment-related functional losses. This volunteer program was the precursor of Reach-for-Recovery, which became an internationally successful self-help program in the 1950s.

While these efforts provided important social supports to individuals and families, the medical community was hesitant to be more inclusive about psychosocial care. In the aftermath of World War II, however, drugs initially developed by the government for use in chemical warfare were successful in treating acute leukemia. This discovery was followed closely by the first curative chemotherapy in the early 1950s.

During the 1950s, America's great decade of prosperity, debate stirred about the commonly accepted practice of withholding a cancer diagnosis from patients and the ensuing impact on doctor-patient trust. Social workers and psychiatrists were in favor of sharing a cancer diagnosis to enable coping and doctor-patient trust while physicians, taking what they saw as a protective role, often remained obstinate that diagnoses should be shared only with family members to "save" patients from having to cope with certain death. Ruth Abrams, a pioneer in oncology social work who was deeply committed to enhancing patient care, worked to improve communication between physicians and their patients. Sparked in part by concerns about patient autonomy and informed consent, this debate continued for several decades until sharing diagnoses with patients became common practice.

The 1960s and 1970s saw increased survivorship through the use of combined treatment modalities, such as the use of surgery in conjunction with chemotherapy or radiation. Under the clinical and research efforts of Elisabeth Kübler-Ross, these decades also saw the first public dialogues about the nature of death and dying with dignity. Also due to the efforts of Kübler-Ross, thanatology, the study of social and psychological aspects of death, became an area of inquiry for the first time. This started an international movement toward hospice care and permitted initial conversations about resuscitation guidelines for the terminally ill. Psycho-oncology organizations proliferated during this period, addressing varied populations and aspects of the cancer experience. The American Cancer Society was a leader in this movement and helped provide the impetus for the first major research conferences on psycho-oncology in the early 1980s. These conferences brought together several budding organizations and stirred discussion about psychological concerns long familiar to medical social workers to the forefront of medicine and psychiatry.

The last part of the twentieth century saw growth in research, funding, and scholarly publications dedicated to psycho-oncology, including an increase in the number of opportunities offered specifically to social workers. Topics now include psychoneuroimmunology (the study of the reciprocal impact of psychological, cognitive, and immunological functioning on each other), cancer prevention through education and lifestyle modification, quality of life assessment, cross-cultural issues, and cancer genetics. At the start of the twenty-first century, psycho-oncology services are becoming increasingly status quo in cancer care (Blum, Clark, & Marcusen, 2001). Oncology social workers have expertise with work in a variety of settings, including research, community, and training hospitals and cancer care centers, community wellness centers, hospices, and other training institutions. In addition, national and international oncology social work organizations have helped centralize macrolevel efforts to improve psychosocial care of cancer patients and their families through the creation of professional standards of practice specific to social work in oncology, position papers on areas such as euthanasia and pain management, national conferences and research awards, and formal continuing education in areas such as end of life care and family centered practice (see [www.aosw.org](http://www.aosw.org)).

## CANCER EPIDEMIOLOGY AND TREATMENT

Over an average life span, one in two men and one in three women will develop cancer (Ries et al., 2003). Given our family and community ties, this means that



everyone is likely to be affected by cancer at some time. The word cancer is used to describe a group of disorders marked by the uncontrollable growth of abnormal cells in the body. The disease starts with damage to genetic material, which leads to the development of abnormal cells—a process called *carcinogenesis*. These cells emerge in a more disorganized manner than healthy cells, dividing more rapidly, failing to mature, and lacking the correct programming to complete genetically assigned functions. When cancer cells attack and destroy healthy tissue or spread through the body, the cell growth is said to be malignant and a diagnosis of cancer is made. If the growth of cancer cells is not arrested, those affected areas of the body will cease to function (Eyre, Lange, & Morris, 2001). For many people with cancer, especially those with fast-growing cancers, this will lead to death. For others, cancer cell growth may be slow, particularly in the elderly, and they may die with cancer but not from it. Some types of cancer are more easily detected than others and some are more easily treated. Today, mortality rates from cancer are decreasing. While survival rates vary based on the type and staging of a cancer diagnosis, overall less than half of all people diagnosed with cancer will die from the disease (Eyre et al., 2001).

Several risk factors are strongly associated with the development of cancer, including age, gender, family history, geography, environment, economics, and race. On the whole, older people are much more likely to develop cancer than younger people; as people age, their bodies are more likely to have been exposed to carcinogens, and due to a decline in immune functioning they are less equipped to fight off cancer cells. While different cancers affect men and women at different rates, men are at an overall greater risk than women for developing cancer.

In some cases, cancer is hereditary. Significantly increased risk is passed from generation to generation in that family's genetic code. Environmental influences, social circumstances, behavioral choices and a lack of adequate medical care can all contribute to cancer expression and related mortality (McGinnis, Williams-Russo, & Knickerman, 2002). These domains include exposure to toxic chemicals, radiation, or viruses, as well as the use of alcohol or tobacco, dietary choices, and reproductive behaviors. One risk factor for breast cancer is having children later in life and thereby prolonging uninterrupted estrogen production.

Geography is also important in considering broad cancer trends and suggests lifestyle, environmental quality, and longevity affect the development of cancer. Finally, low socioeconomic status and racial minority group membership put people at increased risk for developing cancer. For example, while White American women have higher incidence of breast cancer, they are more likely than women of color to be diagnosed at an early stage in disease progression and have higher survival rates (Ghafoor et al., 2003). While genetic factors may play an important role in these differences, diminished access to preventive screening or health insurance, skepticism about mainstream medicine, and the lack of quality care post diagnosis significantly impact marginalized populations.

#### HOW IS CANCER TREATED?

Cancer treatments aim to remove tumors, prevent spread or recurrence of cancer, and provide the best balance between curative measures and quality of life concerns raised by treatment side effects. Treatment decisions are based primarily on the type and stage of cancer. The type signifies the part(s) of the body affected

and the stage signals the degree of advancement in the body. Also taken into consideration when determining treatment options are the general health of the individual, quality of life concerns, financial status and insurance coverage, and effectiveness and side effects of the particular treatment (Eyre et al., 2001).

Cancer patients and their physicians have a variety of conventional, experimental, and alternative therapies from which they can choose to arrest cancer development. Conventional treatments include surgery, chemotherapy, and radiation. Surgery can be used for prevention, diagnosis, and treatment of cancer. Surgical procedures offer doctors a way to get visual confirmation of tumors or to obtain tissue for laboratory testing. When the cancer is contained or easily visible, surgery remains the most successful treatment.

Surgery is frequently used in combination with other treatments, including radiation or chemotherapy. Radiation uses x-rays to cripple and destroy cancer cells, while having only a small impact on healthy cells, making it a central method of treating cancer (Eyre et al., 2001). Radiation, the use of energy particles targeted at cancer cells to alter their genetic code, is frequently the treatment of choice for aggressive cancers since it can be targeted to affected areas. By contrast, chemotherapy attacks cancer cells all over the body and healthy organs are frequently affected as well during treatment. Like radiation, chemotherapy can be used for curative or palliative purposes and is often combined with other treatments depending on cancer type and staging. Chemotherapy often includes a combination of cancer-fighting drugs, and the duration and intensity attempt to maximize the effects of treatment while minimizing the impact on healthy organs (Beers & Berkow, 2004). Side effects of chemotherapy can be quite severe and are often the cause of great anxiety. A nonexhaustive list of side effects includes nausea and vomiting, hair loss, mouth sores, weight gain, fatigue, decreased sex drive, and depression. Social workers can help patients to manage these side effects by teaching them stress-reduction, coping skills, and about the process of cancer treatment in general, thereby lessening anxiety and helping people persevere through treatment.

Experimental approaches to treating cancer are popular choices for people battling cancers that do not respond well to conventional methods and for people experiencing recurrences of the disease or metastases, the spreading of cancer cells to other parts of the body (Eyre et al., 2001). Patients can access these treatments by participating in clinic trials, or research protocols, to test the effectiveness of new interventions. Patients participating in clinical trials generally receive all treatments at no cost, and some are even reimbursed for expenses related to receiving treatment, such as travel or hotel stays. However, barriers to participating in clinical trials do exist. Access to clinical trials is often limited due to strict research protocols, meaning that not everyone who might be helped by an experimental treatment may qualify. Also, experimental treatments are often tested against placebo or FDA-approved protocols, so patients may not be guaranteed access to the new regimens. Finally, clinical trials are generally administered at research and teaching hospitals, which tend to be in urban areas. Travel requirements may be prohibitive for people with financial or instrumental constraints.

Some people with cancer are choosing to compliment conventional or experimental treatments with lifestyle changes. These treatments include nutritional changes, support groups, meditation, exercise, and acupuncture (Eyre et al., 2001). In addition, a host of complimentary and alternative therapies exist that are un-

proven or not recommended by physicians or major cancer organizations. When people with cancer feel desperate or overwhelmed, they may turn to these options and many do not share this information with physicians or oncologists. Alternative and complimentary approaches to cancer care include treatment options that focus on mind-body concerns, energy-based medicine, and homopathy. In the United States, approximately one-third of all adults use some form of alternative or complimentary medicine. This population tends to be highly educated, recently hospitalized, and women ([http://nccam.nih.gov/news/camsurvey\\_fs1.htm#cam](http://nccam.nih.gov/news/camsurvey_fs1.htm#cam)). Alternative and complimentary options exist that are intended to fight cancer but little is currently known about their efficacy for extending life. Social workers should work with physicians to help clients sift through the variety of treatment options to make choices that best balance cancer treatment and quality of life concerns. The National Center for Complimentary and Alternative Medicine is a solid resource for social workers and clients interested in these treatments ([www.nccam.nih.gov](http://www.nccam.nih.gov)).

### CONCEPTUAL FOUNDATION OF PSYCHO-ONCOLOGY

The impact of a cancer diagnosis is far reaching. Physical, emotional, spiritual, and financial questions arise, including: Why me? Will I be able to work? Am I going to die? During the initial phase of diagnosis and adjustment, social worker's key tasks are to help individuals and families cope with their reactions to the diagnosis and to gather emotional and instrumental resources to make treatment decisions.

Newly diagnosed individuals must immerse themselves in a new language. This language must be mastered quickly so that they can ask intelligent questions, select appropriate resources, and make optimal treatment decisions (Holland & Lewis, 2000). It is also possible to become overwhelmed with information (Spencer, Carver, & Price, 1998) and with well-meaning efforts of family and friends intent on helping out. The use of the Internet has expanded exponentially the amount of information available to cancer patients and their families (Eysenbach, 2002; Sharp, 2001). While physicians are more skeptical than patients about the quality of information available online, studies evaluating information on web sites have found information to be 95% accurate, indicating that much of the information available on the Internet is valid and reliable (Eysenbach, 2002).

Once a treatment decision is made and family and friends are informed, social workers can focus on helping clients to understand their course of treatment and the intended impact on the disease. Interventions with clients at this stage should include ongoing assessment of client's individual and family functioning in response to the treatment decision. Each method of treatment has a unique course for which patients and their families must mentally and physically prepare. These regimens are often demanding and restrictive and are frequently accompanied by emotional concerns, such as depression and anxiety (Eyre et al., 2001).

The physical side effects of treatment often carry their own emotional impact. Hair loss and weight change can have a profound impact on psychosocial adjustment simply because they provide visible clues that things have changed (Spencer, Carver, & Price, 2001). Cancer diagnosis and treatment can rob people of important family and social roles, causing an emotional upheaval for all involved. A young mother who needs help caring for her children or a family breadwinner who can no longer work may be devastated by these changes. During this

stage of illness development, social workers must attend to the ambivalence that often arises as patients experience debilitating emotional and physical side effects from treatment. Interventions here can be aimed at educating clients about what to expect during cancer treatments, focusing on elements of control and mastery to combat diminished self-esteem, and reorganizing family structure and routines to incorporate the demands of the illness. Concrete problem-solving and parenting skills are often quite helpful at this stage as families attempt to balance the needs of the person with cancer with other family concerns.

As cancer progresses, finances can become a major concern, especially when there are additional strains on the system. Two-parent families who even temporarily lose an income likely will face significant financial problems. This is more of an issue with single-parent families if the parent is unable to work and loses the family's insurance or sick leave benefits. Patients and their families must quickly become familiar with insurance and disability policies (Smith, Walsh-Burke, & Crusan, 1998). Applications to Social Security take approximately 5 months to process, and while there is an appeal process should applications be denied, the course of the disease can change drastically during this time. Therefore, social workers face the tough task of working with clients to apply in anticipation of future needs given the length of time needed to line up those resources.

The termination of treatment at the end of the prescribed regimen often presents an existential crisis for clients (Arnold, 1999). Many feel that, because they are no longer actively fighting cancer with conventional medicine, they are more susceptible to recurrence (Holland & Lewis, 2000). Each check-up or test may raise concerns and visions of a need to resume treatment. Fear of recurrence may seem overly pessimistic. However, the extraordinarily taxing nature of cancer treatment makes the prospect of a recurrence devastating for the cancer survivor. At this stage of illness development, social workers can assist clients in naming their fears of decreased surveillance. As active cancer treatment ends, many individuals and families are faced with residual emotional distress not addressed during active treatment, and many present to social workers for initial help at this time.

#### CANCER AS A CHRONIC DISEASE

It is estimated that over nine million persons nationwide have survived cancer and mortality rates from the four leading cancers—lung, breast, prostate, and colorectal—have fallen (Ries et al., 2003). Since greater numbers of people are living with cancer and experiencing the long-term side effects of treatment, it can be considered more a chronic, episodic illness than a terminal condition. Major issues with survivorship that social workers must attend to in practice include helping clients adjust to a new normal, including resuming old roles and activities. For some people, chronicity may represent living with the long-term side effects from minor annoyances, such as a dry throat or curly hair, to a devastating heart condition, permanent numbness in hands and feet, or renal failure resulting in the need for kidney transplant or lifelong dialysis (Kornbluth, 1998).

Young cancer survivors face unique medical and psychosocial issues. Research suggests that treatment side effects, which may include developing a different type of cancer as an adult, are not uncommon (Pizzo, 2001). Cancer in adolescence and early adulthood also may lead to different life choices in relation to the opposite sex and planning a future (Roberts, Turney, & Knowles, 1998). Decisions

about future reproductive wishes must be considered prior to treatment, such as whether to harvest eggs or collect sperm for later use. Convincing an adolescent or young adult of this option can be extremely difficult, given the prohibitive costs and the finding that 50% of adolescents fail to adhere fully to treatment recommendations (Keene, Hobbie, & Ruccione, 2000; Richardson & Sanchez, 1998). Social workers can collaborate with physicians and families to provide supportive education about the impact of cancer treatment on fertility and provide a safe and private forum to discuss reproductive options.

#### THE MEANING OF CANCER

Cancer is associated with pain and mutilation of the body, such as that which occurs with mastectomy. It represents vulnerability by striking indiscriminately in the body and spreading to shut down natural processes. Specific meanings of cancer, illness, and death vary with cultures' dominant beliefs. These include ideas about humankind's ability to dominate nature, convictions about God or supreme beings that determine our path in life, and beliefs about luck or fortune. A cancer diagnosis may therefore represent a shameful occurrence for some and a stroke of bad luck for others.

In our society, cancer is often spoken of as evil, predatory, or mysterious, increasing the mythology surrounding the illness (Sontag, 2001). The way our society speaks about cancer gives it life, motivation, and control that contribute to the demoralization people experience when they first hear their diagnoses. This was the argument physicians used for decades to justify withholding a cancer diagnosis from patients. For many, people with cancer are seen as victims of their disease, indicating weakness and vulnerability. Thus, some people want to keep the diagnosis of cancer secret due to the perception that it will "hurt business" or damage a person's chances for success. When cancer is shrouded in secrecy, its impact often goes unnoticed.

Others are blamed for inciting their cancer by making poor lifestyle choices, including smoking, poor diet, or having highly stressful jobs. As new research on the mind and body connection is emerging, myths abound about the power of positive thinking. This idea that we can think ourselves well simultaneously condemns those who have cancer for being unable to prevent it and those who succumb to cancer for failing to have sufficient hope. The meaning of hope changes, however, as cancer progresses. While initially people with cancer and their families hope for cure, as the disease becomes terminal, hope is transformed into a statement about dying with dignity and without pain. Social workers can play a unique role here by facilitating conversations about the meaning of cancer for individuals and their families and communities, and about the meaning of hope in the face of a cancer diagnosis. Additionally, new research suggests that social workers can help with cancer prevention by tailoring individual behaviorally oriented interventions to target harmful behaviors (Gotay, 2005).

Cancer can also be seen as a blessing. It can allow people to reexamine their lives in a manner that makes them take stock, appreciate what they have, and move forward on a positive course. Cancer gives them permission to perform only the tasks that they deem important and the strength to say no to others. No matter what the diagnosis, cancer causes people to have to adjust to a "new normal." They must look at themselves, their families, and their friends through a

different lens. Ultimately, coping is dependent on how they can integrate their prior experiences into this new journey.

When assessing individual and family functioning following a cancer diagnosis, it is crucial for social workers to ask all family members why they believe the cancer occurred. Each person may have a story or there may be a harmful family narrative connected with shame and self-blame. These stories indicate significant worldviews, essential for social workers to access to help families to heal psychologically from the crisis of cancer.

Spiritual and religious beliefs frequently influence coping strategies and the availability of support communities. Many people depend on their faith to get them through the difficult days (Wright, 1999). Some people may even look to spiritual tenets or guides to help in making treatment decisions. Religious congregations often provide significant help with the instrumental tasks of daily living for cancer patients, such as providing hot meals, childcare, and transportation to medical appointments. Spiritual leaders and congregation members also provide emotional support to families during the crisis of cancer. Long-held spiritual beliefs may be called into question following a cancer diagnosis. Individuals and families may feel "let down" by God, and while multiple family members may experience existential doubts, most will keep these to themselves to avoid greater distress or causing additional burden. Conversations about spiritual doubts are frequently difficult to have with spiritual leaders or family members. Many individuals and families lack a forum to explore the physical, emotional, financial, or spiritual issues as they arise. Social workers can be helpful to families facing cancer by probing these areas.

Support groups provide a forum for cancer patients, caregivers, and their families to address some of these issues (Spiegel, Bloom, & Gottheil, 1983). Research has demonstrated that people who participate in support groups feel less distress about cancer and approach problems more efficiently than controls (Spiegel & Classen, 2000; Walker, Cella, Dysart, & Biank, 1999). The research of Spiegel and colleagues involving a series of randomized trials that matched women with metastatic breast cancer in treatment and control groups found participants in support groups lived statistically longer than controls (Lilliquist & Abramson, 2002; Spiegel, Bloom, Kraemer, & Gottheil, 1989; Spiegel & Classen, 2000). Although Spiegel's original study has not been consistently replicated, the original findings are commonly cited as evidence of the healing effects of supportive group therapies for cancer patients.

## CANCER AND FAMILIES

When a parent is diagnosed with cancer, there are reverberations across several societal systems. In addition to the impact on family and friends, a cancer diagnosis affects the workplace, children's schools, and community organizations, such as churches, organized sports, and clubs.

### TELLING CHILDREN

A primary concern of parents is how and when to tell their children. Many families want to postpone this disclosure for as long as possible to avoid "scaring" or



burdening children. In reality, however, children frequently know something serious is happening in the family. Without explanations from trusted adults, however, children frequently rely on magical thinking to explain what they see. In these situations, children may blame themselves for their parent's illness. Ideally, children should be told as promptly as possible (Biank & Sori, 2003). Social workers should encourage and coach parents to include children in discussions about cancer from the beginning, so children will trust the information they receive throughout the cancer experience (Furman, 1974).

Parents should discuss with their children the myths and misperceptions that evolve when a person is diagnosed with cancer. A child will have many questions when they find out that their parent has a life-threatening illness. These questions should be answered in a clear, age-appropriate manner, giving the child the information they need and request and providing them with an opportunity to ask for further clarification (Biank & Sori, 2003). Social workers are valuable resources for parents as they begin to structure these conversations with their children. For example, social workers with expertise in child development can help parents teach their children about cancer in developmentally appropriate language and address issues common to children of varied ages. For example, children must learn that cancer is not contagious and that they did not cause their parent's or other loved one's cancer.

Factors that are associated with adaptive family coping and resilience, particularly during a parent's cancer, include flexibility of family roles and boundaries to allow outside help while maintaining some consistency in family functioning (Walsh, 1998). When one parent knows how to take on the tasks of the other, tension in the household is eased. In families where roles are more rigidly defined, other family members, such as adolescent members of the family, may have to perform tasks beyond their capabilities (Saler & Skolnick, 1992). This is especially salient for children of the same sex as the ill parent. For example, teenage girls with sick mothers frequently take on cooking, cleaning, and childcare responsibilities for younger siblings. When cultural norms frown on outside help, families will have a much more difficult time with the demands of coping with a serious illness like cancer. Families should be encouraged to protect pockets of normalcy and find time for laughter whenever possible.

Marital stressors can compound the tasks of the cancer experience. When couples view cancer as a challenge they must face together, the problems presented by the presence of a serious illness become external to any one person and the couple can unite to fight the battle together (Rolland, 1994). When families are confronted with several stressors simultaneously, such as job loss, or health care for older family members, the cancer experience becomes much more challenging. Faith and spiritual guidance can help to keep families more cohesive and offer greater hope and peace.

Social workers can help families unite with friends, neighbors, and community organizations to form a Cancer Support Team to alleviate some of these stressors. These teams are intended to provide instrumental and emotional assistance to families as they face the changes and challenges presented by a cancer diagnosis. Cancer support teams are helpful for anyone facing a cancer diagnosis, but can be especially helpful for parents with cancer. Forming a Cancer Support Team is a valuable tool that helps parents make the best use of their resources. Since 60% to 80% of adults with cancer experience distress and challenges for which their

skills and support are ineffective, establishing this team early in the treatment phase can be beneficial to both coping and family functioning (Helgeson, Cohen, & Fritz, 1998; Lewis & Hammond, 1992; Spira & Kenemore, 2002; Walker et al., 1999). Certain friends and family members have specific talents that can be helpful during a time of crisis. Defining who has the appropriate talents, from driving, to cooking and meal planning, to researching treatments, to creating and updating an e-mail list, can be quite helpful to a family that desires to keep the status quo whenever possible. Children can be involved in some of the choices, without burdening them, simply by having a voice as to who will watch them or by helping with simple tasks around the home.

#### CANCER AND PARENTING YOUNG CHILDREN

A parent's reaction to cancer frequently changes over time due to medications, treatment, and the progression of the disease. Even in two-parent families, children may feel abandoned because most caregivers must keep their jobs while taking on more tasks at home and spending more time offering support to their ill partners. Other caregivers are forced to return to the workplace, due to the financial strain that cancer can place on a family. The parent with cancer is frequently unable to perform all of the tasks that they were performing prior to their diagnosis simply because they are involved in their own recovery (see Box 17.2).

Although many children see their teachers as grown-ups they can talk to, they often have trouble concentrating in school, because they are concerned about what is going on at home. It is important to remember that, because cancer usually is a chronic disease, it can affect the family system for at least 3 to 5 years. That is 50% of the life of a 10-year-old. Also, since cancer onset ages are decreasing, some children do not have memories of their parents when they were healthy.

Children's peer groups can also shift when a parent is diagnosed with cancer. Children may not want to play with friends, because they are afraid other kids will ask questions that they cannot answer. Social workers can help children and families with these worries by teaching them about the mechanics of cancer at age-appropriate levels and by providing opportunities for children to role-play before talking to friends.

Children also miss having active time with their parents and may forgo playtime with friends to spend quiet time at home. Young children may have particular difficulty understanding cancer and treatment side effects, such as fatigue. Some children will repeatedly ask the same questions and, since a child's responses to illness is shaped by the manner in which information is presented to them, it is important to answer these questions each time they are asked. Social workers can help parents craft answers to these questions so they are prepared when children present concerns. Social workers can suggest or facilitate family meetings in which information is discussed with all family members simultaneously. This provides a structure or framework within which to manage change.

#### CANCER AND PARENTING ADOLESCENTS

Developmentally, adolescence is marked by a systemic shift toward greater flexibility of family boundaries, allowing teenagers greater independence to move out

**Box 17.2****Case Study: The Bennett Family**

The Bennett family presented to a community-based, cancer support center when Mrs. Bennett, age 41, was diagnosed with stage III colon cancer. She had been a kindergarten teacher in the community for the past 12 years. Mr. Bennett was head of security for a major hotel chain. They had been married for 24 years at the time of diagnosis. Together they had four children ages 5, 9, 12, and 15. All the children were struggling with the diagnosis. The Bennetts were particularly concerned with the oldest child, who experienced stomachaches on “chemo days” and insisted on staying home from school, and with the 5-year-old, who was clinging to her older brother and was hesitant to let Mrs. Bennett out of her sight.

The family began participation in several family-oriented support groups at the cancer support center. The two older children joined a process-driven teen support group and the younger children joined a psychoeducational group that was matched with a separate parent support component. The family continued participating in these groups for 16 months while her cancer progressed and her prognosis worsened. During these months, Mrs. Bennett continued working full time. Social workers at the cancer center were asked by the school to provide a workshop about cancer for teachers and parents. Mrs. Bennett, however, did not want to burden the community with her cancer and insisted the workshop be cancelled.

Sixteen months after the family’s initial presentation for services, Mrs. Bennett’s prognosis became terminal. Social workers at the cancer support center coached the Bennetts so they could tell their children that their mother was going to die. Over the next several weeks, the social workers conducted individual counseling and facilitated family conversations about how to approach her death. In this time, the 13-year-old girl became aware that her eighth-grade graduation would be the last thing that her mom would do with her. She regretted that they would never be able to travel to Paris or plan her wedding together. The social worker involved with the children bought wedding magazines and a book on Paris so mother and daughter could have conversations about these events while mom was still alive. The oldest son talked of his concern about being a disappointment to his mother. The social worker coached him to have that final conversation with his mother in which she talked of his being the firstborn and her joy at seeing his face for the first time.

Mrs. Bennett died in the summer, was cremated, and celebrated through a memorial service several weeks later. The school was struggling with the loss of this beloved teacher and again reached out to the cancer support center to intervene. The same social workers involved with the family planned a series of open-house interventions for teachers and parents in the days before the new school year began. Extra support was offered for the teachers who would be taking over her classroom or handling the children that she had just taught. These community interventions addressed concerns about talking with children about cancer and death, and the social workers provided resources for work with children in these areas. The social workers suggested and helped to plan a separate memorial service at the school. Children at the school thanked the cancer support center by decorating holiday trees with homemade ornaments to honor Mrs. Bennett.

Following Mrs. Bennett’s death, Mr. Bennett and the four children participated in the bereavement program at the cancer support center. The social workers provided individual and family counseling as needed, and worked with the children’s school to support each child as they returned to the classroom.

into the world. A parent's cancer diagnosis can draw teens back into the family system at a time when developmentally they should be working toward separation and individuation (Erikson, 1963). Adolescents feel the impact of cancer at a deeper level than younger siblings. They worry that their family will never be "normal" again and that life will change forever. Sometimes they are asked to make sacrifices beyond their years, such as giving up going away to college or getting a job to help out financially. School can either be a respite or a frank reminder that their life has changed dramatically. Adolescents may also become angry and challenge their parent's requests for extra help. Their arguments are a way to provoke their parents into acting as they did prior to the cancer experience. They might think that if a parent is strong enough to engage in a fight, then the cancer must not be so serious. In this manner then, they can deny that cancer exists.

When family energy and attention is directed toward cancer, the normal developmental tasks and accomplishments of teens may go unnoticed. Social workers can help parents maintain clear boundaries and family consistency through the institution of firm house rules. Social workers can aid families with adolescents by encouraging parents to include adolescents in discussions about illness course and treatment or by holding family meetings where each member of the family has a platform to discuss their experience of the cancer. Adolescents need time away from cancer, and social workers can help teens and parents find a balance between helping at home and maintaining friendships.

In the case of children from single-parent households, social workers should attend to any fears of abandonment. From the onset, a single-parent household should have family helpers established as a part of the Cancer Support Team, so that the children don't feel overburdened by the experience. This can be achieved by facilitating discussions to reassure them how their needs will be met in an emergency or if something more permanent were to cause the need for serious change within the family. The entire Cancer Support Team should be included in this plan, namely family, children, close friends, and neighbors contributing to the family's well-being. Bringing together the entire team is frequently a relief for teens, because they no longer feel they carry the entire caregiver burden.

Social workers can also be helpful for parents by connecting them to support resources for themselves, so they do not need to use children or teens as confidants (Cwikel & Behar, 1999). Children who become parent confidants during the cancer experience are already emotionally distressed by family changes and their own fears; holding the fears and worries of parents too is inappropriate and dramatically increases the burden of children (Hermann, 2001). Children and adolescents should also be connected with resources, such as a suitable support group, where their needs and concerns can be addressed (Christ, 2000).

#### WHEN A CHILD HAS CANCER

Parents are devastated when they are informed that their child has cancer. The helplessness that overcomes them has them asking: "Why isn't it me instead?" They show outward signs of emotional shock and can develop a deep sense of grief as they realize that many of the hopes and dreams that they held for their child may never be realized.

Initially parents are overwhelmed with learning about the illness, the treatment, and how to care for their ill child at home. Their emotions are challenged as they watch their child undergo prolonged, painful medical procedures and repeated hospitalizations. Parents may experience guilt for failing to recognize symptoms in their child or thinking that they failed to properly care for them. They may become overprotective of their child in an effort to decrease their sense of anxiety. This can interfere with the child's school experience and the development of self-confidence. Parents also experience separation anxiety as they struggle to care for their child while earning a living, performing normal household responsibilities, and caring for their other children (Shilds et al., 1995).

Out of necessity, some families decide to have a child treated in another city. This can separate the family and cause the development of a strong coalition between the ill child and the caregiver parent, reorganizing family relationships and alliances. This can be detrimental to the well-being of the remaining siblings, who may feel slighted, ignored, or abandoned (Hamama, Ronen, & Feigin, 2000). All children, both ill and well, are impacted by the emotional reactions of parents. Ill children often feel guilty for causing their parents so much worry. Well children often hide their own fears and anxiety so as not to cause their parents additional concerns. Social workers must assess parental reactions and their impact on children and refer distressed families for consultation.

For children, serious illness may impede the resolution of normal tasks of each stage of psychosocial development (see Table 17.1). When a child is diagnosed with cancer, they can experience increased anxiety, depression, isolation, and regression (Zebrack & Chesler, 2001). Children may develop eating problems as a mechanism to help them gain control over their situations. Physical changes may lead to shame and social isolation. Many fear being teased about never having a normal appearance. Others have anticipatory symptoms including nausea and vomiting prior to treatment as a result of classical conditioning or anxiety.

For adolescents, cancer interferes with sexual development. Psychosexual losses include fertility, menses, pubic hair, libido, and erections. Cancer can also interfere with an adolescent's exploration of his or her sexual identity; for example, there can be a loss of sexual identity as girls experience baldness. Half of adolescents diagnosed with cancer are said to feel uncomfortable with the opposite sex and to avoid dating (Zebrack & Chesler, 2001). They tend to live at home longer, be less likely to marry, and to marry when older. They fear recurrence, which can interfere with a desire to embrace life, think about progeny, and dream of a future.

Social workers should be aware that nonadherence to treatment is reported in 33% of children under 13 and 59% of adolescents (Keene et al., 2000; Richardson & Sanchez, 1998). While parents are responsible for their children's compliance, a child may still refuse. Physicians should be notified immediately if noncompliance is a problem. Social workers can intervene first by refocusing the child's need for control toward other, less harmful behaviors, and second by assessing how parenting styles may be problematic for the child. Also, cancer breeds self-absorption and hypervigilance about one's body and health. While this self-absorption is a normal part of adolescent development, those who experience a serious illness often have trouble growing out of it as they become young adults. This skews development toward an egocentric focus, leaving adolescents prone to relational difficulties later in life.

**Table 17.1**  
Childhood Cancer and Psychosocial Development

Age	The Impact of Cancer on Childhood Development Based on Erikson's Stages of Psychosocial Development (Erikson, 1963; Sori & Biank, 2004)	Impacted Virtue
Under 18 months	Hospitalizations, separations from parents, painful procedures may interfere with the establishment of trust and attachment.	Hope
1–3	Child may have limited opportunities for self expression. Parental control may be intensified, enhancing passivity, interfering with the establishment of autonomy. Child may feel little control over life.	Will
4–5	Child may feel guilty for being sick, for worrying parents, and for receiving more attention than well siblings. This can lead to excessive inhibition of initiative (versus guilt) and interfere with the development of conscience. This may impact school work.  Note: There is a higher incidence of problems in children just starting school for the first time [presumably because a life-threatening illness interferes with normal separation and individuation during this period of development.	Purpose
6–11	The child may feel a sense of inferiority and inadequacy, rather than a normal progression towards industry, achievement and accomplishment.	Skill
Adolescence	Illness may interfere with the tasks of establishing clear concepts of role and identity (including sexual identity), autonomy, and differentiation of self.	Fidelity
Young adulthood	Illness often leads to a focus on physical symptoms and bodily changes, which foster self-absorption and may lead to a sense of isolation.	Intimacy and love

#### CANCER IN THE CLASSROOM

School experiences have a significant impact on development and support during childhood cancer. Children often miss significant amounts of school, which impacts classroom learning and peer relationships. The teacher is the first line of defense when a family has a member diagnosed with cancer. Because a teacher is the key point of contact for an ill child, the family must convey accurate information about the child's condition and treatment. While respecting the child's wishes, a plan should be developed to inform classmates and their parents about the child's condition and projected date of return. Social workers can help parents, children, and teachers explore ways of sharing this information by facilitating meetings between families and teachers. Social workers can also participate in training teachers and school personnel about how to address concerns of other parents and children and to care for the ill child in school as needed.

From the time of initial diagnosis, children should be encouraged to maintain contact with one or two close friends. This can be a benefit for all of the children;



the ill child maintains school bonds and friends see his or her cancer as something other than a death sentence (Biank & Sori, 2001). Well children feel good about helping friends rather than feeling guilty for abandoning them. Social workers should explore the possibility of presenting during a teacher-led discussion about cancer. Permission must be received from the family before such a conversation, but the lessons may prove invaluable.

School reintegration is a major area of concern for children and families. Children may have trouble with school reentry simply because they have been away from the classroom for long periods of time. Helping the child return to school is an important role for the school social worker, school nurse, and teacher. Oncology social workers should partner with school social workers to facilitate this transition.

Students in the child's class must be prepared for any physical or emotional changes in the child and helped to understand how they can support their classmate. Sometimes difficult side effects such as fatigue, slurred speech, and temper outbursts need to be tolerated in the classroom. It is imperative that any substitute teacher be alerted as to the special needs of a child who has cancer. Teachers should stay in touch with their own emotional reactions to the child while establishing a balance for the child when returning to school; too much attention can make them feel different and can alienate peers, while not enough can cause them to feel unsafe. Establishing a signal between the teacher and the student, such as a subtle thumbs-up sign, so that each knows how the other is feeling can be helpful.

The greatest obstacle when returning to school is the child's fears of classmates' reactions (Shilds et al., 1995). School officials should have accurate medical information to dispel myths, superstitions, and negative attitudes. Families must also be aware of school policies that may affect their child, such as the no hat rule or not eating snacks at their desks. Schools must work together with families to help children be comfortable upon their return to the classroom. Realistic standards should be set for such children, combining appropriate school rules to maintain normalcy while making specific illness-related allowances. Parents need to be informed of the services available for their children such as tutoring, special classroom placement, and home school. Regular meetings between school officials, the school nurse, social worker, teacher, and the parents should be scheduled. Social workers should also keep in close contact with school nurses, who frequently act as the liaison between home, classroom, and hospital.

For the child with cancer, the school social worker is a valuable asset. It is important that they get involved with the family as soon as the child is diagnosed. This will help the child stay connected during treatment and facilitate a smooth reentry when appropriate. The social worker should begin with an assessment of any premorbid social, academic, and family factors that may hinder school reentry. Teachers are integral in this assessment, and should be given sufficient information to quell anxieties of other students and parents. Since siblings of children with cancer are often significantly adversely affected by cancer, staff trainings should be held to alert other teachers to the child's situation (Hamama et al., 2000).

Finally, the oncology social worker should collaborate with the school social worker to arrange any special assessments that the ill child may need after treatment. The school social worker should be encouraged to attend staff meetings

with the health-care team, teachers, and parents. Since learning disabilities can develop as a result of chemotherapy and radiation, the school social worker should meet regularly with teachers to assess academic progress and with the child to assess depression, anxiety, or family problems (Shilds et al., 1995). Referral for individual psychotherapy is especially crucial, if the child has on-going social, emotional, or family difficulties.

#### ELDERLY FAMILY MEMBERS WITH CANCER

Elderly individuals face unique challenges when diagnosed with cancer. First, while age is the greatest risk factor for cancer, few programs or research protocols address, or even include, the needs of the elderly. They are frequently excluded from clinical trials solely on the basis of age, and physicians may refrain from offering aggressive treatments under the assumption that elderly patients cannot physically handle adverse side effects (Marcusen & Clark, 2001).

Multiple losses in many areas (social, financial, and physical) are not uncommon for elderly adults. Cancer challenges an already limited social and instrumental support network. As adults age, friends and family die or move away, leaving them to face cancer alone. With increasing mobility of families, elder adults are less likely to live near extended family and therefore are less able to rely on them for help. For families, the loss of an elderly member to cancer may be the family's first significant loss. The death of a grandparent can be a traumatic event for children, especially for younger children who do not yet understand death or disease. The death of one's parents can leave adults feeling vulnerable and alone, symbolically marking them as the next to face illness and death.

Financial losses, including those associated with decreases in postretirement fixed incomes, and benefits, limit resources available to elderly adults that might have been useful to cope with a cancer diagnosis. Difficulty paying for treatments not covered by Medicare, difficulty finding transportation to and from treatment facilities, and the need for help with normal daily routines are frequent challenges. When people don't have medical insurance or are underinsured, they frequently go bankrupt paying for cancer treatments or are forced to wait on long waiting lists for treatments covered by public aid. For those who do qualify for Medicare, only standard treatments are covered. It is incumbent on the oncology social workers to stay current with these issues since they frequently change as new state and federal policies are implemented.

Physical losses, both in general and those associated with cancer treatment, are common for the elderly, limiting independence and mobility. Among these losses are changes in sexuality and self-image, topics frequently ignored or avoided by health-care professionals and well-meaning family members (Rohan, Berkman, Walker, & Holmes, 1994; See Chapter 12 on Sexuality). The loss of hair, a breast, or the possibility of an erection can be devastating. Given these changes, it is understandable that elderly adults are at great risk for depression. Depression in the elderly, however, is frequently either misdiagnosed as dementia or considered part of the natural process of aging, preventing elderly adults from receiving appropriate treatment (Marcusen & Clark, 2001).

As adults age, they experience a greater risk of multiple diagnoses and are frequently required to manage multiple treatment regimens. Older adults may miss early cancer warning signs, mistaking symptoms for general aches

and pains of aging or as symptoms of a different disorder. If cancer is not detected until it is more advanced, it is less likely to be successfully treated. An elderly adult may be responsible for ill spouses or adult children while coping simultaneously with their own declines in functioning. Given limited financial resources and potentially limited health literacy, older adults may use medications improperly or try to stretch their supply, thereby inadequately treating their cancer or associated pain. While many elderly adults experience chronic pain, it is frequently undetected and untreated (Rohan et al., 1994). In these situations, social workers can advocate on behalf of their clients to physicians, facilitate discussions with physicians to secure adequate pain medication, and be alert for signs of depression.

One major change in physician patient relations over the past few decades is the expectation that patients take more control in choosing a course of action to fight cancer. While this provides patients with more power in the face of an overwhelming disease, many elderly adults are not accustomed to such self-advocacy and prefer to maintain a more traditional relationship with doctors, accepting their recommendations (Marcusen & Clark, 2001). Elderly patients, unaccustomed to the new consumer oriented health-care movement, may see the physician as expert and authority. They may even feel uncomfortable with specialists, preferring the counsel of family physicians. This can lead to uncoordinated service delivery and poor care. Social workers can be instrumental with elderly clients facing cancer by conducting thorough assessments addressing available support networks and resources as well as depression and pain. Familiarity with Medicare regulations and connections with community programs will help support elderly clients in their own communities, preserving autonomy and dignity.

## CONCLUSION

Social work in oncology presents a unique challenge. The direct practice work with patients and their families is frequently both physically and emotionally taxing and, despite our best efforts, the work does not make cancer go away. As families require ongoing intervention and consultation, social workers build long-term relationships with clients, many of whom will die. Much of the work involves traveling with clients and families down treacherous roads, aiding them in sorting through existential and ethical dilemmas about the quantity versus quality of life. The results of social work efforts are often unseen, akin to planting a seed for families that will grow long after contact with them is terminated, either through cure or death. This underscores the need for adequate self-care and ongoing peer support.

Self-advocacy, a long-time cornerstone of social work practice, is essential for social workers in oncology to survive in the field, both personally and professionally (Stearns, 2001). Downsizing is common in hospital social work departments, and as resources become scarce for the oncology social worker, resources become inaccessible for cancer patients. Institutional and public advocacy on behalf of the profession and our clients is essential to maintaining adequate and high-quality services. Political activity and policy development, particularly in partnership with national organizations continues to be a powerful tool for change, both in improving the lives of our clients and advancing the profession.

## SUGGESTED LEARNING EXERCISE

### OUT-OF-THE-HAT SUPPORT GROUP

One common psychosocial intervention to help people coping with cancer is the support group. These groups are frequently composed of participants coping with different types of cancer at varied stages. Group members bring unique family and work concerns to the group for consideration. The role of the oncology social worker with this intervention is to provide a safe place for participants to name these concerns and to find common elements in their stories to facilitate connections.

For this exercise, select six students from the class to role play a session of such a support group. Six roles, including group facilitator and five group participants, will be written on slips of paper and placed in a hat. Group participant slips should include basic cancer and demographic information. The student facilitator should not take on a role, but should come to the mock-up with her own personal history and lead the group as she would in any real clinical setting. Each student will pull one slip of paper from the hat and will act out that role for 10 minutes in the mock-up support group. Once the role play is complete, the student should have an additional 10 minutes to process her experience of leading, participating in, or observing the interaction, providing feedback to each other and processing any concerns.

For the Instructor: This activity can be modified to address different populations, for example distressed caregivers, children with cancer, or bereaved adolescents.

## SUGGESTED RESOURCES

A host of resources are available for oncology social workers, including books, magazines, audiovisual materials, telephone hotlines, Internet web sites, and chat groups. These resources can be used both by social workers and by clients to provide reliable information and support about cancer, treatments, and recovery. Below is a short list of national organizations and web sites that provide reliable information and support for oncology social workers and their clients.

### ONCOLOGY SOCIAL WORK SUPPORT ORGANIZATIONS

- American Psychosocial Oncology Society ([www.apos.org](http://www.apos.org))
- Association of Oncology Social Work ([www.aosw.org](http://www.aosw.org))
- Association of Pediatric Oncology Social Worker ([www.aposw.org](http://www.aposw.org))
- International Psycho-Oncology Society ([www.ipos.org](http://www.ipos.org))
- Society of Behavioral Medicine ([www.sbm.org](http://www.sbm.org))

### NATIONAL CANCER ORGANIZATIONS

- American Cancer Society ([www.acs.org](http://www.acs.org))  
(800) ACS-2345
- Cancer Care, Inc. ([www.cancercare.org](http://www.cancercare.org))  
(800) 813-HOPE
- National Cancer Institute ([www.cancer.gov](http://www.cancer.gov))  
(800) 4-Cancer

WEB SITES

- American Society of Clinical Oncology ([www.asco.org](http://www.asco.org))  
Association of Cancer Online Resources ([www.acor.org](http://www.acor.org))  
Cancer News ([www.cancernews.com](http://www.cancernews.com))  
National Center for Complimentary and Alternative Medicine ([nccam.nih.gov](http://nccam.nih.gov))  
National Coalition for Cancer Survivorship ([www.cansearch.org](http://www.cansearch.org))  
Oncolink at the University of Pennsylvania Cancer Center ([www.oncolink.org](http://www.oncolink.org))

GLOSSARY: EXCERPTS FROM THE  
AMERICAN CANCER SOCIETY

- Adenoma:** A noncancerous tumor.
- Alopecia:** Hair loss.
- Antiemetic:** A drug that prevents or relieves nausea and vomiting, common side effects of chemotherapy.
- Basal cell carcinoma:** The most common nonmelanoma skin cancer. It begins in the lowest layer of the epidermis, called the basal cell layer. It usually develops on sun-exposed areas, is slow-growing and is not likely to spread to distant parts of the body.
- Biopsy:** The removal of a sample of tissue to see whether cancer cells are present.
- Bone marrow aspiration and biopsy:** A procedure in which a needle is placed into the cavity of a bone to remove a small amount of bone marrow for examination.
- Bone marrow transplant:** A treatment used when cancer is advanced or has recurred, or for leukemia or lymphoma. A portion of the patient's or donor's bone marrow is withdrawn, cleansed, treated, and stored. The patient is given high doses of chemotherapy to kill the cancer cells. The cleansed marrow is given by transfusion (transplanted) to rescue the patient's immune defenses.
- BRCA1/BRCA2:** Genes which, when damaged (mutated), place a woman at greater risk of developing breast and/or ovarian cancer, compared with women who do not have the mutation.
- Carcinogen:** Any agent—chemical, physical or viral—that causes cancer. Examples include tobacco smoke and asbestos.
- Carcinoma:** A malignant tumor that begins in the lining layer (epithelial cells) of organs. At least 80% of all cancers are carcinomas.
- Chemoprevention:** Prevention or reversal of disease using drugs, chemicals, vitamins, or minerals, such as Tamoxifen for breast cancer prevention.
- Chemotherapy:** Treatment with drugs to destroy cancer cells.
- Clinical trials:** Before a new treatment is used on people, it is studied in the lab. If lab studies suggest the treatment works, it is tested for patients. These human studies are called clinical trials.
- Gene therapy:** A treatment in which defective genes are replaced with normal ones.
- Genetic testing:** Tests performed to see if a person has certain gene changes known to increase cancer risk.
- Immunosuppression:** A state in which the ability of the body's immune system to respond is decreased. This condition may be caused by certain cancer

therapies, such as cancer-cell killing (cytotoxic) drugs, radiation, and bone marrow transplantation.

**Immunotherapy:** Treatments that promote or support the body's immune system response to a disease such as cancer.

**Leukemia:** Cancer of the blood or blood-forming organs. People with leukemia often have a noticeable increase in white blood cells (leukocytes).

**Lumpectomy:** Surgery to remove the breast tumor and a small amount of surrounding normal tissue.

**Lymphoma:** A cancer of the lymphatic system, a network of thin vessels and nodes throughout the body that fight infection. The two main types of lymphoma are Hodgkin's disease and non-Hodgkin's lymphoma. The treatment methods for these two types of lymphomas are very different.

**Mammogram:** An x-ray of the breast; method of finding breast cancer that can't be felt.

**Mastectomy:** Surgery to remove all or part of the breast and sometimes other tissue.

**Melanoma:** A cancerous (malignant) tumor that begins in the cells that produce the skin coloring (melanocytes). Melanoma is almost always curable in its early stages.

**Metastasis:** The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.

**Palliative treatment:** Treatment that relieves symptoms, such as pain, but is not expected to cure the disease.

**Primary site:** The place where cancer begins. Primary cancer is usually named after the organ in which it starts.

**Prognosis:** A prediction of the course of disease.

**Radiation therapy:** Treatment with high-energy rays (such as x-rays) to kill or shrink cancer cells. The radiation may come from outside of the body (external radiation) or from radioactive materials placed directly in the tumor (internal or implant radiation).

**Recurrence/relapse:** Cancer that has come back after treatment.

**Remission:** Complete or partial disappearance of the signs and symptoms of cancer in response to treatment; a remission may not be a cure.

**Sarcoma:** A malignant tumor growing from connective tissues, such as cartilage, fat, muscle, or bone.

**Staging:** Staging is the process of finding out how far the cancer has spread. The TNM system is the one used most often. T describes the size of the tumor, and whether the cancer has spread to nearby tissues and organs. N describes how far the cancer has spread to nearby lymph nodes. M shows whether the cancer has spread (metastasized) to other organs of the body. Letters or numbers after the T, N, and M give more details about each of these factors. In general, the lower the number (stage 0/I), the less the cancer has spread. A higher number, such as stage IV (4), means a more serious, wide-spread cancer.

**Stem cell and stem cell transplant:** A variation of bone marrow transplantation in which immature blood cells called stem cells are taken from the patient's blood and later, in the lab, stimulated with growth factors to produce more stem cells which are returned to the patient by transfusion.



**Thanatology:** Study of the social and psychological aspects of death and dying.  
**Tumor:** An abnormal lump or mass of tissue. Tumors can be benign (not cancerous) or malignant (cancerous).

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## CHAPTER 18

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# Social Work and Chronic Disease: Diabetes, Heart Disease, and HIV/AIDS

WENDY AUSLANDER and STACEY FREEDENTHAL

**T**HIS CHAPTER DESCRIBES direct practice issues that increasingly challenge social workers who work with persons who have a chronic disease. Rates of chronic disease continue to increase. Psychosocial problems often accompany or arise from chronic disease. Yet, people with chronic disease face many difficulties in maintaining complex and burdensome treatment regimens. As members of the health-care team with expertise in mental health and behavioral issues, social workers are in a unique position to help people with a chronic disease. This chapter provides a discussion of critical direct practice issues for social workers who work with chronically ill individuals.

First, we provide an overview of the epidemiology of heart disease, diabetes, and HIV/AIDS, three common diseases that social workers encounter within health-care and community settings. Second, we describe a systematic practice model for social workers to promote patient adherence to treatment. Third, we review strategies for social workers to enhance patient recall of information and instructions in their role as educators; and finally, we describe the relationship between mental health problems and chronic disease. There are many other direct practice issues that are important for social workers working with persons with chronic disease, such as family and individual coping, social support, developmental issues as they relate to illness, and the economic and cultural factors that influence disease management, to name a few. Many of these issues are discussed in detail elsewhere in this *Handbook*.

### CHAPTER OBJECTIVES

- To be knowledgeable of the epidemiology including racial and ethnic disparities of heart disease, HIV/AIDS, and diabetes in the United States.
- To be able to identify and assess psychosocial factors that influence adherence to treatment among individuals with chronic disease.

- To be able to incorporate a systematic model of adherence counseling in their practice with individuals with chronic disease.
- To understand the importance of communication techniques in patient education and adherence counseling with individuals with chronic disease.
- To understand the relationship between mental health and chronic disease.

### CURRENT TRENDS IN CHRONIC DISEASE CARE

Significant changes in the health status of Americans have occurred within the past century due to some relatively recent trends. The first trend is that individuals are living longer than ever before. The average life span in the United States increased by 27 years in the past century—from 49.2 years in 1900 to 76.5 years in 2000 (Guyer, Freedman, Strobino, & Sondik, 2000)—largely due to public health measures such as vaccinations, antibiotics, and other methods of controlling infectious diseases (Centers for Disease Control and Prevention [CDC], 1999a). A second trend is the increase in the number of individuals living with chronic diseases due in part to advances in medical treatment and technology and the increasing average life span. Third, chronic diseases have replaced infectious diseases as the leading causes of death in the United States (Guyer et al., 2000). For example, in 1900, the top causes of death were pneumonia, tuberculosis, and intestinal problems such as diarrhea (CDC, 1999b). Combined with diphtheria, these acute diseases accounted for one third of all deaths in the United States a century ago (CDC, 1999b). Today, heart disease, diabetes, and AIDS are chronic diseases that are among the top causes of death. Although still incurable, they often respond to medications, surgery, or other types of medical management.

The increase in chronic disease in the United States has led to a major shift from viewing individuals as consumers of health care to seeing them for what they really are: *providers* of health care. Most of the responsibility for the prevention and management of chronic disease lies with the patient and the patient's family. Individuals with chronic disease and their family members are the members of the health-care team who take responsibility for the day-to-day activities necessary for the treatment regimen. Because of this shift in perspective, there has been an increased interest in the past 2 decades in understanding how to promote patient adherence to treatment. In particular, diabetes, HIV/AIDS, and heart disease are chronic diseases that, once diagnosed, demand adherence to complex and challenging treatment regimens. Prevention of these diseases involves behavioral changes such as weight loss, exercise, dietary changes, and reducing sexual risk behaviors, all of which may be difficult to maintain in the long term.

In addition to the importance of patient adherence in chronic disease prevention and management, other issues related to chronic disease are also important for social workers to understand. First, there are no known cures for chronic diseases such as diabetes, heart disease, and HIV/AIDS, and they are usually progressive in nature. Unlike some disabilities or acute illnesses, chronic diseases fluctuate in symptoms and disease-related complications. Disease-specific complications among individuals with chronic disease can be viewed as "predictable crises" (Hamburg & Inoff, 1983) in that they can cause a state of anxiety and disequilibria in a manner that is expected, given what we know about how the disease progresses. Second, because of the progressive nature of chronic diseases, the patient and family must adjust to continual treatment changes. For example,

new medications are continually being developed that often subject the patient to new side effects. The past few decades have seen new medical technologies for patients to manage diabetes (e.g., insulin infusion pumps and home glucose monitoring), yet, they all include some costs (e.g., financial and physical pain) along with the benefits they provide for patients. Last, because chronic diseases usually continue throughout the patient's lifetime, developmental and lifestyle changes (such as pregnancy, puberty, divorce, or college) often influence or pose additional challenges to the person with chronic disease. Each of these challenges (i.e., disease, treatment regimes, and developmental changes), unique to chronic diseases, offers opportunities for social work intervention to promote positive adaptation and management behaviors among patients.

### EPIDEMIOLOGY OF DIABETES, HEART DISEASE, AND HIV/AIDS

Social workers encounter people with heart disease, diabetes, and HIV/AIDS in virtually all health-care settings, including emergency rooms, hospitals, outpatient clinics, community centers, hospices, nursing homes, and rehabilitation centers. Before we describe some practice issues for social workers who work with individuals who have been diagnosed with diabetes, heart disease, and HIV/AIDS, an overview of disease rates, risk factors, racial and ethnic disparities, and other information related to these three major killers in the United States and worldwide is presented (see Table 18.1 for an overview).

#### HEART DISEASE: A LEADING KILLER

Heart disease is an umbrella term for any of several cardiac conditions, including coronary artery disease, congestive heart failure, and heart attack. Heart disease itself is a type of cardiovascular disease, along with hypertension and stroke. Stroke also is a major leading cause of death in the United States (CDC, 2004b) and results from the brain being deprived of oxygen, usually due to plaque in the arteries. Although stroke and hypertension are themselves important public health problems, this section focuses only on chronic diseases directly related to the heart (see Table 18.2).

*Gender and Heart Disease* Many people mistakenly believe that heart disease primarily affects men. In fact, heart disease is the major cause of death among women (CDC, 2004b). Men have experienced a decline in heart fatalities in recent years, but rates continue to increase among women (American Heart Association, 2002). Women's hormones, particularly estrogen, appear to protect many women from heart disease until after menopause, although a causal relationship is not certain (Barrett-Connor, 2003). However, research indicates that hormone replacement therapy for postmenopausal women actually increases the risk of heart disease (Manson et al., 2003).

*Racial and Ethnic Disparities in Heart Disease* Like diabetes and AIDS, heart disease disproportionately affects certain racial and ethnic minority groups. Of the 700,000 people who died of heart disease in the U.S. general population in 2002, 17.3% were younger than 65. Yet among American Indians, 33.8% of people who



**Table 18.1**  
Epidemiology of Chronic Diseases in the United States

	Heart Disease	Diabetes	HIV/AIDS
Deaths (in 2001) <sup>a</sup>			
–Ranking	1	6	19 <sup>b</sup>
–Number	700,142	71,372	14,175
Percentage in the United States	29.0%	3.0%	0.6%
People living with disease	18 million <sup>c</sup>	13.4 million (6.6%) <sup>d</sup> to 16.7 million (8.3%) <sup>e</sup>	HIV: 800,000 <sup>e</sup> AIDS: 362,827 <sup>d</sup>
Possible symptoms	Chest pain or tightness Shortness of breath Fluid retention	Excessive thirst Frequent urination Extreme hunger Unusual weight loss Fatigue Blurry vision	Rapid weight loss Recurring fever or night sweats Profound fatigue Swollen lymph glands Chronic diarrhea Pneumonia
Risk factors	Diabetes High cholesterol High blood pressure Smoking Physical inactivity Obesity Older age Family history	<i>Type 2 only:</i> Obesity Physical inactivity Older age Family history Black, Hispanic, or American Indian/ Alaska Native High blood pressure	Unprotected sex Injection drug use
Preventive measures	Exercise Diet rich with fiber, fruits, & vegetables No smoking	<i>Type 2 only:</i> Weight control Healthy diet	Condom use Clean needles Blood donor screening

<sup>a</sup>From *Web-Based Injury Statistics Query and Reporting System (WISQARS)*, by Centers for Disease Control and Prevention, 2004b, retrieved December 17, 2005, from <http://www.cdc.gov/ncipc/wisqars>.

<sup>b</sup> HIV ranks as the 6th leading cause of death for the 15 to 54-year-old age group.

<sup>c</sup>From “Prevalence of Diabetes and Impaired Fasting Glucose in Adults: United States, 1999–2000,” by C. C. Cowie, K. F. Rust, D. Byrd-Holt, M. S. Eberhardt, S. Saydah, L. S. Geiss, et al., 2003, *Morbidity and Mortality Weekly Report*, 52, pp. 833–837.

<sup>d</sup>From *Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2002* (DHHS Publication No. PHS 2004-1550), by U.S. Department of Health and Human Services, 2004, Hyattsville, MD: Author.

<sup>e</sup>From Centers for Disease Control, 2001, *HIV/AIDS Surveillance Report*, 13, 1–44.

**Table 18.2**  
Major Types of Heart Disease

Name	Description
Coronary artery disease	Arteries become hardened and narrowed by plaque (arteriosclerosis), decreasing blood flow to the heart and oxygen to the heart muscle.
Acute myocardial infarction ("heart attack")	A blood clot cuts off blood to part of the heart, resulting in damage to the heart muscle and sometimes death.
Congestive heart failure	The heart fails to pump blood effectively, resulting in shortness of breath, fluid retention, and fatigue.
Congenital heart defects	The heart or blood vessels around the heart failed to develop properly at birth.
Cardiomyopathy	Weakening of the heart muscle.
Angina	Chest pain or discomfort caused by the heart not getting enough blood, usually from arteriosclerosis (hardening of the arteries).

died of heart disease were younger than 65 (CDC, 2004b). For African Americans and Hispanic Americans, the rates were 31.5% and 23.5%, respectively (Oh et al., 2004). The reasons for the disparities are not fully understood but may include such factors as differences in access to medical and emergency care, diet, exercise, risk behaviors (such as smoking), and health behaviors (such as checking blood pressure regularly). As examples, the proportion of American Indians who smoke is double that of White Americans; African Americans are more likely than White Americans to have high blood pressure; and African Americans, American Indians, and Hispanic Americans are more likely than White Americans to lack health insurance coverage (Bolen, Rhodes, Powell-Griner, Bland, & Holtzman, 2000). Physician bias may also contribute to racial and ethnic disparities in heart disease fatalities. In an experiment using videotaped, hypothetical case scenarios, physicians were almost twice as likely to recommend a heart procedure to White American people and men than to African Americans and women despite identical symptoms among all the characters (Schulman et al., 1999).

#### DIABETES: A NEW EPIDEMIC

Diabetes mellitus affects the body's ability to metabolize blood glucose (sugar). A healthy person's pancreas produces sufficient insulin for cells to absorb and convert food into blood sugar. With diabetes, the person's body either fails to use insulin properly or produce it at all. Many people with diabetes must therefore limit their sugar intake or take insulin by either giving themselves injections or using an insulin infusion pump. When diabetes is uncontrolled and blood sugar levels get too high (hyperglycemia), the individual may experience shortness of breath, nausea, vomiting, excessive thirst, and a life-threatening, precoma condition called diabetic ketoacidosis. With controlled diabetes, there is always the

risk of hypoglycemia or low blood sugar caused by too much insulin or medication. Symptoms and signs of hypoglycemia include shakiness, irritability, heart palpitations, hunger, and sweating. Left untreated, severe hypoglycemia can lead to loss of consciousness, seizures, and coma.

Most people with diabetes live and function many years with the disease. Many people with diabetes are not even aware they have it because the onset of symptoms is gradual. Yet, diabetes can take an enormous toll on a person's health and quality of life. People with diabetes commonly develop an array of complications that can include cardiovascular disease, vision problems (including blindness), amputations, kidney failure, and nerve damage. Ultimately, diabetes can be fatal. It ranked as the sixth leading cause of death in the United States in 2001, resulting in 71,372 deaths (CDC, 2004b). Mortality rates underestimate the true extent of diabetes' lethality because the damage it exacts on lungs, tissues, and organs contributes to other major causes of death: heart disease, stroke, and kidney disease, to name a few (National Center for Health Statistics [NCHS], 2004). Two out of three people with diabetes eventually die of heart disease or stroke (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2004).

*Types of Diabetes* There are four major types of diabetes. *Type 1 diabetes*, formerly called juvenile diabetes, primarily occurs in children and young adults and accounts for 5% to 10% of all diabetes cases. Type 1 diabetes is an autoimmune disease, whereby a person's immune system inappropriately attacks necessary tissues. With type 1 diabetes, the immune system destroys the cells that produce the hormone insulin, which metabolizes blood sugar. People with type 1 diabetes must take insulin every day, sometimes before every meal, using injections or an insulin infusion pump.

*Type 2 diabetes* accounts for 90% to 95% of all diabetes cases (NIDDK, 2004). With type 2 diabetes, formerly called adult-onset diabetes, the body may still produce insulin but the body's cells cannot absorb it. Eventually, the pancreas may lose the ability to produce insulin altogether. This type of diabetes is frequently associated with being overweight and physically inactive. Many people with type 2 diabetes control their blood sugar by managing their diet, losing weight, exercising regularly, and taking oral medications to control their blood sugar. Only one-third of people with type 2 diabetes require insulin, either by itself or in combination with medication (CDC, 2004a).

*Gestational diabetes* is a form of glucose intolerance that occurs in about 14% of women during pregnancy (Kim, Newton, & Knopp, 2002). The condition typically disappears after childbirth, but various studies have shown that, depending on the length of time that passes, 2.6% to 70% of women with gestational diabetes develop type 2 diabetes (Kim et al., 2002).

*Other types of diabetes* include conditions caused by genetic defects, drug use, infection, or less common forms of autoimmune illness (American Diabetes Association, 2004). These types of diabetes are the least common, making up only 1% to 5% of diabetes cases in the United States (NIDDK, 2004).

*Epidemic Rates of Diabetes* Diabetes has been diagnosed in more than 13 million people in the United States, and an additional 5.2 million people are believed to have diabetes without being aware of their condition (NIDDK, 2004). Diabetes

rates have increased substantially in recent years, including a 33% increase in the 1990s (Mokdad et al., 2000). Rates are increasing so rapidly nationally and worldwide that the World Health Organization (WHO) regards it as an epidemic with premature deaths of a similar magnitude, though less recognized, to HIV/AIDS (WHO, 2004). More than 3 million people worldwide die from diabetes or diabetic complications each year (WHO, 2004). About 171 million people worldwide have been diagnosed with diabetes, and the number is expected to increase to 360 million over the next 25 years (WHO, 2004). The number of Americans with diabetes is expected to grow to 29 million by 2050 (Boyle et al., 2001).

*Risk Factors for Diabetes* Type 2 diabetes is considered to be largely preventable. The increasing rates of type 2 diabetes parallel increases in obesity, sugar and fat consumption, and physical inactivity in today's society (Mokdad et al., 2001). Diabetes is almost twice as common in developed countries than in developing countries (Black, 2002), reflecting the excess fat consumption and lack of exercise that often accompany affluence.

*Racial and Ethnic Disparities in Diabetes* People from certain racial and ethnic minority groups are especially vulnerable to diabetes (Black, 2002). Compared to non-Hispanic White populations, Hispanic people in the United States are 1.5 times more likely to have diabetes, African Americans are 1.6 times as likely, and American Indians and Alaska Natives are 2.3 times as likely (NIDDK, 2004). For example, almost 1 in 4 African American women between the ages of 65 and 74 has diabetes (Tull & Roseman, 1995). In some areas of the country, more than 1 in 3 American Indians has type 2 diabetes (Lee et al., 2000). Pima Indians in southern Arizona have the highest rate of diabetes in the world, with 1 of 2 tribal members diagnosed with the disease (Black, 2002; Knowler, Saad, Pettitt, Nelson, & Bennett, 1993). Minorities' higher rates of diabetes are attributed to lower access to health-care and genetic differences in glucose tolerance, in addition to the other primary risk factors of diabetes, including higher rates of obesity and inactivity (Black, 2002).

Racial and ethnic minorities in the United States also tend to suffer greater negative effects from diabetes than White Americans. For example, compared to White Americans in the United States, death rates due to diabetes among African Americans and Hispanic Americans are twice as high and are three times as high among American Indians (CDC, 2000).

#### HIV/AIDS: FROM TERMINAL ILLNESS TO CHRONIC DISEASE

The first case of acquired immunodeficiency syndrome (AIDS) was reported in 1981 in the United States (National Institute of Allergy and Infectious Diseases [NIAID], 2003). Within just 4 years, AIDS afflicted 16,000 people in the United States, 8,000 of who died (Center for Infectious Diseases, 1985). A diagnosis of human immunodeficiency virus (HIV) or AIDS used to be a virtual death sentence. The median amount of survival time left for a person in the United States newly diagnosed with AIDS in the mid-1980s was 11.6 months (Jacobson et al., 1993). No effective treatments existed, and patients' suppressed immune systems made them vulnerable to dying from infections not typically deadly among young individuals, such as pneumonia.

The loss of lives in the United States slowed down in 1996, when patients began taking potent medications called highly active antiretroviral therapy (HAART). This therapy combines different types of medications in what is frequently called a *drug cocktail*. The medications in a drug cocktail are reverse transcriptase inhibitors, which prevent the virus from making copies of itself, and protease inhibitors, which control the enzyme in HIV that spreads infectious viral particles. Antiretroviral therapy does not cure HIV or AIDS, but it does reduce the amount of virus and prolong both the quality and length of lives. After the introduction of antiretroviral therapy in the United States, deaths from HIV declined dramatically—from 31,130 deaths in 1996 to 16,516 in 1997 (CDC, 2004b). The same year, HIV/AIDS fell out of the top 10 causes of death.

In recent years, AIDS statistics have held steady in the United States, causing about 14,000 deaths annually and vacillating between the 18th and 19th leading cause of death (CDC, 2004b). Almost all deaths from AIDS occur in younger people; among youth and adults aged 15 to 54 years old, HIV is the sixth leading cause of death in the United States (CDC, 2004b).

*Definitions* The HIV and AIDS are two different but overlapping entities. HIV infects the body's immune system, in particular cells called T4 lymphocytes (T cells), which protect against infection and other threats. AIDS is the most advanced stage of HIV infection and is defined as a specific group of diseases or conditions that severely suppress the body's immune system (CDC, 2001). An HIV-positive person is diagnosed with AIDS when he or she has fewer than 200 T cells per cubic millimeter of blood, in comparison to levels of more than 1,000 in healthy adults (NIAID, 2003). It can take 10 or more years for an HIV-positive person to develop AIDS (NIAID, 2003). This lag time makes the virus especially dangerous because infected individuals may unknowingly pass HIV on to others.

HIV is transmitted through contact with infected blood, which can occur from sexual contact, sharing needles, or blood transfusions. Women also can pass the virus on to their babies during pregnancy or birth. The use of condoms during sexual intercourse prevents the transmission of HIV. Public health approaches to preventing HIV include screening blood donations, promoting nonsharing of needles, and distributing free condoms on many college campuses.

*AIDS Worldwide: The Leading Cause of Death* At least 20 million people worldwide have died from AIDS since the very first case was reported fewer than 25 years ago (Joint United Nations Program on HIV/AIDS [UNAIDS], 2004). The devastation is enormous, particularly in southern Africa. In 2003 alone, 2.2 million people in southern Africa died of AIDS (UNAIDS, 2004). New, potent antiretroviral AIDS medications are financially out of reach to people in these poorer countries. Furthermore, rates of HIV continue to increase. In 2003, an estimated 4.2 to 6.3 million people in the world acquired HIV (UNAIDS, 2004)—meaning that about 14,000 people around the world are infected with HIV each day (Lampthey, 2002).

Almost all new HIV infections (95%) occur in the world's poor countries and they most commonly spread through heterosexual contact. In Africa, more than 80% of HIV infections among women result from heterosexual contact, and the remainder are transmitted from mother to child or blood transfusions (Lampthey, 2002).

*Gender and AIDS* For many years, AIDS was identified in the United States, often pejoratively, as a “gay disease” (Herek & Glunt, 1988) because the majority of AIDS-related cases occurred among men who had sex with men without using a condom to protect against sexually transmitted diseases (CDC, 2001). Yet, even from its earliest days, the disease also claimed the lives of women who had sex with HIV-positive men, infants and children born to AIDS-infected mothers, people who received tainted blood transfusions, and injection drug users who shared contaminated needles.

The disease still disproportionately afflicts men who have sex with men in the United States, but that is changing. About 10% of men and 60% of women living with AIDS in the United States contracted HIV through heterosexual contact (CDC, 2001). Nationally, HIV is more common among men than women. Worldwide, almost half of all people with AIDS are female, and heterosexual contact is the primary means of infection (UNAIDS, 2004). For example, 75% of young people infected with HIV in southern Africa are women and girls (UNAIDS, 2004). Gender inequalities, including violence against women and men’s refusal to use condoms, are blamed for women’s disproportionate burden of the disease in Africa (UNAIDS, 2004).

*Racial and Ethnic Disparities in HIV/AIDS* In wealthier, industrialized countries such as the United States, deaths from AIDS have dropped for all racial and socioeconomic groups since antiretroviral therapies began, but the progress has been smaller for some vulnerable groups. The decline in deaths was lowest among African American women and highest among White American men and residents of more affluent areas (Karon, Fleming, Steketee, & DeCock, 2001). Furthermore, HIV rates are increasing among African Americans, Hispanic Americans, Asian/Pacific Islanders, and American Indians (CDC, 2001). Although African Americans make up 13% of the U.S. population, 42% of the people living with AIDS in 2001 were African American (CDC, 2001). A study of 25 states that keep track of HIV cases found that 51% of men and 71% of women newly diagnosed with HIV were African American. The disparities largely reflect differences in HIV testing patterns and access to new drugs (Karon et al., 2001). Minorities, women, and low-income people may be less likely to have access to and receive effective therapy for HIV and AIDS (Andersen et al., 2000).

*AIDS in the United States: A Continuing Public Health Problem* Although more people with HIV and AIDS in the United States survive and function well with antiretroviral therapy, the conditions still represent a major, national public health problem in this country (Arias, Anderson, Kung, Murphy, & Kochanek, 2003). In 2002, 14,095 people died of AIDS or other HIV-related complications (CDC, 2004b). Even though deaths from AIDS have declined, the number of HIV cases reported each year continues to grow (Karon et al., 2001). HIV primarily affects young people, especially minorities. Medical researchers caution that the new drug therapies have resulted in treatment-resistant types of HIV. Even when the drug cocktails are effective and accessible, many people fail to take them properly because of complicated dosing regimens and side effects (Fleming, Wortley, Karon, DeCock, & Janssen, 2000). Immediate side effects can include rash, recurrent or chronic diarrhea, vomiting, and fatigue, and long-term effects can include pancreatic, liver, and kidney dysfunction (Sax & Kumar,



2004). It is also believed, though not thoroughly documented, that the new, effective treatments lead to complacency among high-risk groups who used to protect themselves against HIV infection (Fleming et al., 2000). For these reasons, social workers in health-care settings will continue to encounter people who are HIV-positive or living with AIDS.

### ADHERENCE TO TREATMENT REGIMENS

The successful management of diabetes, heart disease, and HIV/AIDS depends largely on the extent to which patients adhere and take responsibility for their treatment regimens. As such, facilitating patient adherence to medical regimens has emerged as an important function for the social worker on the health-care team for individuals with chronic disease. Adherence is defined broadly as the extent to which a patient's behavior corresponds with medical advice (Meichenbaum & Turk, 1987). Although *adherence* and *compliance* are sometimes used interchangeably, adherence implies an active and collaborative role with health-care professionals, whereas compliance connotes a more passive, submissive role. Treatment effectiveness for many chronic diseases, such as diabetes, heart disease, and HIV/AIDS, is strongly influenced by the patient's willingness and ability to adhere to a complicated medical regimen.

For example, the diabetes treatment regimen involves multiple daily insulin injections or use of an insulin infusion pump for type 1 diabetes or oral medications for type 2 diabetes, frequent daily blood glucose testing, adherence to a meal plan, and a regular exercise program. Adherence to treatment for heart disease involves diet and exercise as well as oral medications, blood pressure and lipid monitoring, and regular visits to the cardiologist for routine stress tests and electrocardiograms. For HIV/AIDS, adherence to preventive behaviors (e.g., use of condoms and clean needles) is necessary to reduce the risk of transmission or infection; once infected, adherence to treatment is critical for slowing progression and delaying complications of HIV. Current treatment guidelines for HIV recommend HAART, a complex regimen of usually 3 to 4 antiretroviral drugs (Deeks, Smith, Holodniy, & Kahn, 1997).

The magnitude of nonadherence to medical regimens has been studied for decades. In a review of 50 years of research across 569 studies, adherence ranged from 4.6% to 100%, with an average of 75.2% (DiMatteo, 2004). In this review, adherence was significantly higher in more recent smaller studies, those involving pharmacological treatment rather than modified health behaviors, and populations with greater resources such as higher education and income.

Many studies have examined the correlates or predictors of adherence among individuals with diabetes, such as familial, psychosocial, and demographic factors (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Auslander, Thompson, Dreitzer, White, & Santiago, 1997; Glasgow & Toobert, 1988; Jacobson et al., 1990). Results across several studies indicate that the degree of adherence to one aspect of the diabetic regimen is unrelated to adherence to other aspects of the regimen (Glasgow, Wilson, & McCaul, 1985). These data suggest that there are multiple influences on patient adherence and highlight the complexities involved in facilitating behavioral changes among individuals with chronic disease.

More recently, there has been an increase in studies on adherence to HAART in HIV-infected patients. This is due in part to the fact that effective treatment requires at least a 95% adherence rate to HAART required to reduce viral loads and

prevent drug-resistant HIV variants (Chesney, 2003). Because nonadherence among these patients can significantly increase the risk of death, studies have focused on the barriers to adherence as well as factors that promote adherence behaviors (Chesney, 2003; Garcia & Cote, 2003; Steele & Grauer, 2003). Identified barriers to adherence include complicated dosing schedules and food restrictions, medication side-effects, psychosocial issues (i.e., substance abuse, depression, stress), and unsupportive relationships with providers (Chesney, 2003).

#### A SYSTEMATIC MODEL OF ADHERENCE COUNSELING

Many studies have focused on interventions designed to improve adherence to treatment regimens, particularly in diabetes and HIV/AIDS (e.g., Anderson, Brackett, Ho, & Laffel, 1999; Smith-Rogers, Miller, Murphy, Tanney, & Fortune, 2001; Wysocki et al., 2000), yet few studies have specified the process of adherence counseling in detail. The adherence counseling approach described in this chapter has a cognitive-behavioral orientation and integrates classic works by Becker (1974; Becker & Maiman, 1980), Meichenbaum and Turk (1987), and Marlatt and Gordon (1985). This approach has been utilized by social workers and psychologists for patients in clinical research protocols that included newly diagnosed children with type 1 diabetes, adults following intensive medical regimens, and adolescents with poorly controlled diabetes (Auslander, 1993; Auslander, Bubb, Peelle, & Rogge, 1989; Bubb, Auslander, & Manthei, 1989; Lorenz et al., 1996). This approach to adherence counseling emphasizes the influence of individual, family, social, economic, and work factors in implementing a realistic treatment plan. As shown in Table 18.3, adherence counseling includes four distinct phases that the social worker implements: (1) Assessment and identification of adherence problems, (2) Planning the medical treatment regimen, (3) Facilitating behavioral change, and (4) Maintaining patient adherence.

#### PHASE 1: ASSESS AND IDENTIFY ADHERENCE PROBLEMS

The assessment phase focuses on those factors that are most likely to influence adherence. Clinical experience and health behavior research have identified several areas that are associated with a patient's willingness and ability to follow a treatment regimen (Marlatt & Gordon, 1985; Meichenbaum & Turk, 1987). These areas include social support, lifestyle, financial status, health beliefs, psychological well-being, past adherence history, and satisfaction with the treatment regimen (see Table 18.3). Assessment of these factors provides information that is important in developing a realistic treatment plan designed to increase the probability of regimen adherence.

*Social Support* The family assessment is designed to identify family strengths and risk factors associated with adherence. The family assessment should include: (a) the family's social and economic status; (b) the family's willingness to be supportive and their competence to do so (i.e., family member's disease knowledge, technical skills, ability to learn, problem-solving ability, and organizational skills); (c) family stressors such as divorce, remarriage, loss of a job, a new baby, or a death in the family; and (d) observation of family interactions to provide information about the family's ability to work together and resolve conflict. This is an

**Table 18.3**  
Adherence Counseling for Chronic Disease Management

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**Phase 1: Patient and Family Assessment**

Social support  
Lifestyle and daily schedule  
Psychological factors  
Health beliefs  
Prior adherence history and treatment satisfaction

**Phase 2: Planning the Treatment Regimen**

Promote a realistic medical regimen  
Encourage patient participation in regimen planning  
Facilitate communication  
Encourage joint decision making

**Phase 3: Facilitate Behavioral Change**

Initiate new behaviors  
–Translate treatment goals into behavioral goals  
–Encourage self-management strategies  
–Teach patients to plan for high risk situations  
Activate social support  
–Family support: Increase family involvement, promote shared responsibility  
–Strengthen emotional support  
–Social support outside of the family  
–Enhance patient’s ability to activate social and medical support

**Phase 4: Strategies for Long Term Adherence**

Develop skills for maintaining adherence  
Coping with lapses in adherence  
Increase accessibility to health care  
Reinforce positive health-care behaviors

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important area given the wealth of research that shows significant associations between family characteristics and adherence (Anderson et al., 1990; Glasgow & Toobert, 1988; Thompson, Auslander, & White, 2001a, 2001b). Patients spend a great deal of their time at work or school and, as at home, they need cooperation from those around them in order to create an environment that promotes adherence. Patients also need to have competent assistance in the case of a medical emergency. Therefore, it is crucial to assess the extent of support available from friends, teachers, coworkers, employers, and others outside of the family.

*Lifestyle/Daily Schedule* Assessment of a patient’s and family’s daily routine will frequently reveal conflicts between lifestyle and the treatment regimen that can undermine or prevent adherence. This assessment can be accomplished by asking patients to recall the events of a typical day, hour-by-hour from awakening to bedtime, as well as asking them to describe how weekends differ from weekdays. This methodology, a 24-hour recall, has been widely used in research to assess dietary adherence in diabetes and heart disease (Anding, Kubena, McIntosh, & O’Brien, 1996; Johnson, Perwien, & Silverstein, 2000). Often, knowledge of the small details of a patient’s life will lead to an understanding of major adherence problems.

*Psychological Factors* As discussed earlier in this chapter, several psychological problems have been associated with adherence to medical regimens: depression

(Anderson, Freedland, Clouse, & Lustman, 2001; Lustman et al., 2000; Starace et al., 2002), anxiety disorders (Anderson et al., 2002), eating disorders (Jones, Lawson, Daneman, Olmsted, & Rodin, 2000), and substance use (Arnsten et al., 2002). Therefore, it is critical to assess psychological factors since many of these conditions may adversely affect adherence.

*Health Beliefs* The Health Belief Model by Becker (1974; Becker & Maiman, 1980) suggests that patients' health-related decisions and behaviors are influenced more by personal medical experiences, beliefs, and attitudes than by recommendations from health-care professionals. It is important that the health-care team understand the patients' health beliefs so misinformation and misconceptions that could undermine adherence can be corrected. Becker's model points to several key assessment areas: (a) Patients' beliefs of whether the disease is serious enough to warrant the effort involved in following the treatment regimen; (b) Patients' beliefs about the probability of the treatment regimen improving the medical condition; and (c) Patients' beliefs about the likelihood that the benefits of treatment will outweigh the difficulties and inconveniences of adherence.

*Adherence History/Treatment Satisfaction* A review of the patient's past adherence performance is important since practitioners consider past adherence behaviors good predictors of future adherence. Adherence behavior patterns can be assessed by asking patients specific questions about how often they follow each aspect of their prescribed regimen. For example, the patient can be asked how frequently during the previous day, week, or month, he or she exercised. It should also be determined when and where adherence is most difficult. During the assessment of the patient's adherence history, the social worker can also identify why the patient did not follow a specific area of treatment. The social worker can determine if, for example, nonadherence resulted from the patient's misunderstanding of the prescribed regimen. In the assessment of previous adherence history, it is important to determine their satisfaction with adherence performance. If patients are dissatisfied with their performance, then they may already have a plan and be motivated to change adherence behaviors. In contrast, if they are nonadherent according to the assessment but satisfied with their performance, their readiness to change will be limited. This situation demands renegotiation of treatment goals between the health-care provider and patient, which is discussed in Phase 2.

## PHASE 2: PLAN THE MEDICAL TREATMENT REGIMEN

Social workers must take an active role in treatment planning as they often can enhance the plan's effectiveness and increase patient adherence by assuring that psychosocial and behavioral factors are not overlooked or disregarded. Several key aspects of the social worker's role in treatment planning are briefly examined.

*Promote the Development of a Realistic Medical Regimen* By encouraging patients and health-care professionals to utilize the social worker's adherence assessment, a medical regimen can be developed that is feasible in terms of the patient's real life situation. Patients are more likely to be adherent if the regimen is tailored to

the patient's lifestyle, behavioral changes are minimized, and convenience is enhanced (Chesney, 2003; DiMatteo, 2004).

*Encourage Patient Participation in Regimen Planning* Adherence can be enhanced by developing individualized medical regimens that reflect patient preference. It is important that the social worker urge the health-care team to actively involve the patient in treatment planning and to seriously consider the patient's desires and expectations. The social worker should ensure that the patient has been informed of all treatment options, including the risks and benefits of each option.

*Facilitate Communication* Several research studies have found positive correlations between a physician's communication style and the patient's comprehension, satisfaction, and adherence (Roter & Hall, 1997). Physicians and other health-care providers may communicate more effectively with patients after social workers consult with the health-care team regarding the patient's individual life demands and adherence difficulties. Patients, too, must be willing to listen to and understand their health-care providers. To ensure accuracy of understanding, social workers should encourage health professionals to routinely ask patients to restate important medical information and instructions. Misunderstandings can then be corrected. In the end of this chapter, we review strategies that social workers can use to enhance patient recall of information delivered.

*Encourage Joint Decision Making* Once effective communication is established, the social worker can encourage and guide health-care professionals in negotiating a treatment plan with the patient. Negotiation is important because the patient's treatment goals often differ from those of the health-care professionals. For example, in the case of diabetes treatment planning, the diabetes team might prescribe a treatment designed to normalize blood sugar levels when the patient's goal is to prevent uncomfortable episodes of low blood glucose, thus intentionally keeping blood sugars higher than normal. The patient may then be adherent in terms of behaviors to reach his goals but nonadherent from the perspective of the health-care professional.

### PHASE 3: FACILITATE BEHAVIORAL CHANGE

Patients with recently diagnosed chronic disease must often develop new behaviors and change established behaviors in order to implement the recommended treatment regimen. Strategies that can be used by social workers to facilitate behavioral change can be grouped into three categories: (1) Initiating new behaviors, (2) Activating social support, and (3) Enhancing the patient's ability to activate support.

*Initiating New Behaviors* Early success in the process of behavioral change reinforces and motivates the patient. The techniques described below are designed to ensure that patients feel a sense of accomplishment as soon as possible after they begin to establish new adherence behaviors (Meichenbaum & Turk, 1987). The first technique is to assist the patient in *translating treatment goals into behavioral goals*. Patients must understand exactly what new or changed behaviors are

required in order to achieve their treatment goals. They must plan specifically how, when, and where the new behavior(s) are to occur. If the treatment goal is to increase exercise, simply advising patients to exercise more frequently will not be as effective as guiding them in devising a plan specifying, for instance, the type of activity, exercise frequency, and when and where they are to engage in the activity. Meichenbaum and Turk (1987) warn that the plans should be moderately specific but not overly rigid for best results.

A second technique is to *encourage patients to use self-management strategies*. Once behavioral goals are set, patients can be encouraged to establish a daily self-monitoring or self-recording system. Changes seem easier to achieve when taken day by day. Daily monitoring or recording also reinforces the patients' efforts by giving them a sense of immediate achievement. In addition, information from self-monitoring forms can be used by the patient and health-care provider to more effectively manage the treatment regimen. Small changes are easier to make than big changes. Patients may be more successful if they graduate the treatment plan, that is, change their behaviors in a step-by-step fashion. For example, a patient who is instructed to exercise 5 times a week may be overwhelmed by the task. It may seem less daunting to the patient to begin by exercising twice per week, gradually adding more activity. Another self-management strategy is to structure the physical environment by organizing the home and worksite. This often entails encouraging the patient to make simple adjustments such as keeping tempting high fat foods out of the house, setting up an exercise mat in a convenient place, or keeping blood testing equipment in a convenient place. Last, *cueing* is another self-management strategy that has been successful in increasing patient adherence. Patients can be taught to use cues to prompt them to remember new behaviors. Patients can use routine events, such as a favorite television show or the evening news, as a prompt to take medication. Medication containers separated into daily doses are also helpful. Be creative, even humorous, in helping patients identify behavioral cues.

A third technique to foster the initiation of new behaviors is to teach the patient to *plan ahead for high-risk situations* (Marlatt & Gordon, 1985). During the assessment, the patient may have identified or given clues to behaviors, situations, events, or persons that are likely to interfere with adherence to the treatment regimen. Anticipating these obstacles to adherence and planning ways in which to manage them is a key strategy in initiating successful behavioral change. Role-play and rehearsal are useful in preparing patients to cope with the challenges of everyday living.

*Activate Social Support* Results of a wide range of studies strongly suggest that social support and social relationship have a positive effect on health, in part through health behaviors (Heaney & Israel, 1997). Strengthening and expanding the patient's support network, within the family and without, is an essential component of the third phase of adherence counseling.

Knowledge of family strengths and risk factors as revealed in the initial adherence assessment enables the social worker to focus interventions on areas where the need is greatest. In general, to activate effective family support, the social worker can encourage family involvement and competence, promote shared responsibility among family members, and strengthen the family's emotional sup-



port for the patient (Anderson et al., 1990; Glasgow & Toobert, 1988). To encourage family involvement and competence, it is crucial that the social worker encourage the health-care team to include family members in disease-related education and regimen planning, especially those members who play key roles in areas related to adherence. For example, family members who do the shopping and cooking must learn about the recommended diet for individuals with heart disease or diabetes and help the health-care team tailor the patient's diet to the at-home situation. In order to accomplish this type of involvement, classes or meetings must be scheduled at a time convenient not only for the patient and health-care team but for family members as well. If family members are reluctant to learn about the disease or seem hesitant about helping with the regimen, the social worker can talk with the family about the reasons for their reluctance to become involved. Do they fear medical procedures? Do they know how to help? Are they resentful of the demands being placed on them? Once surfaced, the social worker and family can openly deal with these issues. Family members are more likely to want to continue helping if they know their efforts have made a difference and are appreciated.

*Promoting shared responsibility* among family members is another way to improve the effectiveness of family support. Because research has shown that disagreements between family members regarding the division of responsibility for disease-related tasks have been associated with problems with adherence (Anderson et al., 1990), patients and their families should be encouraged to discuss and decide on the tasks and roles each person is willing to assume. Families are often anxious about handling medical emergencies, so it is often useful to devote the first meeting to helping the family plan what must be done in an emergency and who will carry out each task.

Emotional support can be strengthened by encouraging family members to openly share their feelings. Often, the patient and family try to hide painful emotions such as sadness, grief, or anxiety in order to protect each other. In doing so, they miss an opportunity to comfort one another and grow closer as a family. Social workers can also encourage families to share angry feelings so that differences can be negotiated and conflicts resolved. Many studies have found that cohesive families with low levels of conflict have better adherence and improved medical outcomes (Hanson, De Guire, Schinkel, & Kolterman, 1995; Herskowitz et al., 1995).

Adhering to a treatment regimen for heart disease, diabetes, or HIV/AIDS may be difficult, if not impossible, if the patient has uninformed or unsympathetic friends, coworkers, boss, or teacher. Encouraging the patient to educate at least one or two coworkers or fellow students can strengthen the supportive atmosphere and increase the probability of adherence. Support from others at work or school can be encouraged by educational efforts by the patient. In children with diabetes, personal contacts by a member of the health-care team may be used to reinforce parental education of school personnel.

Linking patients with support groups frequently reduces the patient's sense of isolation and provides opportunities for learning practical ways of dealing with adherence problems. Linking patients with appropriate community resources, a traditional and essential social work function, helps the patient access supplies and services that are important for regimen adherence.

Patients will be better served in the long run if they learn how to activate their own support. Patients can be guided in identifying those persons who might provide social support by having them recall people who have helped them in the past and asking them to think of those who might be willing to help in the future. The social worker can further prepare patients to ask for support and cope with refusals by using role play and rehearsal techniques as described by Marlatt and Gordon (1985). Patients who are uncomfortable about "bothering the doctor" can be taught "patient activation" or assertiveness skills to obtain medical support. One patient activation strategy is to encourage patients to prepare a list of questions before telephone calls to the doctor or office visits (Roter, 1977). Other strategies include encouraging patients to learn about their medical condition by reading their medical charts and assisting patients to negotiate medical treatment decisions with the health-care providers. In a study of the cognitive and behavioral determinants of adherence to the diabetes regimen, Amir, Rabin, and Galatzer (1990) found that the patient's ability to assertively request follow-up with a specific doctor was significantly correlated with adherence.

#### PHASE 4: MAINTAINING PATIENT ADHERENCE

Marlatt and Gordon (1985) observed that the high rate of failure associated with attempts to change behaviors may stem from a lack of emphasis on the maintenance phase of treatment. Chronic disease patient education and management programs commonly suffer from a lack of attention to maintenance issues. Health-care professionals are often naive in assuming that their job is done once the patient has been educated and launched on to a new treatment regimen. However, for the patient, the challenges are just beginning. The following strategies have been helpful in facilitating long-term adherence.

*Assist in Maintenance Skills* Many of the strategies described previously as effective in initiating behavioral change are also effective in maintaining behavioral change. In general, the most successful strategies will be those directed toward helping patients develop a sense of personal responsibility for their own adherence and helping them acquire the skills needed to carry out this responsibility (Meichenbaum & Turk, 1985). One of the most crucial of these skills, described earlier in this chapter, is the ability to anticipate and plan ahead for situations that are likely to result in nonadherent behaviors. This skill is particularly important in light of Marlatt and Gordon's (1985) findings that most episodes of nonadherence occur in a limited number of high-risk situations that are unique to each individual.

Other skills that will help the patient to independently maintain adherence are problem-solving skills, assertiveness skills, interpersonal skills, and stress management skills (Meichenbaum & Turk, 1985). When a patient is deficient in these areas, the role of the social worker is to strengthen these skills as they relate to adherence. The patient also can be referred to skills training programs offered by community agencies. The social worker can then help the patient apply the knowledge and skills learned from the training program to their personal regimen adherence problems.

*Teach Techniques for Coping with Lapses* To maintain long-term adherence, patients must learn to cope successfully with lapses in adherence. Marlatt and Gordon (1985) stress the importance of cognitive reframing for patients who view each slip in adherence as a sign of personal inadequacy or as an indication that adherence is not achievable. Patients who think this way become easily discouraged and lose motivation. Cognitive reframing involves helping the patient to view lapses as errors or mistakes in the process of learning new behaviors, not as indications of personal deficiencies. Patients can then understand, as with any mistake, the possibility of corrective learning. The social worker can then assist the patient in reviewing and debriefing the lapse so that causes can be identified and strategies devised to prevent recurrences. Marlatt and Gordon (1985) also suggest *lapse rehearsal* as a technique for preparing patients to handle lapses in adherence. Lapse rehearsal gives patients an opportunity to anticipate an adherence lapse, to imagine their response to the lapse, and to receive feedback and coaching from the social worker.

*Utilize Follow-Up Techniques* There are a number of very direct ways that the health-care team can encourage long-term maintenance, some of which involve ongoing communication between the patient and health-care professional. Regular phone calls and reminders help some patients keep on track.

The social worker can utilize strategies to reduce health-care costs, such as locating low cost sources of medications and supplies and making referrals to state and federal agencies for financial and medical assistance. Chronic disease such as HIV/AIDS, diabetes, and heart disease can be very expensive to manage because of the high cost of prescription drugs, blood glucose testing supplies, dietary restrictions, frequent doctor visits, medical transportation, childcare and laboratory tests. Patients frequently fail to maintain their regimen because of the hardships these expenses cause their families over time. In the long term, other financial demands may take priority over disease-related expenses. The social worker should be aware that changes in adherence over time may be due to competing financial needs.

Social workers must consistently recognize and reinforce the patients' positive health-care behaviors. Reinforcement will be more effective if done in such a way that patients realize their successes are due to their own efforts rather than those of health professionals (Meichenbaum & Turk, 1987). Patients need self-confidence and a belief in their own self-efficacy to successfully follow the treatment regimen for a lifetime.

#### APPLICABILITY TO DIVERSE POPULATIONS

This approach holds promise for individuals of diverse socioeconomic and ethnic backgrounds because it utilizes an ecological approach for assessing barriers and facilitators to adherence. This approach also acknowledges and examines the influence of the broader social context, such as societal and cultural factors, that affect adherence behaviors. For example, cultural factors such as health beliefs and extended kin social support networks among minority patients may differ from those of the majority culture and are crucial to successful adherence counseling. Furthermore, this approach to adherence counseling can be used as a strategy to prevent adherence problems from developing among newly diagnosed patients or

patients who are changing their regimens. Clinical wisdom as well as research in chronically ill children suggests that it is easier to prevent the occurrence of family-related adherence and disease management problems than it is to reverse already existing negative patterns within the family (Auslander, Anderson, Bubb, Jung, & Santiago, 1990; Auslander, Bubb, Rogge, & Santiago, 1993).

## ADHERENCE AND PATIENT-PRACTITIONER COMMUNICATION

### OUTCOMES ASSOCIATED WITH POSITIVE PATIENT-PRACTITIONER COMMUNICATION

After more than 2 decades of research on patient-practitioner communication, several consistent findings that characterize interactions between patients and practitioners have been shown to be associated with adherence to treatment. For example, when practitioners engage in more positive and less negative talk, ask fewer questions, and offer more information, patients are more likely to be adherent. In fact, more information-giving is associated with better patient recall and more partnership building (Hall, Roter, & Katz, 1988; Roter & Hall, 1997). Although many of these studies have been conducted with physicians as the practitioner, general principles and techniques used to improve communication skills can be extrapolated to other members of the health-care team, such as social workers, nurses, and dietitians.

Likewise, the strongest predictor of patient satisfaction is how much information is provided to the patient; simply, patients who receive more information are more satisfied with medical care than those who get less information (Hall et al., 1988). The strong relationship between greater information and greater satisfaction may be due to the need that patients have for knowledge about their condition. It may also be related to the perceptions by patients that practitioners who share more information with them are more concerned and caring people. Studies even link patient-practitioner communication with health outcomes, such as improved recovery from surgery and decreased use of pain medication (Roter & Hall, 1997). As patients with chronic disease take greater responsibility for their own treatment and health, their needs for information will increase. Social workers can lead the medical team in changing the interaction between patients and providers to a more collaborative style of communication. (See Chapter 9 in this *Handbook* for further discussion of these issues.)

### INFORMATION GIVING AND THE EDUCATOR ROLE

Patients with chronic disease are continually coping and adapting to changes, whether they be the co-occurrence of a mental health problem, changes in their medical condition, changes in their treatment regimen, or developmental or lifestyle changes. All of these changes pose demands on the patient to continually seek out new information and learn new ways of coping. In response to this patient need, social workers play a large role in delivering information to patients and educating them about disease-related and psychosocial issues. Although there is an emphasis on conducting psychosocial assessments in most social work programs, little attention is spent on training social workers to deliver informa-

tion to patients. Research in patient-practitioner communication indicates that patients are dissatisfied and nonadherent when (a) they do not understand what they are told and don't ask questions, (b) they forget what they are told, and (c) too much time is spent on assessing personal histories as opposed to providing patient education (Robbins et al., 1993; Roter, 1977; Roter, Hall, & Katz, 1987).

#### COMMUNICATION TECHNIQUES TO ENHANCE INFORMATION RECALL

Much of what practitioners tell patients is forgotten by the time they leave the building. To increase the amount of information recalled by patients, the following communication strategies have been identified as useful in the medical encounter. The first strategy is to *use explicit categorization*. When giving a lot of information to patients, present the information in categories or blocks and describe each category in advance. For example, "I am going to tell you the various types of support groups that are available for you and your family, what the potential benefits are to participating in these groups, who facilitates or sponsors each of these groups, and where and when these groups are held and how you can sign up for them."

A second strategy is the use of *repetition*. Combined with explicit categorization, repeating the most important information to patients and their families can increase recall. In one of the pioneer studies on patient-practitioner communication, providers asked patients to repeat the information back to the physician to make sure they understood what they were told. Any information that was misunderstood or forgotten was repeated again to the patient. Results of this study showed that individuals in the experimental group were better able to recall information from the physicians and also more satisfied with the medical visit (Bertakis, 1977).

Another strategy to enhance recall of information is to *provide specific instructions*. Patients can remember and more easily follow concrete or specific, detailed advice or information more easily than general, abstract information because the former enhances greater imagery than the latter. For example, the classic general statement, "You should reduce the sugar in your diet," is often ignored by patients, not only because it is difficult to achieve, but because it does not provide specific enough advice. A more specific statement would be, "Substitute fresh fruit and crackers for dessert after meals in your diet." In using specific instructions, avoid medical jargon and long sentences that are difficult to follow.

Ley (1982), another pioneer in studying information-giving to patients, examined the ordering of information presented to the patient. Results indicated that laymen presented with information in a medical encounter remember best what they are told first and what they consider most important. Because practitioners often end their visits with patients by providing them with information and recommendations, patients may be more likely to forget this information. Instead, Ley's early work suggests that social workers should *present the most important information early* in their visit with patients, so the patient is more likely to remember it. Last, practitioners should *elicit patient expectations and involvement*. None of these techniques will improve the interaction with patients unless the practitioner asks what the patients wants to know and encourages the involvement of the patient in the interaction.

Previous research on adherence and communication between practitioners and patients has led us to understand that health-care professionals are most effective when they adopt a collaborative style with patients. When patients choose not to adhere to their treatment regimen, it should be viewed as a logical, motivated choice. The solution lies in renegotiating the agreed upon prescribed treatment so that it can realistically be followed by the patient. Lessons learned from a multi-site, controlled trial of intensive therapy (the Diabetes Control and Complications Trial) for individuals with type 1 diabetes (Lorenz et al., 1996) demonstrated that for intensive therapy to be successful, health professionals must change as much as patients.

### THE RELATIONSHIP OF MENTAL HEALTH TO CHRONIC DISEASE

One of the most important issues for social workers who work with chronically ill patients is the co-occurrence of mental health problems. People with a chronic illness such as heart disease, diabetes, or HIV/AIDS have higher rates of emotional problems than the general population. Chronic illness can cause functional disabilities, ongoing pain, burdensome medication regimens, reliance on caregivers, and awareness of one's mortality—any of which can lead to feelings of grief, anxiety, and depression. But the relationship between mental disorder and chronic illness goes beyond the easily explainable premise that chronic illness causes distress. Research also indicates that the relationship occurs in the other direction as well—that is, distress can be a causal factor in the etiology of chronic illness. Depression can increase the risk of heart disease, diabetes, and HIV/AIDS through direct and indirect pathways.

Social workers bring a holistic, person-in-environment perspective to the care of people with chronic illness. Part of this perspective requires knowledge of how mental illness and other physical illnesses can inextricably converge. To summarize such knowledge, this section examines the prevalence of mental disorder among individuals with heart disease, diabetes, or HIV/AIDS, the bidirectional relationship of these chronic illnesses and mental disorders, factors associated with mental health in people with chronic illness, and approaches to providing social work services for people with a mental disorder and heart disease, diabetes or HIV/AIDS.

#### PREVALENCE OF MENTAL DISORDER AMONG PEOPLE WITH HEART DISEASE, DIABETES, OR HIV/AIDS

*Heart Disease* An estimated 15% to 20% of people with heart disease also have depression, compared to 4% to 7% in the general population (reviewed in Lett et al., 2004). Research shows that depression can exacerbate heart disease, perhaps because of behavioral consequences of depression such as poor eating and exercise habits, or because of physiological correlates such as decreased heart rate variability and platelet activity in depressed individuals (reviewed in Ferketich, Schwartzbaum, Frid, & Moeschberger, 2000). In 20 studies that followed patients with heart disease for up to 15 years, people with heart disease and depression were, on average, two times more likely to die of cardiac complica-



tions than people with heart disease and no depression (reviewed in Barth, Schumacher, & Herrmann-Lingen, 2004). Studies generally indicate that people who experience coronary artery disease, acute myocardial infarction, congestive heart failure, or heart surgery and who subsequently experience depression are 1.5 to 2.5 times to die from their cardiac condition than people with heart disease and no depression (Lett et al., 2004). Although depression is a major risk factor for suicide (Harris & Barraclough, 1997), a review of studies on suicide and medical illness found no increased suicide risk for such cardiac conditions as hypertension and heart transplant (Hughes & Kleespies, 2001).

*Diabetes* Studies consistently show the risk for depression is two times higher among people with type 1 or 2 diabetes, compared to those without diabetes (reviewed in Anderson et al., 2001). This effect is consistent for women, men, children, and adults, as well as for different types of diabetes. In general, a review of 39 studies including 20,218 participants indicated that 11% of people with diabetes had major depression and an additional 31% had a high number of depression symptoms (Anderson et al., 2001). In a longitudinal study of children with type 1 diabetes, 28% developed depression over a 10-year period (Kovacs, Goldston, Obrosky, & Bonar, 1997). Psychiatric disorder occurred most commonly in the 1st year after treatment. Depression among people with diabetes is related to poor nutrition, lack of medication adherence, increased health problems, and lower quality of life (Anderson et al., 2001; Ciechanowski, Katon, & Russo, 2000). Various studies have shown that depression relates to a greater likelihood of hyperglycemia, eye damage, heart disease, hospitalization, and other complications among people with diabetes (Clouse et al., 2003; Kovacs, Mukerji, Drash, & Iyengar, 1995; Lustman et al., 2000; Rosenthal, Fajardo, Gilmore, Morley, & Naliboff, 1998). The severity of diabetes and functional impairment appears to increase the risk for depression (de Groot, Anderson, Freedland, Clouse, & Lustman, 2001; Lustman et al., 2000).

Other emotional problems and disorders, particularly anxiety and general psychological distress, also occur with higher-than-average frequency among people with diabetes. Anxiety is twice as likely in people with diabetes (Kruse, Schmitz, & Thefeld, 2004), and it is especially associated with hyperglycemia (Anderson et al., 2002). Overall, 14% of people with diabetes also have generalized anxiety disorder, and an additional 40% have elevated symptoms of anxiety (reviewed in Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002). In a study of almost 10,000 people in New York City, people who had been diagnosed with diabetes were twice as likely as those without diabetes to be in serious psychological distress, defined as at least 13 symptoms of anxiety, depression, schizophrenia, and other mental disorders (McVeigh, Mostashari, & Thorpe, 2004). Researchers have yet to adequately examine whether psychological disorders occur at equal rates among people with diabetes of different races and ethnicities (de Groot & Lustman, 2001).

Finally, the need to continually focus on food and exercise may give rise to eating disorders in some people with diabetes. Some adolescent and young adult women with type 1 diabetes engage in what is called "insulin purging" (Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997), by which they regulate their weight by withholding insulin and thus purging themselves of food that would

be stored as fat. However, it is not clear whether eating disorders occur more frequently in people with diabetes than people in the general population (Rubin & Peyrot, 2001).

*HIV/AIDS* Because the human immunodeficiency virus invades the central nervous system, numerous types of psychiatric complications can accompany HIV and AIDS (Forstein & McDaniel, 2001). HIV-associated dementia and minor cognitive-motor disorder can result from the virus' involvement with the central nervous system. Studies have reported high prevalence rates (4% to 19%) of HIV/AIDS among people with serious mental illness, but these studies lacked random samples or control groups (reviewed in Lyon, 2001). Furthermore, the risk for suicide among people with HIV/AIDS is generally two times higher than average (Dannenberg, McNeil, Brundage, & Brookmeyer, 1996; Marzuk et al., 1997), although earlier studies produced dramatically larger estimates (Coté, Biggar, & Dannenberg, 1992; Marzuk et al., 1988). A study of 1,504 people who died by suicide in New York City in the early 1990s, including 133 HIV-positive people, found that the association between HIV/AIDS and suicide is strongest among women and people of color (Marzuk et al., 1997).

Treatment for HIV/AIDS also can trigger psychiatric problems. For example, antiretroviral therapy can induce psychosis in some patients, which may subside once the therapy is withdrawn and anti-psychotic medication introduced (Foster, Olajide, & Everall, 2003). At the same time, antiretroviral therapy has been associated with a decline in cases of AIDS-related dementia (Ferrando, van Gorp, & McElhiney, 1998) and with improvement of depression in people with HIV/AIDS (Low-Beer et al., 2000).

#### DEPRESSION AND OTHER MENTAL ILLNESS: CAUSE OR CONSEQUENCE OF CHRONIC ILLNESS?

Chronic illness can engender sufficient stress and anxiety to affect a person's mental health. But what about the possible influence of mental health on the etiology of chronic disease? Indeed, evidence is building that poor mental health can increase the risk for chronic illness. The research involving depression, in particular, is the strongest; studies across many diseases indicate that depression can both directly and indirectly increase the risk of certain health conditions.

*Heart Disease* Studies have found that depression increases the risk of subsequent heart disease by an average 1.5 to 2 times (Lett et al., 2004; Wulsin & Singal, 2003), almost as much as smoking, which increases the risk of heart disease by 2.5 times (U.S. Dept. of Health and Human Services, 1983). One of the first studies of this phenomenon, the Epidemiologic Catchment Area study, found that people with no history of heart disease and a history of major depression in 1981 were 4.5 times more likely to have had a heart attack by 1994 than those with no depression history (Pratt et al., 1996).

The relationship between depression and heart disease complications may be more profound for men than women. One study found that men with depression were 2.75 times more likely than men without depression to develop heart disease, but depression did not increase risk of heart disease for women (Hippisley-Cox, Fielding, & Pringle, 1998).

It is not known why depression increases the risk of heart disease and heart-related complications. One hypothesis asserts that behavioral consequences of depression—specifically smoking, alcohol use, or physical inactivity—and physiologic effects increase the risk of heart disease or complications (Lett et al., 2004). Depression's effects on motivation, energy, and hopefulness are known to impair compliance with treatment regimens, which can in turn lead to graver health outcomes. Physiologic effects of depression that may encourage heart problems include alterations in blood platelet activity, serotonin dysregulation, inflammation, and diseases such as diabetes, obesity, and hypertension (Lett et al., 2004). Antidepressant medications that target serotonin (Prozac, Zoloft, and other selective serotonin-reuptake inhibitors) provide evidence supporting a relationship between serotonin and heart disease. At the same time, Lett and colleagues (2004) caution that factors related to both depression and heart disease need more longitudinal study before any causal relationships can be established.

*Diabetes* Although we know that depression may follow a diagnosis of diabetes, depression is also associated with increased risk of acquiring diabetes (Eaton, Armenian, Gallo, Pratt, & Ford, 1996; Kawakami, Takatsuka, Shimizu, & Ishibashi, 1999). It is not clear why depression may increase the risk of diabetes. As with heart disease, one possible explanation is that depression itself leads to poor diet, lack of exercise, smoking, social isolation, and stress—all risk factors for diabetes (Barth et al., 2004; Rozanski, Blumenthal, & Kaplan, 1999). Another possibility is that depression produces biochemical changes that make an individual more susceptible to other types of illness or that depression directly affects cardiac and metabolic regulation.

Diabetes is also associated with other mental illness besides depression. People with schizophrenia have higher rates of impaired glucose tolerance than people in the general population, even when no anti-psychotic medications that might affect physiology are taken (Ryan, Collins, & Thakore, 2003). In fact, people with schizophrenia who take anti-psychotic medications are at an elevated risk for developing diabetes (Koro et al., 2002; Leslie & Rosenheck, 2004; Sacchetti et al., 2005). This relationship is particularly strong among newer anti-psychotic medications such as olanzapine (Zyprexa), risperidone (Risperdal), and quetiapine (Seroquel). One study found that 1% of people developed diabetes within 3 months of initiating Seroquel (Koro et al., 2002).

Weight gain, which is another side effect of the medications (Allison et al., 1999), may help explain the increased risk of diabetes. For these reasons, it is especially important that people who start taking anti-psychotic medications be monitored regularly by a physician, eat low-fat and high-fiber diets, and act preventively in general. Yet, schizophrenia itself may affect the metabolic system (Ryan et al., 2003), and the challenges posed by schizophrenia can make it difficult for people to diligently exercise and eat well.

*HIV/AIDS* In the case of HIV/AIDS, in which transmission of the disease is preventable with behavioral measures (e.g., condom use), mental illness indirectly increases the chances of acquiring the sexually transmitted disease. Feelings of hopelessness and lethargy produced by depression can inspire risky sexual behavior. In a study of 460 gay men, those with dysthymic disorder were 2.4 times more likely than those without any depressive disorder to have engaged in

unprotected anal intercourse with a casual partner in the previous 6 months (Rogers et al., 2003). Cognitive problems, particularly those in schizophrenia, can hinder a person's understanding of the magnitude of HIV/AIDS and methods for prevention (Lyon, 2001). Even after an individual contracts HIV, depression is associated with graver outcomes. A 7-year study of 1,716 women with HIV found that the proportion of women with chronic symptoms of depression who died of AIDS was double that of those with few or intermittent depression symptoms (Cook et al., 2004).

#### MENTAL ILLNESS AND ADHERENCE TO TREATMENT REGIMENS

Not surprisingly, depression, anxiety, schizophrenia, substance use disorders, and other types of mental disorders can negatively affect a person's compliance with treatment recommendations. Depression itself is perhaps the largest culprit (DiMatteo, Lepper, & Croghan, 2000). The nature of depression lessens motivation, concentration, energy, and hopefulness. These problems make it difficult to exercise, eat healthfully, test blood sugar regularly, and maintain medications (Ciechanowski et al., 2000; Rubin, Ciechanowski, Egede, Lin, & Lustman, 2004).

Depression hinders compliance with treatment for heart disease, diabetes, and HIV/AIDS (Ciechanowski et al., 2000; DiMatteo et al., 2000; Starace et al., 2002). Women with mental health problems are more likely to comply with antiretroviral therapy for HIV if they also receive treatment for their mental health problems (Cook et al., 2002).

Illicit drug use also influences adherence. In a study of 85 current and former drug users infected with HIV, only 27% of cocaine users adhered to their medication regimen compared to 68% of people who reported no cocaine use during the 6-month study (Arnsten et al., 2002). Although depression and other mental illness may disturb a person's motivation and ability to follow a medical regimen of diet, exercise, and medication, Rubin and Peyrot (2001) stress that many people with depression do adhere to their treatment plan and, likewise, many people who do not follow their medical regimen are not depressed.

#### PROTECTIVE FACTORS AND MENTAL HEALTH IN CHRONIC ILLNESS

Not everybody with a chronic illness develops a mental disorder. Most people with heart disease, diabetes, or HIV/AIDS do *not* merit a diagnosis of major depression, despite managing constant stress and fears related to their illness.

What helps people to cope with their chronic illness without suffering depression, anxiety, or other mental disorder? Studies generally find that marriage and higher levels of education, income, and social support relate to fewer psychiatric complications with diabetes (Blazer, Moody-Ayers, Craft-Morgan, & Burchett, 2002; McVeigh et al., 2004; Peyrot & Rubin, 1997). In cases of diabetes, well-controlled blood sugar is associated with a decreased risk for depression (Rubin & Peyrot, 2001), as are lower weight, insulin treatment, and older age (Katon et al., 2004). White Americans with diabetes are less likely to experience major or minor depression than African Americans (Blazer et al., 2002) and other people of color (Katon et al., 2004).

It is hard to know whether depression or poor health habits (such as control of blood sugar) come first because of the reciprocal effect they have on each other.

This is also true of exercise, diet, and sleep, which can help prevent depression but can also be dramatically affected by depression. As Rubin and Peyrot (2001) note, "The helplessness and hopelessness often associated with depression may contribute to a vicious cycle of poor self-management, worse glycemic control, and exacerbation of depression" (p. 461). A synergistic effect seems to exist when a person has comorbid physical and mental illnesses: The worse the physical or psychosocial situation, the worse the consequences for one's mental health. It is likely that psychological, economic, social, and physical health problems interact with each other in what can be a vicious or productive cycle, depending on the circumstances.

#### INTERVENTIONS TO IMPROVE MENTAL HEALTH IN PEOPLE WITH CHRONIC DISEASE

Social workers have numerous interventions available to help people with mental health problems. Medical crisis counseling, psychotherapy, and relaxation training are briefly described here. Antidepressant medication is omitted because social workers do not prescribe medications, but rather work with psychiatrists and other physicians who do prescribe them. However, it is helpful for social workers to be aware of the benefits and risks of psychiatric medications, so that they can educate and advocate for their patients. For example, antidepressants can effectively reduce depression but also carry risks, including the occasional occurrence of suicidal thoughts in children, adolescents, and adults (U.S. Food and Drug Administration, 2004; Wooltorton, 2003).

*Medical Crisis Counseling* Medical crisis counseling is a short-term intervention that centers on fears, anxieties, disabilities, and other problems posed by a person's medical condition (Pollin, 1995). The premise of medical crisis counseling is that eight fears impede a person's ability to cope with illness: (1) loss of control, (2) loss of self-image, (3) dependency, (4) stigma, (5) abandonment, (6) fear of expressing anger, (7) isolation, and (8) death. The counseling typically lasts for only 10 sessions or less, and an active, problem-solving approach is stressed. The role of the social worker or other therapist "is that of a facilitator, problem-solver, health educator, and coach to the patient with a solution-focused orientation" (p. 53). The ultimate therapeutic goal is to help people with illness feel some sense of control over their situation and, in turn, cope more effectively. A small, randomized controlled trial indicated that crisis counseling may help increase social support for patients with diabetes, heart disease, and other conditions without increasing costs (Koocher et al., 2001).

*Psychotherapy* Various studies attest to psychotherapy's effectiveness in general (Craighead, Hart, Craighead, & Ilardi, 2002; Weisz, 2003), but mixed evidence exists in relation to psychotherapy and people with specific illnesses. Psychotherapy may vary by orientation (cognitive-behavioral or interpersonal), mode (individual or group), or focus (cognitive distortions, grief, or stress).

Cognitive-behavioral therapy has effectively reduced depression among people with type 2 diabetes (Lustman, Griffith, Freedland, Kissel, & Clouse, 1998). Rubin and Peyrot (2001) propose that interpersonal psychotherapy would also benefit people with diabetes because so much of the illness' management



requires effectively interacting with other people. In one of the first studies to examine stress reduction training and heart disease outcome, men who had a heart attack and received stress reduction training had lower fatality rates than those with no psychological intervention (Frasure-Smith & Prince, 1985).

Not all studies of psychotherapy effectiveness yield positive results. An intervention including group and individual psychotherapy failed to reduce rates of depression, recurrence of heart attack, or death rates among 2,328 people with a recent heart attack (Jones & West, 2004). A large study of individual and group cognitive-behavioral therapy for adults with depression and a recent heart attack showed that the intervention related to improved depression and increased social support. However, within the average follow-up period of 29 months, 1 in 4 people had died regardless of whether they received psychotherapy (Berkman et al., 2003). More research is needed into the effectiveness of different types, modes, and foci of psychotherapy, specifically with people with chronic illness.

*Relaxation Training* Relaxation techniques have generated considerable evidence of effectiveness among people with chronic health conditions. In his classic book *The Relaxation Response*, Benson (1976) showed that meditating for 10 to 20 minutes a day can produce physiologic changes such as lower blood pressure and heart rate. Progressive muscle relaxation is associated with improved blood glucose control among people with diabetes (Lammers, Naliboff, & Straatmeyer, 1984; Surwit & Schneider, 1993). Deep relaxation techniques can help children and adolescents with type 1 diabetes feel less fear and anxiety when receiving injections and other stressful medical procedures (Sewell, 2004).

Numerous types of relaxation training exist. In meditation, a person sits still while concentrating on counting, repeating a phrase, or visualizing an object. In progressive muscle relaxation, a person breathes deeply and relaxes specific muscle groups one at a time, starting either from the head and going down to the feet or vice versa. In hypnotherapy, also called deep relaxation (Sewell, 2004), another person induces relaxation in the patient by directing the patient to focus his or her attention on an object or a visualization. For detailed instructions on how to use relaxation techniques with clients, see Bernstein, Borkovec, and Hazlett-Stevens (2000) or Payne (2000).

## CONCLUSION

Social workers in all types of health-care settings frequently work with people who have heart disease, diabetes, HIV/AIDS or some other chronic disease. As this chapter demonstrated, chronic disease brings ongoing challenges to patients, particularly in issues of mental health, treatment adherence, and gathering information to better cope with ongoing changes associated with the disease. Chronic illness may lead to mental health problems such as depression and anxiety, which in turn can exacerbate physical complications of chronic illness. Mental health problems such as depression can also negatively affect a patient's ability to follow through with medication, diet, and other components of the medical regimen. Adherence to medical treatment is of utmost importance for people with chronic illness. How patients live on a daily basis—whether they eat, exercise, take medication regularly, or act preventively—can profoundly impact the course and outcome of their illness.



There exist multiple roles for social workers in their work with chronically ill patients—that of an adherence counselor, a mental health specialist, and an educator. All of these roles demand that social workers are knowledgeable about the patients' disease and its treatment, in addition to their unique psychosocial issues. Perspectives on nonadherence have changed—from one of blame to one of choice, whereby the practitioner and patient must take responsibility for renegotiating the agreed on treatment.

Future trends in health care may influence the roles that social workers assume in health-care settings and in the community. For example, increased rates of obesity and diabetes among individuals of all age groups, even children and adolescents, will strengthen social work's role in promoting lifestyle changes and adherence. The relatively new emphasis on prevention of heart disease, diabetes, and HIV/AIDS will enhance social workers educational role in community-based public health settings such as schools, primary care clinics, and mental health and social service agencies. Finally, the continued disparities in health found between people of color and White Americans will highlight the need for social workers' expertise in sociocultural and family factors that influence health outcomes. Knowledge of heart disease, diabetes, and HIV/AIDS is critical for social workers who work with growing numbers of individuals who are actively preventing and managing these chronic diseases.

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#### SUGGESTED LEARNING EXERCISE

Read a book about an individual's struggle to cope or adapt to a chronic disease. The book can be a personal account (autobiographical) or written by someone else. In a case study presentation or paper, analyze the individual's ability to manage the disease using the Adherence Counseling model described in this chapter. First, describe the disease, its etiology, symptoms, treatment, and progression. Then analyze how various factors, such as family social support, lifestyle, cultural factors, mental health status, emotional reaction to the diagnosis, health beliefs, and treatment satisfaction may affect their ability to manage their disease and adhere to treatment. Based on this assessment, how might a social worker intervene with the client and family to facilitate behavioral changes, activate social support, and help them to cope more effectively?

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## CHAPTER 19

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# Social Work and Genetics

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and LUBA DJURDJINOVIC

**A**PRIL OF 2003 marked two important events in human genetics, the fiftieth anniversary of the publication of the landmark paper by Nobel Laureates Francis Crick and James Watson describing the structure of deoxyribonucleic acid (DNA) and the announcement of the completion of the Human Genome Project (HGP) by the International Human Genome Sequencing Consortium (National Human Genome Research Institute, [NHGRI], 2003). In April 2003, the National Association of Social Workers marked the two events by issuing its Standards for Integrating Genetics into Social Work Practice (Stoesen, 2003). The new standards reflect the importance of integrating the knowledge generated by the HGP into social work theory, practice, policy advocacy, and research.

Social workers in health care have historically been involved in helping families cope with the psychosocial implications of genetic conditions (Schild & Black, 1984). Social workers have facilitated individuals' and families' understanding of the nature of genetic conditions, the meaning of testing for families, and ways to cope with the information obtained. Today, the social work profession has an expanding opportunity to participate in the burgeoning field of genetics. From their early work in genetics, primarily in the field of mental retardation, to the present, social workers have been involved in genetic-related counseling across medical specialties and mental health. The genetic revolution is contributing to the integration of physical and mental health in the United States and offers a variety of opportunities for social workers to participate in the comprehensive care of patients and families to address the entire range of health concerns, including genetic aspects of well-being.

Although assisting individuals and families with the processes involved in *genetic testing* and diagnosis may be the primary focus of health social work practice in genetics, there are other areas of interest and activity as well. Over 5,000 single *gene* mutations lead to illness or disability and are diagnosable through genetic testing. However, the genetic influence on one's health and well-being is far more complex than single-gene mutations alone. In general, genes provide the structural foundation of biological expression that is moderated by the environment. These complex interactions are not easily explained.

The genetic foundation of a person's identity is neither certain nor fixed. Genes mutate in response to various environmental exposures, including external and internal physical events and psychosocial events such as stress. The complexity and importance of gene-environment interactions places the social work profession in a unique position to contribute to the well-being of the population.

Social workers are increasingly challenged to learn about the influence of genetics in their clients' lives, well-being, and behaviors. Social workers are confronted with new theories of how genetics and environment interact and have a role in advancing the emerging knowledge-base around the interplay of nature and nurture in human development and behavior.

## CHAPTER OBJECTIVES

- Explore the relationship of social work practice to genetics.
- Introduce some basic information about genetics.
- List some key skills for integrating genetic knowledge into practice.
- Examine ethical issues raised with regard to genetics.
- Explore recent policy developments regarding genetics.
- Introduce basic information about social work research and genetics.
- List future issues for social work and genetics.

## AN INTRODUCTION TO GENETICS

That children inherit traits from their parents has long been recognized. When we see a newborn, we are likely to say, "he has his father's eyes" or "she is the spitting image of her mother." Mendel's 1866 paper first explained the transmission of traits from one generation to the next, a process called *genetic inheritance*. Since the rediscovery of Mendel's paper in 1900, genetic science blossomed and has since grown exponentially (Schild & Black, 1984). Mendel's explanation of how the "factors" that create traits are passed from parents to child remains the foundation of genetic science. We now know that the process of inheritance is more complex than described by Mendel. Traits are determined by numerous genes working together. We now know more about the chemical structures and processes that guide inheritance and genetic expression.

### IMPORTANT TERMS

Each of us has a unique *genome* that is passed to us by our parents. The HGP has demonstrated that all people share 99.9% of the same genetic information and it is the 0.1% variation that creates unique individuals. The genome is the sum total of a person's genes, and the expression of a person's genome, or *genotype*, is called the *phenotype*. The genome is composed of genes, each parent contributing half at conception. It is the mixing of maternal and paternal genes that creates each of us as a unique individual.

*Genes*, which were called "factors" by Mendel, are the smallest unit of inheritance. Genes are composed of DNA, and each gene carries a set of specific instructions to regulate the activities of cells. These instructions create proteins, regulate the activity of other genes, and guide the development and reproduction of cells. The HGP recently reported that each human has approximately 20,000 genes (NHGRI, 2003).

DNA is made of two long chains of base pairs that resemble a ladder that is twisted into the shape of a double-helix. This pattern is created by the specific matching of the four bases that compose DNA. The bases—adenine, cytosine, thymine, and guanine—are notated by their first initials, A, C, T, and G. This is the “alphabet” of the DNA molecule, and the genetic message is coded in this language. A specific gene code is “read” by the cell and a specific protein is produced. Genes act in combination with one another to produce traits. One gene may be active in various combinations with others to be part of the definition of more than one trait.

Genes may have alternative forms derived from variation in the DNA-based pair configuration. The alternative forms are called *alleles*. Different combinations of alleles result in different traits. Some alterations are benign, such as those associated with eye, hair, and skin color. Other alleles are responsible for or contribute to illness. A substitution of a specific base with another results in a *mutation* or altered protein; the function of that protein will be changed and it may contribute to a medical condition. Mutations may occur spontaneously or in response to various environmental exposures. If the mutation occurs in *germ* cells, ova or sperm, then the alteration is passed on to following generations. If the alteration occurs in *somatic* cells (all the nongerm cells), it will affect the specific individual but not be inherited by the next generation. Not all individuals who have a specific genetic change in a gene have medical expression of a condition.

Genes are located on *chromosomes*, which are structures found in all cell nuclei. Chromosomes are composed of tightly wound DNA molecules. Each biological organism is characterized by the number and make-up of its chromosomes. Humans have 46 chromosomes in 23 matched pairs, one set coming from the sperm and the other coming from the ovum. Of these 46 chromosomes, 44 are called *autosomes*, and the other two are referred to as sex chromosomes. The autosomes are designated as 1 to 22, from largest to smallest. The sex chromosomes are designated by X and Y. Some of the genes on the X and Y chromosomes regulate the cascade of estrogen and testosterone during embryonic development and determine sex. Assuming no other intervening factors, a person with two X chromosomes will be female, and a person with an XY genotype will be male.

#### THE DIFFERENCE BETWEEN INHERITED AND GENETIC CONDITIONS

Congenital malformations are a major cause of infant mortality and morbidity in the United States. Approximately one-third of all hospital admissions are related to birth defects (Lynberg & Khoury, 1990). The causes of birth defects are numerous and need to be systematically considered. Some are genetic and some are inherited. These two terms are critical in appreciating current and future risk.

Fetal development follows a choreographed building plan that is directed by information encoded in units called genes. Specialized genes direct cell division, fetal development, and growth. A disruption of the choreographed sequence of genes required in early fetal development may result in a birth defect. The disruption can occur through at least two mechanisms: (1) inadvertent environmental exposures (e.g., viral, chemical), or (2) a direct interference of the activation of the correct sequence of genes required for normal development. This spontaneous and sporadic *genetic* event originates within the individual and is not related to



genetic information inherited from either parent. When this type genetic mechanism is the basis of an infant's major birth defects, the risk to a future pregnancy is very low.

In some families, a gene can exist in an altered form that predisposes the developing fetus to aberrations in the highly choreographed sequence of genes required for fetal development. The altered gene is passed down in the family; it is *inherited*. Family history is central to determining a risk of recurrence in the family.

#### MODES OF INHERITANCE

Mendel described three modes of inheritance—*autosomal dominant*, *autosomal recessive*, and *sex-linked recessive*. Autosomal dominant genes express their variation directly without having to be paired with another altered gene. Dominant inheritance is characterized by its presence in every generation. Examples of autosomal dominant disorders are Huntington's disease, Marfan syndrome, and some cancer syndromes. Children of a parent with an autosomal dominant gene have a 50% chance of inheriting that gene. The affected parent has one altered and one unaltered gene. Only one of those genes will be passed to the child in the sperm or ovum. If the gene in the germ cell is the altered one, the child will express that gene.

Autosomal recessive genes express themselves only in the presence of a second altered gene. Examples of recessive gene disorders are cystic fibrosis, sickle cell anemia, and Tay-Sachs disease. A person with one recessive gene will express the phenotype of the unaltered gene and is said to be a *carrier* of the trait. Carriers do not have the disorder associated with the altered gene, but can pass the altered gene to their children. When two carriers have a child, that child has a 25% chance of expressing the trait associated with altered gene. The germ cells of each parent have a 50% chance of having the altered gene. Thus, there are four possible combinations of the gene: (1) an affected maternal gene and an unaffected paternal gene; (2) an unaffected maternal gene and an affected paternal gene; (3) an unaffected maternal gene paired with an unaffected paternal gene; and (4) an affected gene from each parent. The first two combinations result in a person with carrier status. In the third combination, the altered genes and the associated trait are not passed on. The fourth results in a person who expresses the trait. The frequency of its appearance in families depends on the distribution of the gene in the population, and thus, the likelihood that two carriers will have children together.

X-linked recessive traits act in the same way as autosomal recessive genes, except that they lie within the X chromosome and are not matched by the genes on the Y chromosome. The unmatched altered gene will be expressed in men but not in women, who have an unaltered matching gene on their second X chromosome. Men are most likely to express X-linked recessive traits. Hemophilia, color blindness, and Duchene's muscular dystrophy are examples of X-linked recessive traits. Because the altered gene is on the X chromosome, an X-linked recessive trait is passed from a mother who carries the gene to her son. Thus, each of her sons has a 50% risk of expressing the trait. An affected father will pass the gene for the trait to all of his daughters, because he has only one X chromosome to pass on.

These three modes of inheritance describe the transmission of single-gene traits. Over 5,000 known single-gene disorders have been identified. As noted

earlier, most traits result from the interactions of numerous genes and can have environmental influences. The modes of inheritance for these multigenic traits are more complex than the Mendelian single-gene inheritance. Risk of inheritance is, therefore, not easily determined.

#### GENETIC TESTING

Genetic testing is a medical procedure that analyzes a blood or tissue sample for metabolites indicative of genetic abnormalities, examines chromosomes for structural anomalies, and attempts to identify DNA alterations as genetic markers. Except in newborn screening, genetic testing is often accompanied with genetic counseling. The number of disorders for which genetic testing can be done is increasing rapidly as a result of the HGP. There are several types of genetic testing, six of which are discussed in this chapter from a life-span perspective.

*Carrier Screening* Couples who are planning a pregnancy and have a family history of genetic illness or who are in a high-risk group for a genetic illness may request carrier screening. Some of the disorders for which carrier screening is available are Tay-Sachs disease, sickle cell disease, and cystic fibrosis. If recessive genetic disorders are known to exist in a family, a person may choose to know her carrier status for the disorder. Carrier screening may reveal that a person has an altered gene for the disorder, and if the person's partner is also a carrier, the couple can determine the risk to their offspring for inheriting that disorder. If only one person is a carrier, the couple's offspring will not be affected; thus, a single test may be all that the couple will have. Cystic fibrosis testing demonstrates some of the potential difficulties with carrier screening.

In October 2001, the American College of Obstetrics and Gynecology (ACOG) endorsed a practice standard of offering cystic fibrosis carrier screening for all pregnant women at high risk. More than 1,000 gene alterations result in cystic fibrosis, however, all but about 1% of cystic fibrosis cases can be accounted for by 13 alleles (Shulman, 2005). The expression of cystic fibrosis depends on which alleles a person is carrying and whether the alterations are *homozygous* (the same allele from each parent) or *heterozygous* (different altered genes, one from each parent).

Cystic fibrosis is not equally distributed throughout the population. It occurs in European Caucasians in the United States in about 1 in 2,500 persons. Thus, the carrier rate among this population is about 1 in 25. Among Latinos, the cystic fibrosis frequency is 1 in 8,000; among African Americans, it is 1 in 17,000; and among Asian Americans, it is 1 in 32,000 (Shulman, 2005). The groups specified by ACOG to be actively offered screening are Eastern European Jews (Ashkenazi), non-Jewish European Caucasians, individuals with a family history of cystic fibrosis, or reproductive partners of a person with cystic fibrosis (Shulman).

Two ethical concerns were raised by the testing recommendations. First, because of the relatively low frequency of cystic fibrosis in non-White populations, recommendations for carrier screening in these groups are not routinely offered, and some minority group members have suggested that they were being subjected to discrimination by not being offered the test. A clear explanation of the risk profiles for these populations is the best response to these concerns.

The second ethical and practice concern is related to the order in which partners should be tested. If one member of the couple is not a carrier, children of the

couple will not be affected. However, if one is found to be a carrier, then the other partner should be tested. Testing can take place with both members of the couple simultaneously or in sequence. If the testing is done sequentially—a cost savings—which member of the couple should be tested first? No protocol currently exists, but the woman is usually the first tested. Feminists point to this practice as burdensome to the woman and take the position that both partners should be tested simultaneously.

*Preimplantation Genetic Diagnosis (PGD)* PGD was first developed in 1990 and by early 2005 had been used in over 3,000 in vitro fertilization (IVF) cycles, resulting in over 700 births (Klipstein, 2005). PGD is a technically complex and expensive procedure by which the embryos produced through IVF are first examined for a specific genetic disorder. Only those that are determined to be unaffected are then implanted. PGD allows couples at risk to begin a pregnancy with an embryo known to be free of the disorder in question. PGD can currently be used to detect chromosomal *aneuploidies* (an abnormal number of chromosomes) that produce disorders such as Down syndrome (trisomy 21) or Turner syndrome (monosomy X) and approximately 100 single gene disorders. Tay-Sachs, cystic fibrosis, and Huntington's disease are three such single-gene disorders that can be diagnosed via PGD.

*Prenatal Diagnosis* Genetic diagnosis during pregnancy is done using several different methods. Some states mandate that women be offered blood tests to screen for fetal metabolites that may indicate chromosomal aneuploidies or neural tube disorders. Women with abnormal values on these tests will be offered further testing to determine a diagnosis.

Women who are at high risk for genetic disorders due to advanced maternal age (> 35) or family history may be offered prenatal testing of fetal cells. CVS and amniocentesis remove and isolate fetal cells that are then grown and examined for chromosomal anomalies, metabolites that indicate a genetic disorder, and DNA markers. CVS can be done earlier in pregnancy (between 10 and 13 weeks) than amniocentesis (after 14 weeks) and has slightly higher risks of spontaneous abortion.

Ultrasound imaging has become standard practice for all pregnant women. If the ultrasound indicates unusual findings, a woman may be referred for prenatal testing of her fetus.

*Newborn Screening* All states mandate that newborns be tested for various genetic disorders. Although all states test for phenylketonuria (PKU), each state has its own panel of disorders for which it tests. When state-mandated newborn screening reveals a metabolic or genetic abnormality, that information is sent to the parents and the infant's pediatrician. The pediatrician generally refers the infant for follow-up genetic services and may also refer the parents for genetic counseling so that they can better understand the risks for future pregnancies.

*Diagnostic Testing for Childhood and Adult Onset Disorders* Pediatricians may refer parents for genetic counseling when a child's development seems unusual or if the child exhibits somatic abnormalities that may be associated with a genetic disorder. After testing is completed, the pediatrician will continue to provide primary and specialty care for the child with consultation from a geneticist. As a

rule, children are only tested for childhood-onset disorders. The professional ethics of both geneticists and genetic counselors do not support testing children for adult onset disorders because they believe that the child should have the right to elect for the testing when he or she reaches adulthood and is better able to understand the results of testing.

Adults in families with known genetic risks may seek genetic counseling. Since genetic services are provided by specialists, people have access to those services via referrals from primary care providers. Adult testing falls into one of two categories: presymptomatic diagnostic testing for a specific disorder or testing for the presence of predisposing genes that increase risk for a disorder.

Some gene alterations, such as the one for Familial Adenomatous Polyposis (a form of inherited colon cancer), diagnose an illness prior to the expression of symptoms. In this case, the individual with the altered gene will develop the disease later in life and having that information may help the person to prepare for later illness.

Other gene alterations do not diagnose an illness but, rather, change a person's susceptibility to disease. A person with this type of mutation will be at greater risk of becoming ill than the general population. The BRCA1 and BRCA2 gene alterations are known to increase a woman's risk for breast cancer. Although accounting for only 5% to 10% of all breast cancers (McClintock, Conzen, Gehlert, Masi, & Olopade, 2005), those with BRCA1 and BRCA2 gene alterations are estimated to have up to an 85% risk of developing breast cancer. It is also important to note that even with a gene alteration in one of these two genes, one may never develop breast cancer.

### CONNECTIONS: WHY SHOULD SOCIAL WORKERS BE CONCERNED WITH GENETICS?

The primary goal of social work in genetics is not to prevent genetic disorder. The major aim is to improve the quality of life of affected individuals in the face of any limitations or liabilities that might be imposed by the genetic problem and to influence the development of genetic services that are sensitive and responsive to the needs of genetic clients. (Schild & Black, 1984, p. 8)

The earliest articles in social work literature about this area of practice were published nearly 40 years ago. Two seminal articles, one by Schild (1966) and the other by Schultz (1966), discussed advances in genetics and how they might influence social work practice. Both emphasized the need for psychosocial support for individuals and families dealing with genetic disorders and suggested that social workers were particularly well-suited to be genetic counselors. Many changes have occurred since the two articles were published.

Perhaps the biggest change in social work's role in genetics came from the evolution of genetic counseling as a unique profession. The first class of master's level genetic counselors graduated from Sarah Lawrence College in 1971, and the field's professional organization, the National Society of Genetic Counselors (NSGC), was established in 1979. As of 2004, NSGC membership was approximately 2,200 persons from both the United States and Canada (NSGC, 2004). Today, master's prepared genetic counselors are the primary providers of genetic counseling, along with medical geneticists.

The second significant change in the past 40 years came from the HGP. In 1990, the HGP was launched to identify all the genes on the human chromosome and their related diseases and traits. The promise of this research lay in the development of methods of prevention, treatment, and cure of genetic disorders. At present, however, the knowledge necessary to identify the genes that cause particular genetic disorders has substantially outpaced the knowledge necessary to prevent, treat, or cure them.

Research assessing the psychosocial aspects of genetic testing, while currently limited, provides intriguing findings. Lerman, Croyle, Tercyak, and Hamann (2002), in studying breast cancer screening, reported that it was the *perceived risk* rather than the scientific risk that influenced individual's decision making and emotional outcomes after testing. Genetic disorders are biopsychosocial, trans-generational processes (McDaniel, 2005). The importance of this complex set of interactions has been recognized, and the HGP dedicates an expenditure of 5% each year on projects investigating the ethical, legal, and social implications. Social workers can provide education, interventions, research, and advocacy for families.

Despite ceding the genetic counseling role to genetic counselors, there are many important reasons why social workers should understand genetics and be prepared to use their knowledge in practice. Social work theory recognizes people as biopsychosocial beings. As such, an individual's state of health (mental and physical) has considerable bearing on his or her psychosocial needs. Furthermore, a person's psychosocial status has a bearing on his or her health (Berkman & Kawachi, 2000). Thus, the three components of being—biological, psychological, and social—must be conjointly considered in determining a person's functional status.

A person's genetic endowment has significant influence on his or her well-being; thus, to fully comprehend the biopsychosocial self, social workers need at least a basic understanding of genetics. That knowledge base should include an understanding of what the concepts of genetics and inheritance mean, how genes work, the basic modes of inheritance, the difference between predisposition and predictive testing, and the various roles of members of transdisciplinary genetics services teams.

#### TRANSDISCIPLINARY PRACTICE SKILLS REGARDING GENETICS

We are currently experiencing a shortage of health professionals with sufficient knowledge to assist individuals and families to address genetic conditions. In its 1994 report, *Assessing Genetic Risks*, an Institute of Medicine (IOM) Committee asserted that there would be a shortage of specialized genetics personnel to provide services and called for professional education in this area (Institute of Medicine, 1994). Social workers have an opportunity to contribute to the health-care response to this rapidly expanding area and are well prepared to help respond to the current and projected shortage. The National Coalition of Health Professionals for Education in Genetics (NCHPEG), an independent organization that originated within NHGRI, is an interdisciplinary group comprising leaders from approximately 120 diverse health professional organizations as well as consumer and voluntary groups, government agencies, private industries, managed-care organizations, and genetics professional societies. Both the National Association of Social Workers (NASW) and the Council on Social Work Education (CSWE) were original member organizations. NCHPEG is dedicated to providing education for

health-care providers to advance the delivery of genetic services in the United States. It has developed core competencies for all professionals. NCHPEG recognizes that transdisciplinary teamwork is the key to providing comprehensive care for genetic conditions.

The transdisciplinary team's composition varies by location. For example, for cancer genetic care, an oncologist, geneticist/genetic counselor, a surgeon who treats cancer, and a social worker may compose the team. Psychiatric genetic care may be provided by a psychiatrist, psychologist, social worker, and geneticist/genetic counselor. As genetic counseling and testing move into the primary care arena, it may be the primary care doctor, geneticist/genetic counselor, and social worker who provide care. Whatever the exact composition, the team should provide comprehensive biopsychosocial care.

A collaborative approach to care enhances the individual's and family's ability to make a decision that is helpful to them. The medical team members can help the psychosocial team members understand medical implications while psychosocial team members can assess the family's ability to cope with this type of information and provide them with guidance. While scientific journals report new technological findings about genomic science weekly, it is equally important to study the psychological and interpersonal aspects (McDaniel, 2005). Further research is needed to capture the psychosocial aspects of genetic conditions.

#### GENETIC SOCIAL WORK SETTINGS

Social workers in all settings, especially health care and public health settings, are likely to meet with clients who have genetic concerns. Some examples of how genetics may exert influence in nonhealth settings can be found in Box 19.1.

Because nearly all illnesses have some genetic component, health social workers may want to address issues related to genetics with any patient. In many large and regional hospitals, outpatient clinics specialize in care for relatively common genetic illnesses. These clinics, such as those for individuals with cystic fibrosis, sickle cell anemia, or muscular dystrophy, provide specialized medical care for patients. Often, social workers are also employed in these clinics to provide psychosocial support services for patients and their families.

Tertiary hospitals, especially those associated with academic institutions, may include specialized genetics clinics that serve individuals with rare and complex genetic illnesses (e.g., Retinoblastoma). The transdisciplinary team in these clinics includes medical geneticists, genetic counselors, nurses, and sometimes social workers. Specialized genetic clinics provide several types of services:

- Genetic counseling
- Clarification and confirmation of genetic diagnoses, especially for rare disorders
- Risk assessment
- Carrier testing services
- Predictive testing
- Predisposition testing
- Prenatal diagnoses
- Consultation with primary providers for treatment
- Follow-up of development and other medical treatment needs throughout the life span



**Box 19.1****Genetics in Non-Health Settings: Questions and Situations**

- Child welfare (e.g., adoptions and foster care):
  - Should genetic status be considered in determining a person's eligibility to become a foster or adoptive parent? At present, health assessments for applicants do not include genetic screening, however as more is known, it could become required. Social workers will be challenged to help protect the privacy of prospective parents with regard to potential, but not explicit health problems.
  - Should a potential adoptive couple be able to request genetic testing for a child before committing to an adoption? It is widely believed that as much health information that is known should be made available to adoptive parents, and if a child has an already identified genetic diagnosis, that would certainly be included in that information. Social workers may be involved in the policy planning regarding use of genetic testing in adoptions.
  - Are signs of abuse or neglect actually signs of a genetic disease? One example of genetic illness that is confused with abuse is osteogenesis imperfecta (OI). People with OI have fragile, brittle bones that break with little impact. Children who appear in emergency departments with multiple bone fractures are sometimes misidentified as abused.
- Mental health services: What is the underlying contribution of genetics to a client's mental illness? To what degree does genetics govern behavior? Given the genetic components, can behavior be modified? What are the potential risks of mental illness among family members based on a genetic component?
- Gerontological services: How do genetics govern aging? To what extent are behavioral, neurological, and physical disabilities associated with genetics? In what ways can social workers intervene to provide support for healthy aging for an individual coping with a genetic illness?

**REFERRALS TO GENETICS SERVICES**

People are referred to genetics services for several reasons. Couples who are planning a pregnancy and pregnant women who are at increased risk for genetic disorders may be referred for carrier testing. Other pregnant women may be referred for genetic counseling as a result of findings on a routine ultrasound. Newborns with positive findings on a newborn screen and children who have developmental or physical abnormalities may be referred for genetic diagnosis. Adults with diseases that have a genetic association or who are at risk for adult-onset disorders may seek genetic counseling and testing. Because genetic services represent specialty care, individuals and families are referred by their primary care providers to genetics clinics.

Several reasons why someone might be referred for genetic counseling are to:

- Review familial clinical diagnosis to more fully appreciate risks of recurrence.
- Assist the referring physician to confirm diagnosis through clinical and molecular testing.
- Assist the referring physician in genetic risk assessment and gene testing selection.
- Assist the referring physician in test interpretation.
- Disclose results of genetic screening or testing to the patient and family.

Medical geneticists are specialized physicians who have completed a residency in pediatrics and a fellowship in genetics. They work closely with genetic counselors to provide genetic counseling and medical care. Medical geneticists perform clinical assessments of patients to establish a diagnosis of a gene disorder. They order appropriate testing to confirm a diagnosis and review the diagnosis with the patient and family, with emphasis on prognosis and treatment options. The geneticist may follow a patient over time, but usually remains as a consultant to the referring physician.

Genetic counseling is a communication process that is a unique combination of exploration and discussion that takes the eventual form of an education session and culminates in a discussion of the psychosocial meaning of the information presented. The aim of genetic counseling is to assist an individual or family to more fully appreciate the genetic event or events in their family.

Genetic counselors are trained specialists who provide genetic counseling to clients referred by their physicians. Most genetic counselors have a specialized masters of science degree and are board certified by the American Board of Genetic Counseling. Their primary job is to assist people in making an informed choice about a health-care decision that has to do with genetics. Most genetic counselors meet with clients twice for 30 minutes to an hour per session. During the first session, they collect individual and family history and construct a pedigree, or genogram. The pedigree, which is similar to the ecomap familiar to social workers, graphically depicts the relationships among family members and their important health histories. Using the various data that he or she has collected, the genetic counselor assesses risks for the family and suggests appropriate testing.

After testing, the genetic counselor and client meet a second time. At this meeting, the genetic counselor interprets test findings with the client and, if desired, the family. After the second session, the counselor sends a letter to the client with a detailed description and interpretation of the findings of the genetic tests. This letter provides essential documentation of the counseling to which clients can later refer and share with the medical professionals caring for them.

Throughout their interactions, the genetic counselor pays close attention to the psychosocial needs of the client and family. The counselor's five psychosocial goals are to: (1) understand the client in his or her social milieu, (2) bolster client self-awareness and insight, (3) foster active client participation and mutuality in the counseling interaction, (4) elicit illuminating social narratives, and (5) address outstanding emotional issues. As noted, the average time spent with genetic clients ranges from about 1 to 2 hours. There is therefore little time to address psychosocial needs and almost no opportunity to provide follow-up psychosocial care. Genetic counselors recognize the need for these services, however, and, when possible, make referrals to social workers and other professionals. In Schild and Meier's (under review) qualitative study of genetic counseling practice, counselors reported spending about 10% of their time on psychosocial issues. They also reported that when social workers were available, they often referred their clients to a social worker for further exploration of the psychosocial impact of genetic counseling. The genetic counselors who practiced in areas with no social workers available expressed the need for someone to whom they could refer patients. This finding was similar to that of James, Crandall, Rienzo, and Trottier (1995), who found that physicians, nurses, and genetic counselors who provide genetic services all recognized that social work had much to contribute to

the provision of comprehensive services. At the same time, this study found that many genetic services providers did not have access to social workers to whom they could refer their patients.

There is an important and complementary role for social work in genetic practices. Genetic counselors focus on health education related to the decisions around having genetic testing while also attending to the initial psychosocial impact of genetic information. Social workers are particularly well suited to provide psychosocial services to genetics clients and to do so in a culturally competent fashion. To be effective providers, social workers need to strengthen their knowledge base of genetics (Lapham, Kozma, Weiss, Benkendorf, & Wilson, 2000; Oktay, 1998) to work closely and effectively with genetic counselors to ensure that clients receive the most comprehensive and effective services.

### SOCIAL WORK SKILLS THAT ARE APPLICABLE TO GENETIC ISSUES

Building on the work of genetic social work pioneers (Sylvia Schild, Rita Beck Black, & Joan Weiss), NASW took a leadership role by providing a practice update (Taylor-Brown & Johnson, 1998) followed by the 2003 release of the Genetic Practice Standards (see Appendix at the end of this chapter). These standards provide intervention guidance for all social workers. It is social work's unique emphasis on the person-in-environment fit that supports the profession's role in the development of comprehensive genetics services and appropriate social policies related to those services.

#### ASSESSMENT

Dealing with uncertainty is the cornerstone of genetics work in social work practice. The benefits and risks of testing are not always obvious. Helping individuals understand the limits of current knowledge and providing support when dealing with uncertainty is an important aspect of quality care and treatment.

Social workers, who are often involved with clients on a long-term basis, play an instrumental role in helping individuals and families make the necessary emotional and social adjustments to the diagnosis of a genetic disease, understand the ramifications of the diagnosis, cope with the accompanying concerns, and find appropriate services (Bishop, 1993). Rolland (1994) describes four presymptomatic phases for people who test positive for a genetic mutation: (1) a precrisis phase, when the patient is unaware of a potential problem or not yet actively engaged in consideration of testing; (2) crisis phase one, when testing is actively being considered; (3) crisis phase two, during and just after testing; and (4) a long-term adaptation phase that involves living with the information before the illness actually develops. Social work intervention can help the individual work through the decision of whether to be tested and to examine the familial implications at any phase in the testing process. Testing can be stressful, and psychosocial support may be beneficial. When the individual becomes symptomatic with the condition, intervention shifts to a focus on coping and adaptation.

People often come into a genetic testing situation with expectations that are incompatible with what science has to offer (Freedman, 1998). Very skilled practitioners are needed to help people think through the implications of such testing,

to consider how they would handle the results, who they would want to tell, and possible negative consequences (Oktay, 1998).

The paucity of attention to family systems and family relationships in the collection and dissemination of genetic information places individuals and families at increased risk (Taylor-Brown & Johnson, 1999). The needs of various family members must also be considered. Some may not want to know the results of another family member's testing. Another factor influencing families is that media reports of genetic discoveries may cause heightened anticipation of treatment or cure when in actuality there may be a decade or more of lag time between discovery and treatment (Collins & Jenkins, 1997). Family-centered counseling for individuals and families helps the identified patient consider the broader impact on his or her family. Social workers have the training to help families address this complex situation, which has implications across the family system.

*Genograms and Ecomaps* Genograms and ecomaps provide visual tools for families to understand the impact of the condition on the family system. Transdisciplinary team members may find this equally useful.

Social workers are trained to do genograms and ecomaps. When considering a genetic condition, minor elaborations of the genogram can be very helpful. The genogram graphically captures the biological relationships of family members and helps everyone understand the relationships among family members (see Box 19.2). When examining the impact of a genetic condition, the social worker should insert the family illnesses that are known. Also, they should ask the family about conditions that may affect their coping with this information. Depression, anxiety, mental health concerns, or a history of sexual abuse should be assessed (McDaniel, 2005).

The genogram can be augmented by the ecomap that depicts the quality of these familial relationships, which can guide intervention. Additionally, the family's developmental stage, along with the developmental stage of each member, should be assessed when testing is considered. Genetic testing is often considered at vulnerable times in a family's development—during pregnancy, for example. The stress and related anxiety of testing could adversely impact the pregnancy.

In developing the genogram and ecomap, the social worker can elicit relevant information about the coping styles of family members, which will provide insight into how to proceed. Family communication patterns will influence how the family approaches genetic testing. The stigma of genetic testing may lead family members to be secretive about the issue. Asking about how the family has handled previous secrets can be helpful in the present situation (Imber-Black, 1993).

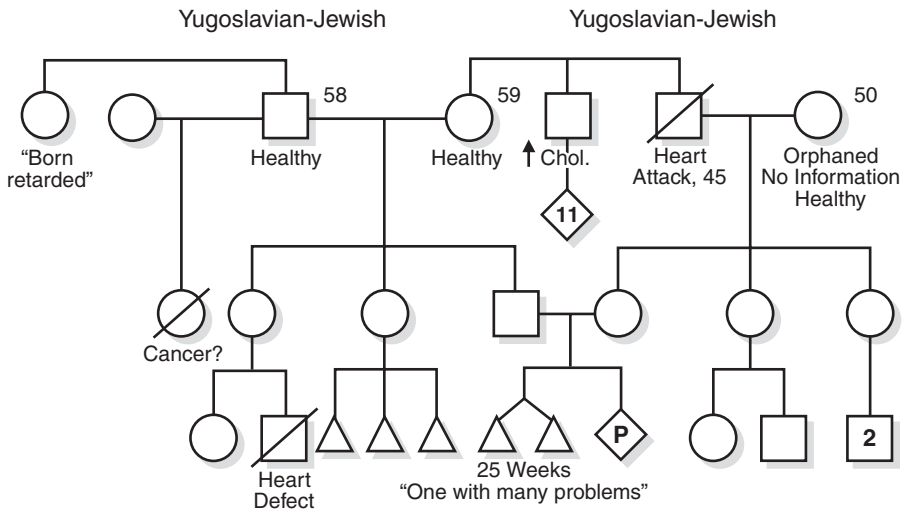
## INTERVENTIONS

Facilitating the family's communication about the testing and its implications is essential. Support for family members undergoing testing and adjusting to the information is important. Since this work is in its infancy, research that documents the personal and interpersonal impact of genetic conditions on families, along with assessment of the psychosocial interventions, is needed. Takahasi and Turnbull (1994), for instance, provide guidance on how to develop a well-defined role for social workers in dealing with psychiatric genetic issues.

**Box 19.2**  
**Family History Drawing—Creating a**  
**Genogram, or Pedigree**

Mr. and Mrs. M. came for a genetic evaluation because they just found out Mrs. M. is pregnant. The physician has told them there is a good chance their baby will be retarded because they are related. They appear quite upset. They don't speak English very well, saying they moved from Europe to the United States recently. You gather the following information and family history.

This is the couple's second pregnancy. The first was a twin pregnancy that ended in a miscarriage at 25 weeks, conceived after 5 years of infertility. The fetuses were both male and one had "many problems." Mrs. M. is the youngest of three girls. Her oldest sister has a daughter and a son and her other sister has two sons, all of whom are healthy. Mrs. M.'s mother is 50 and in good health. She was orphaned and knew nothing about her family. Mrs. M.'s father died at 45 of a heart attack. He had a brother and a sister; the brother has high cholesterol, but the sister is healthy. Both have healthy children. Mr. M. has two healthy sisters. His older sister has a daughter and had a son who died soon after being born with a heart defect. His younger sister is healthy and has had three miscarriages. Mr. M.'s mother is the sister of Mrs. M.'s father. She is 59 and in good health. Mr. M.'s father is 58 and healthy. He had a daughter with another partner prior to his marriage. Mr. M. believes that his half sister is deceased, possibly due to some kind of cancer. Mr. M.'s father had a sister who was retarded and was sent away from home as a child. There is no other history of birth defects, mental retardation, or genetic disease. The couple are from the former Yugoslavia and are Jewish in ancestry.



A peer support group can provide a valuable adjunct to counseling. The Genetic Alliance ([www.geneticalliance.org](http://www.geneticalliance.org)), founded by social worker Joan Weiss, acts as a clearinghouse for support groups across the country and can help connect families to one other. Support groups have begun to take an active role in advocating for the planning, development, and delivery of effective services for

individuals and families affected by genetic disorders. Human service professionals can help genetic support groups mobilize for improved and necessary genetic services and benefits (Black & Weiss, 1990; Weiss, 1993).

Advocacy efforts addressing privacy and discrimination issues, coupled with the social justice issue of who should have access to this emerging knowledge, is a key concern. The Genetic Alliance is actively urging the U.S. Congress to pass genetic privacy legislation. The Genetic Alliance also keeps its members, many of whom are social workers, up-to-date on proposed legislation so that the membership can advocate for an appropriate response from members' congressional representatives.

### ENHANCING SKILLS

Social workers in all settings must educate themselves about the process of genetic inheritance and understand the primary reasons that people seek genetic testing and counseling. Minimally, a social worker should understand the major types of genetic conditions, including single gene disorders, chromosome anomalies, and multifactorial disorders and the effect of harmful environmental toxins on development. Furthermore, an understanding of the patterns of inheritance between generations (autosomal dominant, autosomal recessive, and X-linked recessive) is essential in working with families (Taylor-Brown & Johnson, 1999).

Current social work training is applicable with some adjustment to all populations and settings in which social workers practice. It is important that professional social workers and social work students be educated about the specific application of skills to genetic cases. Social workers are already trained to view people from a biopsychosocial perspective and now must integrate that perspective with the family systems framework, especially during assessment. To identify the patterns of disease in a family, the social worker may need to develop a three generation genogram as part of assessment (Taylor-Brown & Johnson, 1999).

### ETHICAL ISSUES

Genetic testing poses a myriad of ethical challenges. One of the central challenges is that testing one family member for a genetic condition can de facto identify other family members at risk. While some family members may be ready to address the issues surrounding the decision to test, others may not. Whose needs take precedence? How can practitioners help family members approach this question in a way that is respectful to everyone? For social workers in genetics, attempts to deal with ethical dilemmas must rely both on the NASW Code of Ethics (1996) and on reference to major principles of bioethics, such as respect for autonomy, beneficence, nonmaleficence, and justice (Richards & Taylor, 1997). The familial nature of genetics shifts the existing paradigm that focuses on the rights of the individual patient to a broader focus of inclusion of the rights of family members to genetic information. The following section of this chapter highlights some of the more challenging dilemmas confronting practitioners today, including informed consent, testing of minors, and confidentiality of genetic information with regard to disclosure to family members.



The NASW Code of Ethics (1996) provides guidance to social workers working in genetics. Social workers promote social justice and social change with and on behalf of clients. Social work interventions are guided by ethical standards, three of which are particularly relevant to genetics:

1. Section 1.02 on self-determination
2. Section 1.03 on informed consent
3. Section 6.04 on social and political action (Taylor-Brown & Johnson, 1998)

Social workers must advocate for social justice for people who are underrepresented in genetic services. As genetic testing becomes more commercial, there may be a growing disparity between those who have great access to care and those who are uninsured or underinsured. Social workers historically have advocated for access for the underrepresented and this role is highly relevant in the arena of genetics.

#### INFORMED CONSENT

Individuals give informed consent when agreeing to any medical procedure. This consent must be voluntary and based on adequate and accurate information. A person considering genetic testing should engage voluntarily and be able to express her preference. There may be internal pressures (anxiety, fear) or external pressures (family members or health-care providers) to engage in genetic testing. The information contained in the informed consent document can be confusing and may leave a person with unrealistic expectations, even false assumptions, regarding test results (Freedman, 1997). The question of how well a person understands a consent form to a certain extent is subjective and can be influenced by the person's emotional state at the time. The meaning of testing results may be equally hard to comprehend. As discussed previously, while a woman may be negative for a BRCA1 or BRCA2 mutation, she still may develop breast cancer; the BRCA1 or BRCA2 mutations only account for 5% to 10% of breast cancers.

To date, the majority of genetic testing is offered in tightly controlled research settings that require the formal use of informed consent. While signing a form does not ensure that a person understands the procedure completely, it does ensure that the issue of informed consent has been addressed. Due to the shortage of genetic specialists, primary care providers are becoming more involved in genetic testing (Burke, 2004; Hayflick & Eiff, 1998; Touchette, Holtzman, Davis, & Feetham, 1997). As genetic testing moves from tightly controlled research settings with stringent procedures for informed consent to the primary care arena, in which a physician can order a test with little or no pretest or posttest counseling, the potential for misuse of testing increases. Primary care providers experience time constraints that research teams do not. It is possible that a primary care provider will order genetic testing without the individual fully comprehending the implications of the testing. In the extreme, genetic testing is accessible in the public sector via the worldwide web without contact with a clinician (Williams-Jones, 2003). The likelihood of misunderstanding increases as regulation decreases, and the role for social workers may expand to help safeguard clients.

Social workers can assist individuals and families to understand the meaning of genetic testing and related information. Social workers should speak out on issues that undermine clients' rights to informed decision making and voluntary action. Further, collaborating with the Genetic Alliance to get information directly to clients and families may increase the understanding of genetic services in the broader community.

#### TESTING OF MINORS AND OTHER ISSUES RELATED TO TIMING OF TESTING

Children constitute an especially vulnerable group in terms of genetic screening, because they are dependent on adults (Avard & Knoppers, 2001). Some parents may request genetic testing for their minor children. Many parents are anxious about whether their children will be affected by an identified familial genetic condition. Who benefits from this testing? The far-reaching psychosocial risks for children and adolescents, including stigmatization and stress, require caution (Broadstock, Michie, & Marteau, 2000; Michie, 1998). The risks must be seriously considered since the children may not be in a position to decide whether or not to participate. The professional ethics of both geneticists and genetic counselors do not support testing children for adult onset disorders, as they believe that a child should have the right to elect for testing when he reaches adulthood. If no known treatment is available, testing is considered inappropriate (American Society of Human Genetics [HSHG], 1995; American College of Medical Genetics, 1997). As McDaniel (2005) notes, "Many geneticists now recommend that children under 18 not be tested for genetic illness unless they are symptomatic, because it is felt that they cannot truly give informed consent" (p. 33). Despite the lack of professional support for the testing of children, parents may still seek to have a child tested and will benefit from an explanation of why testing is not in the child's best interest. Avard and Knoppers (2001) report that primary care physicians think parents should be able to request that their children be screened for Huntington's and Alzheimer's disease. Social workers can help physicians and parents understand the complexities of testing children and adolescents and the related family issues that are raised by this testing.

The ethical dilemmas related to the testing of children are not limited to parents requesting genetic testing. As our understanding of genetic conditions expands, there will be a push for testing at earlier ages and this is particularly relevant for psychiatric disorders that become apparent during adolescence or young adulthood. There is growing recognition of a child's role in health-care decision making via the concept of pediatric assent. The American Academy of Pediatrics (Committee on Bioethics, 2001) has articulated ethical standards for the role of children in health-care decision making. The academy recognizes that a child's decision making capacity is best determined on the basis of psychosocial development, not age, but the academy has yet to explore the implications of pediatric assent for genetic counseling for complex psychiatric disorders. Nevertheless, there appears to be the following implication: Denying or restricting access to genetic services for adolescents who are capable of mature decision making would not be ethically justified (NCHPEG, 2000). Generally, when screening is carried out, the views of children age 7 or older are considered and consent from adolescents will be recognized (American Academy of Pediatrics, 2000; HSHG, 1995).

If predictive testing for psychiatric disorders becomes available, the testing of minors will be an area of ethical concern more than it has been in the past. The potential for conflict between parents and children will require skillful work by the practitioner to negotiate between the youth and his or her parents. Care should be taken to ensure that the adolescent is informed and developmentally capable of making a decision.

#### CONFIDENTIALITY WITH DISCLOSURE TO FAMILY MEMBERS

Genetic information has been used for good and ill. It is the dark side of genetics, however, that is more familiar to laypersons (Freedman, 1998). Past eugenic movements have clouded history. Therefore, a major fear surrounding the new genetic information becoming available is that it will be used against the very individual it was designed to help (Hudson, Rothenberg, Andrews, Kahn, & Collins, 1995; Johnson, 2004a, 2004b, 2004c, 2004d, 2004e) and this negative sentiment extends to genetic interventions. Singer, Corning, and Lamias (1998) reported that the majority of Americans believe that genetic engineering is more harmful than good. Confidentiality ensures that this information will be safeguarded.

Health care in the United States traditionally has emphasized the rights of the individual to privacy and confidentiality. Health-care providers are mandated by law (e.g., Health Insurance Portability and Accountability Act, [HIPAA]) to protect health information from unauthorized access. Patients are protected from others accessing their health-related information. This protection is particularly important when the condition may be stigmatizing, as in the case of psychiatric disorders.

The genetics revolution is forcing a reconsideration of the emphasis on patient-centered autonomy that has been the dominant model of ethical responsibility in medical decision making (Clayton, 2003). Many questions arise regarding the availability of this genetic information beyond the individual. The familial nature of genetic information will undoubtedly increase the number and intensity of conflicts that come before caregivers or counseling professionals (McDaniel, 2005) who mediate between individuals and families.

Any genetic test provides a window into the genetic composition of an individual's extended family and raises issues of privacy and confidentiality. Testing one family member gives a multigenerational view of the family—past, present, and future. As more genetic information becomes available, there may be conflict between the rights of individual family member and others in the family. Whose needs should take precedence? Today, a patient could refuse to share genetic information with family members. Many family members may be totally unaware of their genetic susceptibility. Each family member will be at different points in his or her understanding of available information. Since testing a family member for a genetic condition has implications for other family members, it is not something that should be done without deliberation regarding familial impact. Providers are challenged about what to do if the tested family member does not want the information regarding a heritable condition shared with relatives who are at-risk for that condition. Equally, some relatives will not want to be told the results of testing. Clinicians have a responsibility to help patients understand the risks faced by family members (Clayton, 2003). But, what will practitioners do if

the patient refuses to share the information with family members who could benefit from care if told?

Some people whom testing identifies as predisposed to cancer subsequently decline to undergo surveillance or other interventions for psychological reasons or because of demands on their time (Clayton, 2003). Genetic information can alter family relationships and create schisms within families. McDaniel, Speice, and colleagues (McDaniel & Speice, 2001; Speice, McDaniel, Rowley, & Loader, 2002) report that women participating in a psychoeducational group for women who tested positive for the BRCA1 or BRCA2 mutation uniformly underestimated what it would mean to them to know that they are positive for the mutations. It is less clear what role the clinician can take in sharing information with relatives. Questions remain about the advantages and disadvantages of families gaining this knowledge.

Psychiatric disorders pose similar challenges, because an individual's susceptibility for a psychiatric disorder comes with information about relatives' susceptibility. Today, relatives do not have access to this information, but as knowledge about psychiatric disorders and treatment increases, the need for relatives to have access to this information may become more germane. The current consensus in the bioethics literature favoring the rights of the individual over relatives may have to be re-evaluated. Care must be taken to weigh the needs of all involved and to work with all family members.

Although broader psychosocial counseling for individuals and their families is not usually available (Oktay, 1998), social workers who are trained to work with families may be the best qualified professionals to assist in weighing the pros and cons of testing. Careful monitoring of the impact on families is needed and social workers can provide research in this area.

Ethical challenges abound and ethical concerns are shifting as the ability to identify and treat genetic concerns advances. Social workers need to keep abreast of emerging technological advances and weigh their impact on contemporary ethical thinking. Familial concerns are becoming more prominent and may compete with the longstanding approach of confidentiality that focuses on the individual. Social workers can facilitate family discussions and collaborate with medical providers to deliver this complex information in ways that are meaningful to the families.

## POLICY CONSIDERATIONS

Policymakers and interest groups recognize the need for policies to address the many aspects of the new genetics. Ownership of genetic information as intellectual property, discrimination, and population screening for genetic disease have all been the subjects of attempted and enacted legislation and policy recommendations in recent years. The National Conference of State Legislatures has a genetics technologies project that produces analysis and briefs to inform policymakers of ongoing activities (Johnson, 2004a, 2004b, 2004c, 2004d, 2004e, 2004f). Another organization, the Partnership for Prevention, has developed a state policy guide to assist legislators in enhancing policies related to genetics (French & Moore, 2003). The Genetic Alliance, an organization founded by social workers and consumer groups, has an active congressional lobbying arm. The following section focuses on four major areas of concern: (1) discrimination in insurance

and employment, (2) privacy of genetic information, (3) access to genetic testing and services, and, (4) newborn screening and population screening. There are numerous additional policy issues that will not be discussed in depth here, for example, those related to federal funding of stem cell research, cloning, and questions of ownership and commercialization of genetic information.

#### DISCRIMINATION IN INSURANCE AND EMPLOYMENT

Questions that people have concerning genetic testing include:

“If I have a genetic test, will that affect my ability to get health insurance?”

“Can I be required to have genetic testing to get life-insurance?”

“How might my genetic status limit my ability to get long-term care or disability insurance?”

“Can a prospective employer deny me a job based on my genetic status?”

“Can my current employer limit where I can work on the basis on my genetics?”

Historical and contemporary concerns about discriminatory practices related to the use of genetic information abound. The eugenics movement emphasized the control of genetic transmission by undesirable members of society. Genetic testing of African Americans in the 1970s resulted in many people who tested positive for sickle cell trait being fired, discharged from the military, or losing medical insurance (Schild & Black, 1984). More recently, the HGP is providing a level of specificity regarding an individual’s genetic makeup that has raised fear that the information accrued will be used against the person it was designed to help (Hudson, Rothenberg, Andrews, Kahn, & Collins, 1995; U.S. Department of Health and Human Services, 1997). Discrimination in obtaining, paying for, and keeping insurance based on genetics has been reported. Further, individuals with genetic diagnoses or who have family members with diagnoses have reported discrimination in employment (Lapham, Kozma, & Weiss, 1996). Hawkins (1997) reported misuse of employees’ genetic information by the Department of Energy. To protect and promote social justice, it is essential that policies protecting individual rights are in place.

Each of the questions at the beginning of this section has been raised in studies, experience, and policy discussions. Unfortunately, there is no simple answer to any of them. Insurance and employment policies are regulated by individual states. Some federal policies are in place, but they are not comprehensive.

For the past several sessions of the U.S. Congress, bills have been introduced to protect against genetic discrimination in all forms of insurance and in employment (Clayton, 2003; Johnson, 2004d, 2004e). Although no bill has yet been successful, the issue has gained significant attention and most policymakers expect stronger and more effective federal policies to be passed in the 1st decade of the twenty-first century.

The primary federal policy that provides protection from genetic discrimination is HIPAA (U.S. Department of Health and Human Services, 1997b), which was passed in 1996. HIPAA amended the Employee Retirement Insurance Security Act of 1974 (ERISA) to allow persons to enroll in group insurance plans of new employers without (or with few) limitations based on preexisting

conditions, if they had been previously covered. A clause in HIPAA protects individuals from rate or eligibility based on a genetic diagnosis if they work for an ERISA-regulated employer. An important limitation of the policy is that ERISA regulation is limited to employers with 50 or more employees, and to those that self-insure (most large corporations). As a result, only about half of Americans work for ERISA-regulated businesses.

Nearly all of the states (47 states as of August, 2004) place limits on the use of genetic information in setting rates or determining eligibility for both group and individual health insurance plans (Clayton, 2003; Johnson, 2004d). In some states, genetic information can be used as actuarial data; in others, genetic information cannot be used for any purpose having to do with health insurance.

Fewer protections are in place with regard to life, disability, and long-term care insurance. Only 18 states place limitations on the use of genetic information in these forms of insurance (Johnson, 2004e). Unlike health insurance, life, disability, and long-term insurance is purchased by individuals rather than groups. As a result, underwriters argue that there is good reason to use all available information, including genetic information, to assess risk and set rates for individuals. Those opposed to the use of genetic testing argue that a group of people could be excluded from insurance protection based on a potential for illness rather than on current health status. Insurers are concerned that if they are limited from using genetic information, they will face the problems of adverse selection. People who are at greatest risk will purchase insurance, but the underwriters will not be privy to that information.

Some states allow the use of genetic information in life insurance underwriting if there is actuarial support for differences in risk due to genetic diagnoses. In others, underwriters are forbidden to require genetic tests, but are permitted to use findings from such tests if they exist (Johnson, 2004e).

Few policies are in place with respect to the relatively newer long-term care insurance market. Because Alzheimer's disease is the most common geriatric neurodegenerative disorder associated with long-term care use, and has been shown to have a genetic component, there is growing interest in regulation of genetic information for this form of insurance (Johnson, 2004e).

As of 2004, 32 states restricted the use of genetic information by employers in the workplace (Johnson, 2004c). Although employers argue that use of genetic information is important to protect individuals from harmful work settings, and thus could improve productivity and reduce absenteeism, at least one federal law and state policies limit its use. In 1995, the Equal Employment Opportunities Commission (EEOC) ruled that genetic predisposition is a protected status under the Americans with Disabilities Act (ADA) (Johnson, 2004c). It should be noted, however, that recent Supreme Court rulings regarding the ADA may place the EEOC's ruling at risk.

In cases of insurance or employment discrimination based on genetic status, social workers may be called upon to advocate on behalf of their clients. It is essential for effective practice that social workers become familiar with the laws of the state in which they practice. Further, as is the case with any policy, it is essential that the social work profession step forward to advocate for appropriate legislation to protect against genetic discrimination at all levels of government.



## PRIVACY OF GENETIC INFORMATION

Should all genetic information about a patient be kept strictly confidential? Should genetic information be treated differently than other medical information, and if so, in what way? In patient-doctor interactions, patients expect their personal health information to be kept confidential. Physicians are bound by law and the professional code of ethics to protect the privacy of their patients' health information. There are times, however, when physicians are compelled by law to break confidentiality (Clayton, 2003). For example, certain communicable diseases must be reported to public health agencies. Physicians also have a duty to warn third parties if a patient expresses a threat against them.

As is the case with any other medical diagnosis, a genetic diagnosis will directly affect the person about whom it is made. However, inherited genetic diagnoses are unique from others in that they are family diagnoses. Although physicians agree that they should tell their patients about the risks to other family members, they do not agree on the advisability of contacting family members if a patient is unwilling to do so. No clear policy exists to compel a physician to break confidentiality in this case, and HIPAA requires that patient privacy be honored. At the same time, there have been at least two court cases in which family members have successfully sued physicians for failing to warn them about genetic risk (Clayton, 2003). Physicians, then, face a conundrum not resolved in law. If they break confidentiality and tell family members of their risk, they are violating HIPAA; if they fail to warn family members, they put themselves at risk for a lawsuit.

Genetic information also is protected as part of medical records. The privacy of medical records is protected at the federal level by HIPAA, and in all states. Some states have specific laws to protect genetic information, thus treating it as a separate form of medical information. Johnson (2004a) states that overall, state genetic privacy laws are designed to provide greater individual control over information by using such means as consent requirements, limits on rights to access, and civil remedies.

## ACCESS TO GENETIC TESTING AND SERVICES

Genetic testing and services are expensive and are not often covered by health insurance. States provide genetic services primarily in the form of newborn screening and for early childhood diseases. No states mandate that genetic testing be an included benefit in health coverage for adult-onset disorders and to date none has considered legislation to do so (Johnson, 2004d). As testing technology becomes more advanced, it is likely to become more affordable. State legislatures may opt to make testing services more available to low-income individuals as the costs of testing are reduced. In making decisions to cover specific tests, policymakers will likely take into account the frequency of the disorder in the population, the cost of testing, and the costs and savings related to treatment of a disorder.

Unlike other diseases that are more likely to occur based on social class, genetic disease is generally equally distributed throughout the population. Access

to services, however, is related to social class. Given the high costs of testing and the potentially higher costs of not identifying a disorder and providing appropriate early treatment, it is the poor who may be most burdened by genetic disease.

Genetic disorders are not equally distributed across racial, ethnic, and religious communities. For example, in the United States, sickle cell disease is most prevalent in the African American population. African Americans are also more likely than White Americans to die from cardiovascular disease, diabetes, and cancer. Latinos are twice as likely to have diabetes than White persons and to die from it (Bonham, Caldwell, Citrin, Hamilton, & Lee, 2001). Cardiovascular disease, diabetes, and cancer all have genetic components. Certain genetic diseases or genes, especially Tay-Sachs, Gaucher, and BRCA1 and BRCA2 are more prevalent among Ashkenazi Jews than among the rest of the White population. In 1995, three universities—the University of Michigan, Michigan State University, and Tuskegee University—formed a consortium to examine the positions of communities of color regarding genetics policy ([www.sph.umich.edu/genpolicy](http://www.sph.umich.edu/genpolicy), 2001). The Communities of Color and Genetics Policy Project developed a set of policy recommendations to address access to genetic testing and services, education, cloning and genetic engineering, genetic privacy, genetic research, genetic testing, and issues of trust and distrust. In each area, the project recommended the inclusion of communities of color in policy making and as equal recipients of services. The project also emphasized the need to reduce mistrust among African Americans of government agencies and researchers. Social workers should advocate for equal access to genetic services to alleviate the inequitable distribution of social costs of genetic illness among sociocultural groups.

#### NEWBORN SCREENING

Since the 1960s, states have mandated newborn screening (NBS) for certain metabolic disorders. The first disorder selected for NBS was PKU, which could be detected by the then newly developed Guthrie test (Koch & Guthrie, 1997). Left untreated, PKU causes irreversible mental retardation. It is fully treatable, however, and mental retardation entirely preventable through the use of a diet free of phenylalanines. After the Guthrie test was developed, parents of children with PKU at first unsuccessfully advocated for a federal law to test all newborns for PKU. Congress did not pass a screening law because the efficacy of treatment for PKU had not been well established. The parent groups then petitioned states to institute screening and after much effort reached their goal. At present, all states test for PKU and provide a special diet to infants who test positive for the disease. PKU testing is efficient because it has high specificity and sensitivity and because treatment has been shown to be effective in preventing the adverse effects of PKU (French, & Moore, 2003).

From PKU screening, testing has expanded to include primary congenital hypothyroidism (CH), a disorder five times more prevalent than PKU (McCabe et al., 1996). Today, the number and type of disorders for which testing is conducted varies from state to state. Each year, new diseases are added to existing screening panels. Many states have added newborn hearing tests, and some states are testing to determine if the hearing impairments are genetically based. The methods that states use to decide which tests to include in NBS vary.

Michigan's NBS program provides an example of how state programs work. The goals of Michigan's program are to provide rapid identification of newborns with rare, serious, but treatable disorders; to ensure early treatment to enhance normal growth and development; and, to reduce the social and economic costs of the diseases for individuals, families, and society (Bach, 2005). Michigan has five criteria for selecting which disorders to include in NBS: (1) the disorder must be serious, (2) a reliable laboratory screening test in the newborn period must be available, (3) the costs of the testing should be reasonable, (4) an effective treatment must be available, and (5) medical facilities must be available to confirm the diagnosis and provide treatment (Bach, 2005). Michigan now tests for 11 disorders. The list is likely to expand as more tests and treatments for disorders become available. NBS is mandated by state law; no informed consent is required for testing. The specimens are collected at birth hospitals or in pediatrician's offices and sent to state laboratories for testing. They are retained for 21.5 years and then destroyed. State law provides that specimens may be used for medical research during the retention period. If a specimen is found to be positive, the parents are notified by telephone or fax on the day of the test. They and their local physicians receive instructions regarding appropriate medical management of the disorder.

An area of concern is the use of NBS to identify an expanding number of genetic conditions or genetic predispositions. A new technology called tandem mass spectrometry (MS/MS) provides another level of cost-effective technical expertise (McCabe, Bradford, & McCabe, 2002) and makes it possible to test for as many as 200 genetic conditions at one time. Some of the tests may identify susceptibility but not be predictive. Further, most conditions involve more than one gene and predictive testing is predispositional. That is to say that positive test for mutations of one or more of these genes increases risk or susceptibility for the disease, but does not ensure that the illness will develop (McDaniel, 2005). The information provided is complex and not always understood completely by health-care providers and parents. That the findings from the tests are often not clinically useful further argues against their use. Families may be confused and overwhelmed by information that only suggests that something could go wrong at some time during the child's life. Parents may become hypervigilant about their child's health and attribute any difference in development or behavior to an errant gene whose influence is unknown. Parents as a rule are not informed that the social environment in which a child is raised is known to have some effect on his or her gene expression.

Some argue that the MS/MS technology should be exploited to its maximum possibilities. The population-based incidence of various gene alterations is important knowledge that has the potential to advance research and understanding of these alterations. Proponents further suggest that parents and providers do not need to be given findings of testing for which clinical benefit is unlikely. Because specimens are kept for a long time, if future research reveals a meaning and treatment for a gene alteration, the families can be informed of the findings later.

In 1999, the American Academy of Pediatrics' Newborn Screening Task Force recommended that the Health Services and Resources Administration (HRSA) develop and implement national NBS standards and practices. The Maternal and Child Health Bureau (MCHB) of HRSA commissioned the American College of Medical Genetics (ACMG) to develop such standards. ACMG brought experts

from numerous fields to establish a scientific process to develop recommendations for a standard NBS test panel (ACMG, 2005). The Task Force recommended that 29 primary disorders as well as 25 secondary disorders that are differential diagnoses for the 29 primary disorders be included on the panel. The decision process was based on the seriousness of the disorders, the ability to treat them, and the frequency of the distribution of them. The report was posted online for public response in March 2005. The final recommendations will be posted at <http://www.mchb.hrsa.gov/screening>.

## RESEARCH

Genetic research is best done by transdisciplinary teams. Social workers bring expertise to these teams that is essential for advancing understanding gene-environment interactions (Grigorenko, 2005). Because factors at a number of levels are known to "get under the skin" and affect gene functioning (McClintock, Conzen, Gehlert, Masi, & Olopade, 2005), it is important to be able to fully delineate social environment and how individuals respond to the environments in which they live and work. For example, Klinenberg (2002) examined the effect of the social ecology of neighborhoods, such as open spaces available to public use, on health.

Social workers may want to expand the understanding of how genetic disease affects families. Do parents change the way they interact with a child with a genetic disease? If parents know a child has a genetic predisposition will they parent differently? What are the psychosocial disruptions faced by families with genetic diagnoses? How are reproductive decisions changed?

Most importantly, social workers must make efforts to learn about new genetic research as it becomes available. To do so requires that they contribute to genetics research and publish their work in social work journals. At the same time, it is important for social workers to read broadly in the nonsocial work literature to expand their knowledge and continue to advance the knowledge base of the profession.

## CONCLUSIONS

The need for close association between social workers and other members of genetic communities is increasingly apparent as more families seek genetic risk assessment for genetic conditions. The promise of individualized medicine that will tailor medication, surveillance, and treatment to unique sets of normal variations in genetic makeup (DNA polymorphisms) is foreseeable. The application of new genetic information must be equitable and just. Its potential misuse is always possible. Social workers frequently provide voice to emerging dilemmas and challenges.

In addition, the psychosocial adjustment to risk information and gene status will be emotionally challenging for some. It is inevitable that some individuals will be challenged by the statistical emphasis about risk and its more subjective existential meaning. Counseling interventions for those persons question the meaning of their "genetic self" in the context of relationship and family and will require the guidance of skilled professionals beyond the initial genetic counseling experience.

Social workers need to continue to support systems that honor differences and challenge efforts to eliminate communities that vary in form, capacity, and perspective. Ethnocultural appreciation of heredity and disease must be honored and opportunities for appropriate community debate and adaptation to new options in health care fostered. Increased options in selection of embryos and early first trimester screening likely will alter the incidence of some conditions. Application of new technologies must continue to be voluntary and support both individuals and communities.

Genetic risk assessment and testing is presently conducted in specialty centers and major medical centers. The rapid integration of genetic information and testing in day-to-day medical practice will result in a growing need for social work professionals to be available to families in primary care centers to provide guidance about the genetic risk assessment and testing process. Additionally, the recent emergence of web-based genetic testing for a range of health conditions from hemochromatosis to cancer presents unique dilemmas to information seekers and their health providers.

Social work has once again taken a role in the direct application of genetic information and testing. The public policy and public health communities are organizing to address issues of access, discrimination, and how to strike a balance between personal and social agendas. Social workers have the opportunity to shape debate, programs, and policy for many years as technologies increase. Genetic determinism must be kept in balance with the numerous social and psychological factors that influence health and well-being.

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### SUGGESTED LEARNING EXERCISES

Read the following exercises and discuss how you would help the clients deal with their genetic concerns.

#### LEARNING EXERCISE 19.1

Jamie and Tom Thompson are referred to assist them in preparing for the birth of a child with multiple birth defects. Jamie is 22 years old and this is her first pregnancy. Jamie and Tom have just learned about the serious medical complication identified by ultrasound for their developing baby. They are 8 weeks from delivery.

Tom has a 10-year-old daughter, Sara, and a 6-year-old son, Will, from a previous marriage who come to their home alternate weekends.

Jamie Thompson is troubled that so little is known about her baby's condition and she wants and needs to understand why this has happened. They met with a fetal-maternal specialist at a research medical center that confirmed the findings and suspicions of her obstetrician.

Tom and Jamie learned their child had a rare inherited condition. This diagnosis was based on the specific pattern of major birth defects in the child and numerous case histories of two unaffected parents with more than one child with this condition. The genetic counselor explored family medical history and documented that no one has reported a stillbirth or neonatal death in three generations. Jamie and

Tom are told that each of them carries a form of a gene that they both share and when they both pass the gene on to a child, the presence of the two altered genes will result in disruption of fetal development. There is no “gene test” to confirm this diagnosis. The future risk for Jamie and Tom is 25% for each pregnancy. There is a 75% chance that a future developing fetus may inherit only one or no altered forms of this important development gene.

Jamie is very concerned about her baby and cannot fully appreciate the risks for the future. Jamie is weepy at work and angry that she needs to wait and see what happens at delivery. Tom is not sleeping and is actively engaging Jamie in discussions about a time line and plans for conceiving the next baby.

1. What are the key pieces of information about the genetic diagnosis?
  - What is the mode of inheritance?
  - Draw a pedigree of this family.
  - What are the possible outcomes for the child?
  - Explain the risks related to future pregnancies for this couple.
2. Make a list of the psychosocial issues for this couple.
3. Prioritize the list so that you can decide with them what you might do to address these issues.
4. What kinds of interventions do you think will be needed for this family?

#### LEARNING EXERCISE 19.2

Karen and Michael have been attempting to achieve a pregnancy for 8 months. Karen is 39 years old and she is anxious about her fertility and her age. Karen asks for a referral to an infertility specialist and she begins to read about other couples experiences at a fertility clinic and the available options. Michael and Karen come to the first appointment with questions in hand and a growing sense of urgency. Their consultation leads to several testing appointments with the good news that no obvious clinical conditions appears to exist.

Karen and Michael meet with a genetic counselor who explains to Karen and Michael their specific age risks for spontaneous chromosome events. Their risk is slightly greater than 1% that any conception may have a chromosome syndrome. Karen is very concerned about the risk and would like to take whatever steps she can to minimize their risk. Michael is somewhat relieved at this risk statement. His interpretation of risk is more positive, a 99% chance that a conception at this age will result in a balanced chromosome complement.

Michael shares with the genetic counselor that he had a second cousin who was identified to have a mental retardation syndrome and who died unexpectedly in an accident. Michael is concerned that his family history will impact their risks. A three-generation family medical history is obtained and Michael is encouraged to ask family members about his second cousin. Karen becomes more anxious about Michael’s family history and her age-specific risks. Karen believes that this is her only pregnancy. She would like to take matters in her own hands. She asks her infertility specialist for fertility enhancement through in vitro fertilization and requests preimplantation genetic screening. Preimplantation genetic screening evaluates the genetic composition of fertilized embryos prior to implantation into the mother’s uterus.



Michael is surprised and troubled. He would like to wait until a full 12 months has passed. They have no obvious fertility concern, only an age effect. They have been encouraged to attempt pregnancy for a full 12 months. At that point, options would be explored. Karen disagrees and feels very disappointed in Michael and begins to experience severe anxiety. She and Michael are referred for counseling.

1. Clearly describe the major issues in this case.
2. In what ways will you discuss the concept of risk with this couple?
3. Discuss the question of perceived burden related to having a disabled child, and how this couple might want to address it.
4. What concerns are raised regarding fertility, and what is the social worker's task with this couple in that regard?

### LEARNING EXERCISE 19.3

Jennifer is 19 years old and this is her first pregnancy. At a routine sonogram at 18 weeks into her pregnancy, Jennifer is told that the visualized bowel of the fetus has a luminescence that is called an echogenic bowel. She is referred to a genetic counselor to review the situation and to decide about additional testing.

Jennifer comes alone to the counseling session. She is very anxious and she reveals that no one knows she is pregnant. The genetic counselor recognizes that the next few weeks may present new challenges and she will need to have a support system around her. She is strongly encouraged to meet with the social worker at the local prenatal clinic. Jennifer is concerned about losing time from work.

Jennifer now needs to appreciate the concerns raised with this ultrasound finding. This luminescence in the bowel of the developing fetus can be an indicator of several conditions. The good news is that such a sonogram finding may not be associated with a medical condition. Yet, some issues need to be considered. The two most common concerns are a chromosome syndrome, like Down syndrome. One in 800 women Jennifer's age deliver infants with this condition.

The other condition that sometimes has this feature is cystic fibrosis (CF). Recently, a recommendation from the American College of Obstetrics and Gynecology has encouraged pregnant women and their partners to participate in screening for alteration in either of the two genes in each parent. Jennifer participated in screening and was told all was okay. Although, her "negative" result reduced her overall chance of being a carrier of a faulty CF gene, she still has a "residual risk." Jennifer is presented with a new dilemma, to evaluate the chance of the developing fetus, it would be best to screen her partner. She is also offered the option of amniocentesis to directly test the cells of the fetus in the amniotic fluid. Jennifer recognizes that she has many serious issues to consider and she feels overwhelmed. She plans to meet with a social worker.

1. List the genetic issues in this case.
2. What are the other major concerns? Make a prioritized list of them.
3. How will you address Jennifer's concern about loss of work time if she meets with you?

4. What other interventions will be important in this case, including those not related to the genetic issues?
5. Do a fish-bowl exercise modeling two sessions between a social worker and Jennifer. Discuss the interactions after each session, and plan what might best occur in the next session.

### SUGGESTED RESOURCES

<http://www.genome.gov/10002096#d>

<http://www.medterms.com>

[www.allwords.com](http://www.allwords.com)

[www.dnapolicy.org](http://www.dnapolicy.org)

American Academy of Family Physicians (ACF; <http://www.aafp.org/x25023.xml>)

With NCHPEG, the ACF offers an Educational Program on Genomics that are eligible for CME credit and also include physician and patient tools, a practice-based quality improvement component, and Web tour of resources.

American Medical Association (AMA; [www.ama-assn.org/ama/pub/category/11832.html](http://www.ama-assn.org/ama/pub/category/11832.html))

The AMA offers a free educational CD on genetic testing to doctors and other health-care professionals.

Coalition for Genetic Fairness (<http://www.geneticfairness.org>)

Genetic Alliance (<http://www.geneticalliance.org>)

Genetic Alliance increases the capacity of genetic advocacy groups to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions. The Alliance has an annual conference, links to support groups, advocacy resources including specialty issue teams (e.g., access, disparities) and news.

Genetic and Rare Conditions Site (<http://www.kumc.edu/gec/support/groups.html>)

The University of Kansas Medical Center has links to lay advocacy and support groups, information on genetic conditions/birth defects for professionals, educators, and individuals, national and international organizations.

*Genetic Family History in Practice* ([www.nchpeg.org](http://www.nchpeg.org))

The new issue of the newsletter has been posted on the NCHPEG web site. Please download and distribute it freely. Topics in this issue include the family history and sudden cardiac arrest, state family history initiatives, the AMA's new family history tools, and the use of famous family histories as teaching tools.

Genetic Resources on the Web (GROW) Listserv (Genetics Resources on the Web) To receive links to the latest articles on cutting-edge genetics research and other genetics-related news, subscribe to the listserv send an e-mail message to [listserv@listserv.geneticsresources.org](mailto:listserv@listserv.geneticsresources.org).

Genetics and Public Policy Center (<http://www.dnapolicy.org/about/visitors.jhtml#Directions>)  
1717 Mass. N.W., Conference Room 500

Hereditary Disease Foundation (<http://www.hdfoundation.org>)  
The Hereditary Disease Foundation focuses on Huntington's disease, a fatal, autosomal-dominant neurological illness causing involuntary movements, severe emotional disturbance and cognitive decline.

Human Genome Project ([http://www.ornl.gov/sci/techresources/Human\\_Genome/home.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml))  
The HGP home page has links to various aspects of the 1990 to 2003 project.

National Coalition of Health Professional Education in Genetics (<http://www.nchpeg.org>)  
Links are updated regularly, and includes core competencies in genetics for health professionals.

National Human Genome Research Institute (NHGRI) at the National Institutes of Health (<http://www.genome.gov>)

NHGRI is one of the 27 institutes and centers at NIH, an agency of the Department of Health and Human Services. The NHGRI Policy and Legislation Database is located on NHGRI's web site. The free, searchable database currently focuses on the following subject areas: genetic testing and counseling; insurance and employment discrimination; newborn screening; privacy of genetic information and confidentiality; informed consent; and commercialization and patenting ([www.genome.gov/LegislativeDatabase](http://www.genome.gov/LegislativeDatabase)).

National Society of Genetic Counselors (<http://www.nsgc.org>)  
This site provides information about genetic counseling and a search to assist people to find a genetic counselor.

The National Society of Genetic Counselors ([www.nsgc.org/consumer/geneticdiscriminationresource.asp](http://www.nsgc.org/consumer/geneticdiscriminationresource.asp))  
This site has a list of resources for patients concerned about genetic discrimination.

*Our Genes Our Choices* (<http://www.pbs.org/fredfriendly/ourgenes/index.html>)  
This site has supporting information for three videos by the same name. The videos, *Who Gets to Know? Genetics and Privacy*; *Making Better Babies. Genetics and Reproduction*; and, *Genes of Trial. Genetics, Behavior and the Law*, are produced by the Fred Friendly Seminars, a PBS series. They are available from PBS.

*Understanding Gene Testing* (<http://www.accessexcellence.org/AE/AEPC/NIH>)  
This resource is from National Cancer Institute and the National Center for Human Genome Research and provides basic information about gene testing and key genetic concepts. This booklet also provides answers to a number of frequently asked questions about the science, potential benefits, and potential risks of gene testing.

University of Kansas Medical Center (<http://www.kumc.edu/gec/geneinfo.html>)

This site provides information for Genetic Professionals with clinical, research, and educational resources for genetic counselors, clinical geneticists, and medical geneticists. This site has links to nearly all of the sites listed next.

#### JOURNALS

*American Journal of Human Genetics*

*American Journal of Medical Genetics*

*American Journal of Public Health*

*Behavior Genetics*

*Genomics and Genetics Weekly*

*Health and Social Work*

*Journal of Genetic Counseling*

*Maternal and Child Health Journal*

*New Genetics and Society*

#### GLOSSARY

**Autosomal dominant mode of inheritance:** A pattern of inheritance in which an affected individual has one copy of an altered gene and one unaltered gene within a pair of autosomal chromosomes. Individuals with autosomal dominant diseases have a 50/50 chance of passing the altered gene and therefore the disorder on to each of their children.

**Autosomal recessive mode of inheritance:** A genetic condition that appears only in individuals who have received two copies of an altered *gene*, one copy from each parent. If both parents “carry” the altered gene, there is a 25% chance of developing the condition. There is a 50% chance of a child inheriting only one altered gene and of being a carrier, like the parents, and there is a 25% chance of the child inheriting two unaltered genes.

**Autosomes:** Any chromosome other than a sex chromosome. Humans have 22 pairs of autosomes.

**Base (a unit of the DNA):** There are four types of subunits to the DNA molecule: adenine (A), guanine (G), thymine (T), and cytosine (C). These subunits are called bases. A sequence of bases (e.g., CAG) is referred to as the genetic code. The bases are the “letters” that spell out the genetic code.

**Base pairs:** Two bases form a rung of the DNA ladder. Each rung has two bases (base pairs). The bases always match as follows; adenine always pairs with thymine, and guanine always pairs with cytosine.

**Carrier:** An individual who carries a gene for a particular disorder without displaying signs or symptoms of that disorder, and who may pass on the gene to his or her offspring.

**Carrier screening:** Testing individuals for the presence of one copy of a altered gene (mutation in a specific gene). Carrier screening is offered to determine the risk to future pregnancies for inheriting two altered copies of the same gene. This results in an inherited autosomal recessive condition. A common example is cystic fibrosis (CF).

- Chromosomes:** The microscopically visible structures of the genetic material. They are composed of deoxyribonucleic acid (DNA) and proteins and, under a microscope, look like little rods. Humans normally have 46 chromosomes—44 autosomes (nonsex chromosomes) plus XX (sex chromosomes) in the case of the female and XY (sex chromosomes) in the case of the male.
- Diagnostic/confirmatory testing:** Used to identify or confirm the diagnosis of a disease or condition in an affected individual. Diagnostic testing may also be useful to help predict the course of a disease and determine the choice of treatment.
- DNA:** Deoxyribonucleic acid is the chemical inside the nucleus of a cell that carries the genetic instructions for making living organisms. The chemical structure of this molecule is a double helix. It is often described as a “twisted ladder.” The rungs of the ladder provide the specific genetic instructions of a gene.
- DNA polymorphism:** A common variation in the sequence of DNA among individuals. A DNA variation is not necessarily disease producing.
- Gene:** A segment of DNA found on a chromosome that codes for a particular protein.
- Genome:** All the DNA contained in an organism or a cell.
- Human Genome Project:** International effort aimed at identifying and sequencing (ordering) all of the bases in the human genome. The American participation in this monumental undertaking has been supported by funds from the National Institutes of Health (NIH) and the Department of Energy (DOE).
- Mutation:** A permanent change to the DNA molecule. The specific change may or may not alter DNA integrity.
- Newborn screening:** Performed in newborns, typically as part of state public health programs, to detect certain genetic diseases for which early diagnosis and treatment are available.
- Pedigree:** A family health history diagrammed with a set of symbols to indicate the individuals in the family, their relationships to one another, those with a disease, and so on.
- Phenotype:** The observable characteristics of an organism, for example hair color, or the presence or absence of a disease. Phenotypic traits are not necessarily inherited.
- Predictive testing:** Determines the probability that a healthy individual with or without a family history of a certain disease might develop that disease.
- Predisposition testing:** Testing for a genetic alternation (mutation) that increases the life-time risk of developing an inherited condition. An example, is BRCA1 and BRCA2 (two breast cancer predisposition genes).
- Preimplantation genetic diagnosis:** Used following in vitro fertilization to diagnose a genetic disease or condition in a preimplantation embryo.
- Prenatal diagnosis:** Used to diagnose a genetic disease or condition in a developing fetus.
- Presymptomatic testing:** Testing for a genetic alteration that determines a very high likelihood that an inherited condition will develop in the individual. An example, Huntington’s disease is an autosomal dominant condition with a 50% risk to each child.
- X-linked:** Relating to genes or characteristics or conditions carried on the X chromosome.

APPENDIX: NASW STANDARDS FOR INTEGRATING  
GENETICS INTO SOCIAL WORK PRACTICE

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NASW STANDARDS FOR INTEGRATING GENETICS INTO SOCIAL WORK PRACTICE

*Introduction*

Current and emerging advances in the science of genetics provide significant promise for enhanced health and well-being and an opportunity for social workers to make a major contribution. As rapid discoveries in genetics (the study of single genes and their effects) and genomics (the study of the functions and interaction of all the genes in the genome) continue to identify genetic components of common diseases such as Alzheimer's, diabetes, cancer, heart disease, mental illness, and even behavioral characteristics, virtually everyone will be affected, our clients as well as ourselves (Guttmacher & Collins, 2002). Knowledge of the genetic makeup of oneself or a family member may present significant dilemmas and may lead to a serious consideration of alternative life plans. A genetic test can alert people to advanced detection and management of some disorders, but currently the ability to test for a genetic disorder often exceeds science's ability to prevent or cure genetic disease. The social worker's role in encouraging clients to become their own advocates in bringing genetic issues to the forefront of quality health care is being defined in part by the completion of the Human Genome Project (HGP), the international effort to map and sequence all the genes in the human body.

A social worker is often the first to provide psychosocial services to individuals and families with genetic disorders. Therefore, it is imperative that social workers become more aware of the ethical, legal, and psychosocial implications of a genetic diagnosis, genetic testing and genetic research in order to empower individuals and families to speak out for their rights as public citizens. In addition, the profession must continue to be active in shaping public policy as well as organizational policy as it relates to genetics and service delivery. Without specialized training, it is inappropriate for social workers to assume the role of genetic counselors, but they have important contributions to make within the social work scope of practice. Social workers can take an active part in ensuring that their clients are protected against genetic discrimination in areas such as health and



life insurance, employment, and adoption. There are increasing opportunities for professional development of social workers in the field of genetics, and social workers should take the initiative to seek out those resources.

As critical issues are identified in the field of genetics, such as the benefits and risks of gene therapy, stem cell research, reproductive technology, and tissue cloning, social workers need to become more informed and sensitive to related ethical, legal, and psychosocial considerations to be helpful to their clients. It is also important that they become knowledgeable about genetic resources in the community.

The ongoing knowledge explosion in genetics and its positive and challenging sequelae present considerable opportunities for the social work profession. Increasingly social workers will be called on to develop as well as confront emerging policies related to genetic testing and treatment.

The National Association of Social Workers (NASW) recognizes the need to integrate knowledge of genetics into social work practice in the context of the NASW Code of Ethics (1999). The standards that are delineated in this brochure represent a foundation for introducing genetics into social work practice.

#### HISTORY OF SOCIAL WORKERS AND GENETICS

For more than 40 years, social work as a profession has recognized the importance of genetic disorders in relation to social work practice and education. The Human Genome Education Model (HuGEM) project, funded by the National Institutes of Health and co-chaired by two social workers, offered workshops and training programs in genetics for social workers and other disciplines across the country from 1997 to 2001 (Lapham, Kozma, Weiss, Benkendorf, & Wilson, 2000). NASW was an active participant in this project, which served as a catalyst for increased involvement in the field. The NCHPEG was formed in 1996 and included two social workers representing both NASW and the Council on Social Work Education (CSWE) on its steering committee. The NCHPEG has developed core competencies in genetics for all health-care professionals; these competencies have been useful in the development of these practice standards for social workers (Jenkins et al., 2001).

In addition to the efforts to improve social work education in genetics, the social work practice community has worked to clarify the social work role in genetics. An NASW Social Work Practice Update in 1998 defined the role of social workers in genetics, emphasizing practice, policy, and ethical issues (Taylor-Brown & Johnson, 1998). The NASW policy statement on Genetics provided a framework all social workers could use to understand ethical and practical issues in genetic testing and research (NASW, 2003). In these NASW documents, it was made clear that social workers in all fields need to understand the ethical and practical issues involved with genetic testing. These include informed consent, confidentiality, self-determination, equal access, and the implications of knowing one's genetic make-up. The Practice Update emphasized the importance of social workers assisting individuals and their families in weighing the positive and potentially deleterious aspects of genetic testing and treatment options. The Policy Statement included a commitment by NASW to continue work to establish the social work profession as a leader in the field of genetics, to support the development of

programs, training, and information that provide social workers with current genetic information for use with clients, and to support policies that provide protection for clients from employment and insurance discrimination.

#### GOALS OF THE STANDARDS

These standards address genetics as an expanding field of knowledge for social workers and emphasize the need for clarification of, understanding of, and education about this specialized area.

The standards are designed to enhance social workers' awareness of the skills, knowledge, values, methods, and sensitivity needed to work effectively with clients, families, health-care providers, and the community and to increase their understanding of the impact that the field of genetics has, and will have, on them.

It is hoped that these standards will lead to the development of clear guidelines, goals, and objectives for expanding current and future areas of social work practice, research, and policy in genetics.

The specific objectives of the standards are:

- To inform social workers about genetics as an expanding field of social work knowledge
- To improve the quality of social work services provided to clients with genetic disorders
- To provide a basis for the development of continuing education materials and programs in genetics
- To ensure that social work services to clients with genetic disorders are guided by the NASW Code of Ethics
- To advocate for clients' right to self-determination, confidentiality, access to genetic services and nondiscrimination
- To encourage social workers to participate in the formulation and refinement of public policy (at the state and federal levels) relevant to genetic research, services, and treatment of populations with genetically identified predispositions or conditions

#### STANDARD 1: ETHICS AND VALUES

When integrating genetics and social work practice, social workers shall function in accordance with ethical principles and standards of the profession as articulated in the NASW Code of Ethics (NASW, 1999).

#### INTERPRETATION

Social workers can make a significant contribution to the field of genetics by advancing a humane and ethical approach. Among the current ethical issues of relevance to the social work profession are

- Equitable access to genetic services, including testing and treatment and financial coverage for these procedures
- Privacy and confidentiality of individual genetic information, particularly in relation to the insurance industry and employers

- Self-determination, including allowing the client to select or refuse genetic testing and treatment in a noncoercive, unbiased manner; allowing the client to exercise the right to know or to refuse to know genetic information
- Informed consent, including protecting the right of the client to make decisions with regard to genetic testing and research based on a clear understanding of the risks and benefits
- Voluntary genetic testing and treatment
- Appropriate authority for genetic decision making on behalf of children and impaired adults
- Protection of the rights of those living with genetically determined conditions

With its historic commitment to serving and empowering populations at risk and promoting human rights and social justice, social work is well suited to address the ethical challenges that arise from new genetic knowledge. The NASW Code of Ethics (1999) provides a philosophical framework for ethical social work practice and a set of ethical standards intended to define acceptable professional behavior. Cultural competence is highlighted and practitioners are enjoined to provide culturally sensitive services. Although the genetic make-up of all individuals across the spectrum of racial and ethnic groups is remarkably similar, the NASW Code acknowledges that members of different cultures have unique norms, traditions, and coping strategies that must be understood and respected. The client's right to privacy and confidentiality, self-determination, nondiscrimination, and social justice are clearly articulated in the Code. Genetic services should be interdisciplinary to achieve a holistic approach to client care. In this context, these standards address mutually respectful relationships among colleagues.

The Code also acknowledges the complexity of ethical dilemmas, which defy simple answers. The Code suggests that the resolution of seemingly contrary mandates is best approached through a reasoned, systematic process that incorporates ethical theory and appropriate peer and interdisciplinary consultation and supervision.

## STANDARD 2: GENETICS KNOWLEDGE

Social workers shall acquire a basic understanding about genetics as a science and a field of study, including its biological, psychosocial, ethical, and legal aspects.

### INTERPRETATION

Advances in the scientific understanding of the human genome leads to better comprehension of diseases, both common and rare, and ultimately leads to better diagnosis and treatment. Because of the rapid increase in genetic knowledge and because most social workers do not have a background in genetics, they need to gain a basic understanding of predisposition to common illness and inherited disease patterns. Social workers must continually update their understanding as new knowledge becomes available.

Social workers need to become familiar with general terminology used in human genetics and basic patterns of biological inheritance and with the role of

genetic factors in maintaining health and preventing disease. Because many diseases are now understood to involve a combination of causative factors, including but not limited to genetics, social workers need to understand how social, behavioral, cultural, economic, and environmental factors interact with biological factors to influence health. It is important to include a relevant medical history in social work assessments in working with families. A family history is crucial in determining a genetic diagnosis and in predicting how various family members might be affected in the future. Social workers therefore have an important role to play in this area, particularly in knowing when to refer their families to genetic counselors and genetic clinics.

Although new information on genetics has increased our understanding of the etiology of physical and mental illness, prevention and treatment of genetic disorders are very limited. This creates difficult dilemmas for people who are now in a position to decide whether to get tested themselves or to have their children tested. People who are at risk of genetic disorders will have increased options to use the new information to guide their reproductive behavior. However, many of the possibilities (e.g., prenatal diagnosis, elective termination of abnormal pregnancies, in-utero treatments, in-vitro fertilization, trait selection combined with selective implantation) raise serious moral questions.

As the genetic basis of common diseases becomes better known, it is especially important for social workers to become knowledgeable about indications for genetic testing and referral resources for such testing. In cases where genetic testing is available, social workers need to understand the potential benefits and risks of genetic knowledge to individuals, families, and communities. Social workers involved in the adoption process need to be aware of the impact of genetic testing on all parties, and place the best interests of the newborns and children first.

Psychosocial reactions to genetic testing, cognitive responses, and coping strategies are important areas of knowledge for social workers, as are family issues. A genetic test may provide people with information that can inform both their reproductive decisions and health behaviors. Because environment affects genetic expression, a genetic test may also alert people to a need to change their physical and social environments—something social workers are particularly skilled in assisting people to do.

Genetic testing has an uneven history in the United States, and social workers need to be familiar with this and have an understanding of how genetic information can be beneficial or misused. Social workers should understand and advocate for legislation that prohibits genetic discrimination and protects against inappropriate disclosure. Social workers working with clients should make efforts to keep current with legislative and legal developments through continuing education and in-service training.

Social workers need to be able to locate genetic resources in their communities and elsewhere.

They need adequate understanding of genetic counseling and how it differs from other types of counseling. This knowledge is helpful in explaining to clients what to expect from genetics professionals and what to expect from social workers. They need to know when referrals are needed and how insurance coverage applies to genetic services.

STANDARD 3: PRACTICE SKILLS IN WORKING WITH INDIVIDUALS, FAMILIES, GROUPS, AND COMMUNITIES

Social workers shall use appropriate practice theories, skills, and interventions that reflect their understanding of genetic factors in their work with individuals, families, groups, and communities.

INTERPRETATION

Basic social work skills can be used to provide genetic services to individuals, families, groups, and communities. A professional commitment to continuing education in genetics is necessary for the integration of current and emerging genetic information and technology into appropriate social work settings. The social workers' biopsychosocial perspective is ideal for their role as liaisons between health professionals and clients, client advocates, and providers of psychosocial support services. Social work interventions can facilitate the identification of individuals in need of medical referral or genetic counseling services, and should include initiating referrals. The social worker should serve as an advocate for these clients, assisting individuals and families in adjusting to chronic health conditions, creating and maintaining appropriate self-help groups, resolving bereavement issues, and taking action at the community level regarding genetic privacy and potential discrimination.

More specifically, social workers should develop skills to:

- Gather relevant genetic family history information, including a multigenerational family history that includes parents, children, siblings, grandparents, aunts/uncles, cousins.
- Identify clients who might benefit from a referral for genetic services.
- Properly communicate to clients the purpose of genetic services and the role of various genetic professionals.
- Provide culturally sensitive services to clients with or at risk of genetic conditions.
- Seek assistance from and refer to appropriate genetics experts and peer support resources.
- Explore with clients the possible range of emotional effects they and family members may experience as a result of receiving or refusing genetic information.
- Assist clients and their families in the genetic decision-making process, and in adapting to genetic information throughout the life cycle.
- Discuss costs of genetic services and insurance benefits.
- Discuss potential risks of discrimination in insurance, employment, adoption, and other areas.
- Safeguard privacy and confidentiality of genetic information of clients to the extent possible.
- Facilitate the creation and maintenance of support resources for genetic service clients.
- Obtain current genetic information from reliable sources, for self, clients, and colleagues.

- Educate clients, professionals, and the community about policy issues regarding genetics.
- Advocate for client-focused public policy in genetics.
- Assist clients in the understanding of the limitations and benefits of participating in genetics research and the importance of informed consent.

#### STANDARD 4: CLIENT/PRACTITIONER COLLABORATIVE PRACTICE MODEL

Social workers shall be able to work with their clients with genetic concerns in a partnership that includes mutual respect, shared information, and effective communication.

#### INTERPRETATION

Individuals and families who have genetic concerns and those serving them have a shared commitment to quality services for everyone. Clients have expert knowledge of themselves and their family situations. Social workers should build partnerships with clients who are affected by genetic diagnoses to create new genetic resources, fight genetic discrimination, and ensure that the needs of individuals and families with genetic concerns are met.

Social workers can be helpful to individuals and families in understanding the information they receive about their genetic makeup. Clients need to have a role in the collaborative team when choices regarding health care and other genetic services are being considered. Social workers should be aware of the psychological dynamics that individuals and families experience when making genetic decisions. In addition, social workers and their clients with genetic conditions should pool their knowledge, skills, and experience to advocate for needed programs and services.

#### STANDARD 5: INTERDISCIPLINARY PRACTICE

Social workers shall participate in multidisciplinary teams that deliver comprehensive genetics services.

#### INTERPRETATION

The complexity of genetic conditions requires a holistic approach to intervention. Individuals and families with genetic disorders, or at risk of them, need to receive services from a variety of health professionals working collaboratively to ensure optimal benefit. Multidisciplinary teamwork is central to the new, dynamic science of genetics (Weiss, Bernhardt, & Paul, 1984). More effective services are provided when an interdisciplinary team shares its expertise with individuals and families with genetic disorders.

By virtue of their education and training, social work professionals are well suited to working as part of a multidisciplinary team. Social workers have expertise in identifying and coordinating services and in bridging gaps in professional communication among service providers.



A common goal for all disciplines is to provide quality services to the population of affected persons and their families. In particular, all disciplines must be attuned to the emotional and social needs of individuals with genetic conditions. Health-care professionals such as social workers, psychiatrists, psychologists, and nurses who provide psychosocial services to individuals and families can include genetic issues in these services. Other health professionals such as audiologists, speech and language pathologists, nutritionists, occupational therapists, physical therapists, and special educators also provide important services to people with genetic disorders. They have much to learn from one another in helping their clients or patients who must cope with these disorders.

Social workers, with a team approach, can establish bridges between clients and health professionals such as genetic counselors, medical geneticists, and primary care physicians. In addition, the support group/professional partnership is essential in empowering individuals and families living with genetic disorders.

#### STANDARD 6: SELF-AWARENESS

Social workers shall have and continue to develop an understanding of their own personal, cultural, and spiritual values and beliefs pertaining to genetics and genetic therapies.

#### INTERPRETATION

Genetic knowledge and practices may conflict with basic beliefs, not only in clients, but in social workers themselves. To be able to effectively assist clients, social workers must continually examine their own backgrounds and identify their assumptions, values, and beliefs related to human reproduction, medical intervention, and the value of life with major disabilities. Social workers must recognize the fact that clients come from a wide variety of religious and cultural backgrounds that may differ from those of the social worker.

Becoming a self-aware and self-reflective practitioner involves the examination of one's own bias about groups with views different from one's own. Social workers need to work to develop an understanding of different views, and to avoid judging clients with different values. They also must understand how a practitioner can subtly influence clients with different beliefs through choice of words and nonverbal expressions and reactions and must learn the skills to avoid doing so in their practice. There may be situations in which social workers will find themselves unable to empathize or remain objective. Self-awareness means taking responsibility for identifying such situations and working on one's issues so that they do not interfere with the client's decision-making. In instances where the social worker is unable to accomplish this, referral should be made to a social worker who can be neutral while assisting clients in this highly sensitive work.

#### STANDARD 7: GENETICS AND CROSS-CULTURAL KNOWLEDGE

Social workers shall have and continue to develop specialized knowledge and understanding about the history, traditions, values, and family systems of client groups as they relate to genetics.

## INTERPRETATION

Social workers need to possess specialized knowledge regarding the influences of their clients' ethnicity, culture, values, religious and health beliefs, and economic situations to understand their client's use of genetic information and services. In providing clinical services, social workers can obtain the sociocultural knowledge through exploration with the client, starting with a family history, or health concern. The social worker will need to assess the meaning the client is placing on this concern. This process of cultural exploration is needed to assist in decision making regarding the pursuit of genetic information and later the results of that decision on the individual, the family, the community and the wider social context. NASW has developed NASW Standards for Cultural Competence in Social Work Practice that establish guidelines for practice (NASW, 2001).

There are many sociocultural barriers to genetic services. Social workers should use and promote the use of appropriate language and literacy levels when discussing genetic information with clients and their families. When taking a genetic family history, they should be culturally sensitive and aware of language and underlying emotional content. The social worker should be alert to cultural factors in working with individuals and families regarding their understanding of genetic information and issues in genetic decision making. As a client advocate, the social worker must address genetic privacy and confidentiality of genetic information with an awareness of possible cultural meaning and social stigma for an individual or a group.

In summary, social workers may assist in overcoming cultural barriers to genetic services by:

- Using and promoting the use of appropriate language and literacy levels when communicating with clients and their families in regard to genetic information
- Being culturally sensitive in obtaining a genetic family history
- Being aware of cultural factors in working with individuals and families regarding the genetic decision making process and in adapting to genetic information
- Addressing genetic privacy and confidentiality of genetic information with an awareness of possible cultural meaning and social stigma for an individual or a group
- Advocating for cultural competence in service delivery and throughout the health system

## STANDARD 8: RESEARCH

Social workers shall contribute to, support, and be cognizant of the development of research-based and practice-relevant knowledge of the psychosocial, cultural, economic, and ethical implications of genetics on individuals, families, and society.

## INTERPRETATION

Much remains to be learned about how to promote the well-being of individuals, families, and society in the context of the genetic revolution. Research is needed on how individuals and families react to learning about their genetic risk status, how they make decisions based on that knowledge, and how society can ensure

that genetic information is used for the common good. Research can inform our understanding of how genetic information may differentially affect the diverse cultural and ethnic groups within our society, and how to be culturally sensitive to these differences. The NASW Code of Ethics (NASW, 1999) states that social workers should “contribute to the knowledge base” of the profession (5.01 (d)), and “promote and facilitate evaluation and research to contribute to the development of knowledge” (5.02 (b)). Moreover, the Code states that “when generally recognized standards do not exist with respect to an emerging area of practice, social workers should . . . take responsible steps (including appropriate education, research) to ensure the competence of their work and to protect clients from harm” (1.04 (c)).

Social work’s “person-in-environment” perspective can make a unique contribution to the understanding of the impact of genetic information on our society (Germain & Gitterman, 1995). Social workers are ideally suited to observe the impact of genetic information on individuals, families, and society; draw preliminary generalizations; and form theories that may be tested in research studies to enhance social work practice. They can initiate surveys among client populations, and document potential problems created by genetic testing, such as discrimination in insurance and employment.

Social work research must be guided by basic ethical and cultural principles, as defined by the Code of Ethics of the National Association of Social Workers (1999). Promotion of the well-being of the client is the primary responsibility of the social worker. Informed consent, the equitable selection of subjects, privacy and confidentiality, the right to withdraw from studies, and avoidance of harm are among the standards that are essential for ethical research studies (National Bioethics Advisory Commission, 2002). The consequences of research must be considered, and appropriate institutional review boards consulted in the early stages of project development. Social workers must also keep current with emerging research by other professionals, and should collaborate in multidisciplinary research with other interested professions, such as medicine, nursing, genetic counseling, psychology, and law.

#### STANDARD 9: ADVOCACY

Social workers shall safeguard the privacy and confidentiality of genetic information of their clients and advocate for and with clients when appropriate to ensure fair social policies and access to quality genetic services.

#### INTERPRETATION

Social workers are keenly aware of the importance of maintaining their clients’ privacy with regard to genetic information, as well as the potential for discrimination based on that information and the need for social advocacy and social action to better empower clients and communities.

To protect clients, social workers must be aware that there are limitations to the confidentiality of genetic test information. Insurance companies, employers, the criminal justice system, and other government agencies have enormous financial incentives to gain access to people’s genetic information. Federal and state policies may not adequately protect people from the use of genetic tests for purposes of discrimination in underwriting and employment. Of particular concern

to social workers is the potential for labeling individuals and withholding services from those with genetic conditions.

The right to confidentiality extends to both the decision whether to be tested and the decision of who is allowed access to the test results. Social workers should inform clients about the possible disclosure of confidential information and the potential consequences before the disclosure is made.

As public policy is developed to define access and funding for genetic services, social workers must be active participants to the process. Social workers should also keep current with federal and state legislation pertaining to genetics and encourage their clients to do the same.

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## CHAPTER 20

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# End-of-Life Care

YVETTE COLÓN

**T**HE PURPOSE OF this chapter is to provide basic knowledge about end-of-life social work practice. Palliative care, an interdisciplinary care model that focuses on the comprehensive management of the physical, psychological, social, and spiritual needs of patients with chronic or life-limiting illness, is an important and growing practice specialty for highly trained physicians, nurses, social workers, and others. Social workers can have a profound impact of the experiences of individuals at the end of their lives, their families, loved ones, and other health providers. Increasingly, however, social workers are challenged to provide services to the increasing number of individuals who need end-of-life care—children and adults who are chronically ill or have life-threatening conditions—as well as those who care for them. Often, they are not prepared for the myriad of complex issues involved in end-of-life practice. Despite their increasing involvement in providing important psychosocial services to dying individuals, social workers do not receive relevant training in their undergraduate and graduate programs.

This chapter examines the individual, social, and organizational contexts of end-of-life care and discusses biopsychosocial assessment and interventions, sociocultural factors, pain and symptom management, multidisciplinary collaboration, and compassion fatigue.

### CHAPTER OBJECTIVES

- Define palliative care at the end of life.
- Describe the roles that social workers can play in end-of-life care.
- Describe the importance of effective communication so that patient and family needs are expressed and appropriate end-of-life care is facilitated.
- Understand the process of end-of-life planning, including advance directives, to promote informed choices and assist patients and families to clarify and communicate their preferences.

- Demonstrate an understanding of factors that influence the death and dying experience of cultural groups and disadvantaged persons at the end of life.
- Describe contemporary grief and loss theories.

The course of death and dying has changed tremendously in the past few decades as a result of social and technological advances. Increases in average life expectancy due to advances in medical science and technology (National Center for Health Statistics, 2004) have influenced our beliefs and attitudes about life and death. The course of illness and dying has changed; where once the onset of illness and subsequent death from certain illnesses was sudden and rapid, now the typical death may be more prolonged. The place where death occurs has moved from the home or community to the hospital, nursing home, or institutional setting. These changes have posed enormous challenges to end-of-life care and to social workers working in the area, including palliative care and hospice.

### PALLIATIVE CARE

Palliative care is an interdisciplinary care model that focuses on the comprehensive management of the physical, psychological, social, and spiritual needs of patients with chronic or life-limiting illness and their families. It is defined as “the active total care of patients whose disease is not responsive to curative treatment.” Control of pain; other symptoms; and psychological, social, and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families (World Health Organization [WHO], 1990, p. 7). Palliative care aims to improve the patient’s quality of life by identifying physical, psychosocial, and spiritual issues and managing pain and other distressing symptoms.

The model applies throughout the entire course of illness and attempts to address the physical, psychosocial, and spiritual concerns that affect both the quality of life and the quality of dying for patients with life-limiting illnesses at any phase of the disease and includes interventions that are intended to maintain the quality of life of the patient and family. Although the focus intensifies at the end of life, the priority to provide comfort and attend to the patient and family’s psychosocial concerns remain important throughout the course of the illness. In the model’s ideal implementation, patient and family values and decisions are respected, practical needs are addressed, psychosocial and spiritual distress are managed, and comfort care is provided as the individual nears the end of life.

Palliative medicine is the medical specialty dedicated to excellence in palliative care. Palliative care specialists, including social workers, typically work on teams and are involved when patients’ disease is advanced, their life expectancy is limited, and medical and psychosocial concerns become complex and more urgent. In practice, these problems often are related to uncontrolled symptoms, conflicted or unclear goals of care, distress related to the process of dying, and increasing family burden. The social worker can educate the family about expected symptoms and their management, clarify information about medications and medical procedures, facilitate their communications with the health-care team, help them make decisions about practical and financial changes in the family structure, normalize their emotional experiences, and teach them effective coping skills.

## HOSPICE

The emphasis in hospice care is on comfort at the end of life through control of pain and other symptoms. Rather than relying on curative interventions and technology, it returns the focus to natural approaches in the care of dying individuals. Hospice focuses on caring, not curing, and, in most cases, is provided in the patient's home. Hospice care is also provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of all ages, religions, races, and illnesses. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed-care organizations (National Hospice and Palliative Care Organization, 2003).

The hospice movement in the United States began in the 1960s, when Dame Cicely Saunders, a British physician, introduced the concept of hospice at Yale University. She came to the United States to introduce the approach to symptom relief for dying individuals and discussed how St. Christopher's inpatient hospice, the first modern hospice, was established in London. Saunders presented the concepts of modern hospice to medical and nursing faculty and students at Yale. Florence Wald, Dean of the Yale School of Nursing, created a multidisciplinary group at Yale-New Haven Hospital to look into changing the way they cared for dying patients, modeling their care after the St. Christopher's approach. In 1975, the first hospice in the United States was opened in Connecticut as a result of the work of this small group of individuals (Saunders, 1999).

Significant barriers to effective end-of-life care exist that include patients' and families' attitudes about death and dying, inconsistent communication between patients and the health-care team, insufficient training of health-care providers, physicians' inexperience with providing care, lack of access to care, and inconsistent reimbursement. The National Academies of Science, through its Institute of Medicine (IOM), produced an important report, "Approaching Death: Care at the End of Life" (2002). Among its recommendations were that:

- Palliative care should be recognized as a defined area of expertise, education, and research.
- Reliable and skillful supportive care should be provided to patients and families facing the end of life.
- Health-care professionals should know and use effective interventions to prevent and relieve pain and other symptoms.
- The public should be educated about end-of-life care and advance care planning.
- Tools should be developed for improving patients' quality of life and that health-care organizations should be required to use them.
- Medical education should be modified to ensure that relevant attitudes, knowledge, and skills regarding end-of-life care are represented and included in teaching.
- Research should be undertaken to strengthen the knowledge base of end-of-life care.

Although efforts have been made to implement these recommendations to improve existing care at the end of life, progress has been slow.

### ANTICIPATING THE END OF LIFE

Patients at the end of life may experience many symptoms that can be distressing to them and their caregivers. Although the dying process is not consistent across individuals and families, some physical, physiologic, and emotional changes can be predicted during the end of life. Advanced stages of illness can result in symptoms such as difficulty breathing, insomnia, loss of appetite, pain, nausea, constipation, and others. Patients may also experience heightened anxiety, depression, anger, or emotional withdrawal. Understanding the nature of the symptoms most frequently experienced by dying people and knowing how to help patients and their significant others cope are critical to effective end-of-life social work practice. The social worker can take the opportunity to educate patients and families about the management of these physical symptoms and psychological responses.

During this important period of care, the social worker can act as a guide to help the patient and family prepare for the end of life. Knowing what to expect is important for social workers so that they can help manage patient and family needs before, at, and after death. Social workers provide anticipatory guidance and expert psychosocial care to promote physical and psychological comfort for the dying person and for family members.

### INTERDISCIPLINARY TEAMWORK

Individuals at the end of life often move between different health-care settings—from home to acute or long-term care facilities, outpatient or inpatient treatment (either curative or palliative), home health care, and hospice settings as their disease progresses. They may receive care from several different physicians, nurses, and other health-care professionals during the course of their illness. Coordinating all necessary care during moves from one setting to another presents considerable challenges to patients, families, and health-care providers. Several different organizations and payment sources may be involved that may present barriers to optimal end-of-life care.

The involvement of an interdisciplinary palliative or hospice care team is an excellent solution to care coordination problems. They typically include:

- Patient
- Patient's family or caregiver
- Palliative care or hospice physician
- Patient's personal physician
- Nurses
- Social workers
- Clergy/pastoral counselors
- Pharmacists
- Home health aides
- Trained volunteers
- Physical, occupational, and speech therapists, if needed

Interdisciplinary teams are common in both hospice and inpatient palliative care settings. The team meets on a regular basis to discuss the patients in their care and to develop individualized care plans that focus on each patient's well-



being and need for pain management and symptom control. Private and public insurance companies to varying degrees pay for end-of-life care services for patients who need them, such as medication and treatments, medical equipment and miscellaneous procedures, and tests necessary to provide comprehensive comfort care. Comprehensive care can include nursing, physician, and home-maker care, personal care (i.e., bathing and dressing), and social work services.

### COMMUNICATION: TALKING ABOUT DEATH AND DYING

Patients, families, and social workers may be influenced by myths about death and dying. They may believe that it is depressing to talk about death or that dying patients and families want to talk only about positive things. They may think that talking about dying will make patients and families upset and angry, that individuals don't always know that they are dying or that dying children don't know how to communicate their concerns and fears, for example. These myths and misconceptions often impede the ability to communicate effectively with patients and their significant others. To communicate clearly at the patient's end of life, social workers must focus on providing clinical care that supports the patient and underlying family values and meanings. Effective communication is critically important to understanding the experiences of others.

Social work traditionally has emphasized therapeutic communication with active listening. For effective communication with patients and caregivers facing the end of life, the first and most important skill that all social workers must develop is listening. Being fully "present" with another person is essential to effective communication. Asking questions or soliciting comments requires truly listening to responses. Listening involves not just paying attention to the words spoken, but to all other verbal and nonverbal cues that are communicated simultaneously, no matter how subtle. Much information can be gained by listening to language content and style, choice of words, pauses, silences, body posture, mood, and facial expressions.

Open-ended questions are useful in gathering information from the patient and family. In contrast to close-ended questions, which allow yes, no, or another fixed response, asking open-ended questions provide an opening or invitation for patients and families to share information that is important to them. Gaining an understanding of the patient's concerns and style of communication, allows social workers to better able to provide the information the patient and family desire in a manner that they can understand (Byock, 1998). Rather than asking close-ended questions, the social worker can ask questions that will elicit more information, such as, "Can you tell me what you understand about the changes in your loved one's condition?" Reflective statements also help to clarify the social worker's and the patient's understanding. An example of a reflective statement is, "What I heard you just say is \_\_\_\_\_. Is this correct? Is that what you intended?"

The ability to make empathic statements, demonstrating an awareness of and sensitivity to another's feelings, thoughts, and experiences (without having the same feelings, thoughts, and experiences of another), is easy for some and difficult for others, but is a simple skill that can be learned and practiced. Listening to

the patient and family, sharing reflective comments about the difficulty of the situation with them, acknowledging their fears and apprehensions, showing concern and looking into their eyes if appropriate are all simple actions which communicate understanding of the patient's experience. Additional techniques for gathering information can be found in Chapter 6 in this *Handbook*.

Communicating with a child who is dying is a special challenge for families and health-care professionals. The death of a child is a unique tragedy and adults, including social workers, may feel a profound need to protect and nurture the child and themselves against the loss, pain, and suffering inherent in the dying process. For these and many other reasons, communicating with dying children is difficult and the resulting discomfort may prevent a social worker from exploring the important needs and concerns of children and their parents.

### END-OF-LIFE CARE CONCERNS RELATED TO A DYING CHILD

Social workers are well equipped to help prepare parents and families to meet the emotional needs of a dying child. Parents and family members are faced with many issues, including concern that they may not be providing care as well as would be the health-care team in the hospital. They need to know that they are doing all that they can to care for the dying child.

It is important that the individual social worker's personal and professional challenges are addressed in caring for terminally ill children and their families. When this is done, social workers are better able to offer support to other members of the health-care team. Health-care professionals, especially physicians, often find it extremely difficult to tell parents that there is no longer any effective cure-oriented treatment for their child. However, if parents are supported in discussing end-of-cure-focused treatment with providers and the need to move to comfort (palliative) care, most end-of-life care providers may be better able to communicate more directly and effectively. The key for the social worker is to recognize the critical role of encouraging and supporting parents in expressing their true feelings, concerns, and goals.

Children are never too young to be told that they or someone close to them is dying (Silverman, 1999). Dying children often know they are dying. Failing to acknowledge death creates a barrier between the child and the adults who are caring for them. Sick children have a common fantasy that they are responsible for their own illnesses; being sick can be interpreted as punishment. Many children who choose not to discuss painful feelings may be trying to protect their parents and siblings from further emotional pain. In the absence of honest discussion, silence only reinforces this and other misconceptions that the child and his or her siblings create. It isolates the child and limits the sharing needed for coping with overwhelmingly difficult experiences. Dying children experience feelings similar to dying adults, namely: anxiety, fear, loneliness, and depression as well as hope and love. Children need to know that they are not responsible for their illnesses. Sharing information in a way that is cognitively and developmentally appropriate is essential.

Dying children of any age, as well as their siblings, have the capacity to communicate their concerns clearly. The ways children communicate depends on their age and developmental stage. Verbal language must be adapted to a conceptual level and vocabulary that the child can understand. Children may express their

fears, worries, or concerns directly, indirectly, or symbolically. They can communicate in many ways other than direct conversation. Music, art/drawing, drama/story telling, and play are some expressive therapies that can be used to foster effective communication with children.

## SPIRITUALITY

Facing death often forces individuals to consider spiritual or existential issues that can be central to end-of-life care. Spirituality can be profound resource for coping with the challenges of all aspects of life and death. Social workers in end-of-life practice must be sensitive to these concerns in their patients and be willing to assist with their spiritual explorations.

As defined by the *Merriam-Webster Dictionary* (1995), religion is “the service and worship of God or the supernatural, a commitment or devotion to religious faith or observance or a personal set or institutionalized system of religious attitudes, beliefs, and practices.” In contrast, spirituality is defined as a sensitivity or attachment to religious values, the quality or state of being spiritual. Spirituality is related to the human spirit as opposed to material or physical things. Definitions of religion and spirituality can be found in the literature discussing the integration of spirituality and mental health practices. Mauritzen (1988) defines spirituality as “the human dimension that transcends the biological, psychological and social aspects of living. It is the ‘agent’ for the integration a person’s identity and integrity. In very general terms the spiritual dimension is the ‘agent’ for an individual’s existence as a person” (pp. 116–117).

Constructing a universal definition of spirituality, however, is difficult. It is important to be aware of the patient and family’s spiritual belief system; awareness and appreciation of a patient’s spiritual orientation is essential to end-of-life care. Impending loss and the reality of death may shake their spiritual beliefs and may leave them feeling angry or hopeless. For believers and nonbelievers, atheists or agnostics, the need to make sense of impending death is central to a person’s struggles regarding meaning at the end of life.

Working in end-of-life care also may raise spiritual issues for the social worker. Witnessing the suffering of others or coping with the stress of working with dying individuals and their families may challenge the social worker’s basic religious or spiritual beliefs. This may require the professional to deal with countertransference issues related to suffering and death (Cornett, 1998). Before social workers can help with these existential concerns, they must understand their own spirituality and religious beliefs and the influence of these beliefs on their professional and personal lives. When patients and caregivers express religious and spiritual concerns, the social worker’s role is to listen so that she can help them find ways to address their needs.

## DIVERSITY AND HEALTH DISPARITIES IN END-OF-LIFE CARE

All individuals’ life experiences contribute greatly to the complexity and uniqueness of the end-of-life issues that we all face. These experiences, as much as anything, shape our desires and beliefs about health, illness, death, and dying. The Diversity Committee of the Last Acts Coalition (2001) advocates recognition, acceptance, and

support of its recommendations concerning individuals' experiences with race; historical oppression; war and its aftermath; cultural, religious, and spiritual practices; affectional orientation; discrimination, and poverty. The true meaning of diversity (especially as it affects the end of life) is as much about these unique, view-shaping experiences as about the narrower, yet more common concept that focuses on ethnicity or religion. (p. 3)

Death and dying among members of different racial or ethnic groups and disadvantaged persons can pose tremendous challenges to social workers. Cultural and economic factors play a significant part in health care, health-care decision making, and end-of-life experiences. Health care is less accessible to the disadvantaged, including people of color, immigrants, elders, children, women, the poor and uninsured, and those who are institutionalized (i.e., nursing homes and prisons; Smedley, Stith, & Nelson, 2002).

Because of group differences in health, the U.S. Congress requested a report from the IOM; disparities were consistently found across disease areas, clinical services, and clinical settings (Smedley et al., 2002). The focus of the IOM report was on conscious and unconscious discrimination or bias and its effect on health-care delivery. The IOM's general recommendation was to increase awareness of disparities among the general public, key stakeholders, and health-care providers. They provided specific recommendations for critical areas, including patient education and empowerment, cross-cultural education in health professions, legal, regulatory, and policy interventions, and health system interventions.

Communication between health-care provider and patient is vitally important to effective end-of-life care. A patient's understanding of his life-limiting illness will affect the course of his palliative care. Health-care professionals must be aware of subtle cultural variations in language, verbal and nonverbal communication, and expressions of distress (van Ryn & Burke, 2000). They must be able to comprehend the effects of ethnicity and spiritual beliefs on the daily lives of patients and families.

Culture influences what is considered a health problem, how symptoms are expressed and discussed, how health-care information is received, what type of care should be given and how rights and protections are exercised (see Chapter 6, this *Handbook*). Additionally, health-care decision making is influenced by demographic factors such as level of education, other socioeconomic status factors, geographic region (urban, rural), and time spent in the United States.

Kleinman (1988a) proposed obtaining a patient's or caregiver's explanatory model of illness, at any stage of the disease continuum by asking a series of questions designed to elicit their understanding of the situation, such as:

- What do you call the problem?
- What do you think caused the problem?
- Why do you think it started when it did?
- What do you think the sickness does? How does it work? How does it affect your body?
- How severe is the sickness? Will it have a long or short course?
- What care do you desire? What are the most important results you hope to get from your care?
- What are the chief problems the sickness has caused?
- What do you fear most about the sickness?

The need to provide culturally competent care has been emphasized in many arenas, that is, to respect and maintain sensitivity to issues related to an individual's culture, race, gender, sexual orientation, and socioeconomic status while providing optimal end-of-life care. In 2001, the National Association of Social Workers (NASW) developed Standards for Cultural Competence in Social Work Practice; NASW defines cultural competence as "the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognizes, affirms, and values the words of individuals, families, and communities and protects and preserves the dignity of each" (p. 11). The standards address the following areas: ethics and values, self-awareness, cross-cultural knowledge, cross-cultural skills, service delivery, empowerment and advocacy, diverse workforce, professional education, language diversity, and cross-cultural leadership.

### ADVANCE DIRECTIVES

Advance directives are written documents completed by an individual that specify treatment preferences for health-care decision making, particularly about end-of-life care and whether to use life-sustaining treatment. They provide an avenue for individuals to make known their wishes about end-of-life treatment. The most common advance directives are the Health Care Proxy (durable power of attorney for health care) and Living Will.

The Patient Self-Determination Act has done much to increase the use and awareness of advance directives. It was signed into law in November 1990 and became effective in December 1991 (Federal Register, 1990). The Act is applicable in all 50 states. The law requires that all facilities receiving Medicare or Medicaid reimbursements discuss health-care directives with newly admitted patients, provide a written explanation of the state's law on health-care directives, and provide an explanation of the hospital's policies in enforcing them. Health-care facilities are also required to record patients' health-care directives as part of their medical records. Additionally, those facilities must educate staff and the community they serve about advance directives and ensure that patients are not discriminated against on the basis of whether or not they have an advance directive. This provides excellent opportunities for social workers to initiate direction and leadership.

A durable power of attorney for health care involves the legal appointment of an individual to speak for a person should that person become decisionally incapacitated. Multiple types of durable power of attorney are available, covering business, financial, or health-care decisions. The purpose of legally appointing a person as a health-care proxy is to ensure that an individual's wishes are followed in the event he is not able to make his own decisions. The person appointed as proxy acts to ensure that health-care providers know of those wishes and can advocate for their enforcement. The person named as an individual's health-care proxy should be someone the individual trusts and someone with whom he feels comfortable in discussing his wishes. The person appointed to oversee an individual's health-care wishes could be a spouse or partner, relative, or close friend. An individual serving as a proxy should be aware of state regulations or variations regarding advance directives. Additionally, they must be aware that they

may have to fight to assert the patient's wishes in the event of a disagreement with the health-care team or with other family members.

A Living Will is a directive to a physician and health-care team that states a person's wishes about what life-prolonging treatment should be provided or withheld should he lose the ability to communicate those wishes. Life-prolonging therapies include mechanical ventilation, blood transfusions, dialysis, antibiotics, and artificially provided nutrition and hydration. A Living Will should be viewed as a way to direct a physician to provide an individual with whatever type of medical care they want, within reason.

Any competent adult can complete an advance directive. They must be completed by the individual to whom the directive applies (i.e., a relative cannot complete an advance directive for the patient even though he or she may be the health-care proxy). Advance directives can be rescinded at any time for any reason. They should be properly signed and witnessed, but a lawyer is not required to complete or rescind a valid advance directive. The patient should retain copies of the directive and also provide copies to the designated proxy and to appropriate health-care providers. Note that advance directives are more frequently used by White, middle to upper socioeconomic status individuals than by individuals from lower socioeconomic status or ethnic or racial minorities. Social workers may need to be proactive in educating disadvantaged persons about the value of advance directives and help them with end-of-life care planning. Research suggests that many ethnic or racial minority groups in the United States fear being denied beneficial treatment at the end of life more than they fear receiving excessive therapy and are therefore less likely to complete an advance directive (Crawley, Marshall, Lo, & Koenig, 2002).

Social workers should discuss advance directives with each of their patients. They can help educate patients and families on the uses and benefits of advance directives and advocate for their choices. They can assist patients to complete an appointment of a health-care agent and a Living Will, ensure that this information is recorded in the patient's medical record, encourage the patient to inform the designated proxy of his wishes and if requested, help the patient discuss his wishes for end-of-life care with the designated proxy. A Consumer's Toolkit for Health Care Advance Planning is available for downloading at the American Bar Association web site (<http://www.abanet.org/aging>). Advance directives for each state and information about advance care planning are also available at the National Hospice and Palliative Care's Caring Connections web site (<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>).

## UNDERSTANDING LOSS

Individuals and families facing end-of-life issues experience many kinds of loss besides impending death. These include multiple losses (outlined next) as the person becomes more ill and withdrawn from his or her prior life and activities. Understanding the common, natural responses to loss can facilitate a social worker's ability to prepare patients and families with anticipatory guidance and help them normalize the possible and often uncomfortable expressions of grief.

Loss is often thought of in relation to the death of a significant loved or valued person. This can include:



- One's self (impending or future)
- Spouse, partner, siblings, children (including through abortion, miscarriage, or stillbirth), other relatives
- Close friends
- Coworkers, business associates, colleagues, acquaintances
- Well-known personalities or celebrities or (i.e., President John Kennedy, Princess Diana)
- Pets
- Loss also can occur through other means such as separation or divorce
- Temporary or permanent placement in a nursing home, hospital, hospice facility, the military, adoptive or foster home, or prison
- Geographic moves due to job relocation or assignment in the military

For the person who is dying, the end of life also brings the loss of part of the self, which includes physical, psychological, and social losses. Physical loss is the loss of body parts (i.e., invasive medical procedures or surgeries) and loss of functioning (i.e., lack of mobility, impaired bladder or bowel control, or reduced sexual functioning). Psychological loss is also relevant for patients at the end of life and can include loss of independence, dignity, self-esteem or self-concept, loss of memory or mental acuity, and loss of opportunity, goals, hopes, and dreams. Social loss includes loss of work or income and loss of social roles (i.e., role of partner/spouse or parent).

Each loss in a person's life is experienced uniquely because it is influenced by multiple factors, that is, characteristics of the individual, the nature of the relationship with the deceased, how the loss occurred, and influences from the past.

Controversy has surrounded the concept of "stages" of loss, in part because it implies a linear movement through a grief process. More recent thinking considers a homogeneous course through which everyone moves in a certain somewhat naive course. Grief is a natural response to loss. It is not merely sadness or crying in response to a loss.

Different conceptual frameworks exist to explain the experience of grief. Rando (1984) conceptualized grief within three broad categories: avoidance, confrontation, and reestablishment. Avoidance includes "shock, denial, disbelief, emotional anesthesia, confusion, numbness, disorganization, and the intellectualized acceptance of the death." Confrontation is a "highly emotional state wherein the grief is most intense and the psychological reactions to loss are felt most acutely." Reestablishment is the "gradual decline of the grief and marks the beginning of an emotional and social reentry back into the everyday world" (pp. 28–29). The tasks of the griever are then to:

- Acknowledge, accept, and understand the reality of the loss.
- Experience the pain of the grief and react to the separation from that which was lost.
- Adapt to a new way of life.
- Reinvest in a new way of life.

There may be ambivalence about the appropriateness of expressing so many emotions and resistance to revealing those emotions to others. Grievers may feel overwhelmed by the intensity of their emotions and exhausted by the process.

They may avoid or repress thoughts, feelings, or memories associated with the deceased. They may protest or feel denial about the death or have feelings of unreality or depersonalization.

Factors that influence how individuals cope with loss include childhood, adolescence, and adult experiences of loss and the recency of those losses, successful or unsuccessful resolution of losses, previous mental health problems (i.e., depression), and any physical health problems, life crises or changes prior to the current loss. The relationship with the deceased also plays a role in coping with the loss: the relationship (partner/spouse, child, parent), length of the relationship, role the deceased occupied, strength of the attachment, and degree of dependency.

Additionally, it is important to consider how the loss occurred. The circumstances surrounding the loss, preparation for bereavement (anticipatory grief), the griever's perception of preventability, their perception of the deceased's fulfillment in life, and any unfinished business that was present in the relationship with the deceased all play a role in the grief process. These factors make grief a very personal and individual process.

Grief counseling involves normalizing the grieving person's feelings and behavior and helping the griever identify and express his feelings, actualize the loss, facilitate his ability to live without the deceased, reengage with life, and provide continuing support throughout the process. Social workers should be alert to symptoms of complicated or troubled grief while providing counseling to help patients and families normalize their often-difficult responses to grief. Uncomplicated grief is a grief reaction that, although painful, moves the survivor closer to acceptance of the loss and enhances the ability to carry on with life. In contrast, complicated grief is a grief reaction that includes difficulty acknowledging the death, intrusive thoughts about and yearning for the deceased, and feelings of futility and purposelessness about the future.

### ANTICIPATORY MOURNING

Grieving that begins before a death occurs is known as *anticipatory mourning*; the physical and emotional reactions involved are often the same as those experienced in normal grieving. Rando (2000) defined anticipatory mourning as "the phenomenon encompassing seven generic operations grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing conflicting demands, and facilitating an appropriate death that, within a context of adaptational demands caused by the experiences of loss and trauma, is stimulated in response to the awareness of life-threatening or terminal illness in oneself or a significant other and the recognition of associated losses in the past, present and future" (p. 51).

Involving the whole family, as defined by the patient, in his care and treatment can decrease anxiety and allow for a sense of control, participation, and support. Meeting with the entire family as a group and establishing a personal relationship with each family member (if possible) is crucial. Within their ability, social workers can help families to appropriately express their anticipatory grief and develop or maintain open communication. Equally important is advising the family about the practical realities of illness and the death. Dying patients may be very concerned about these practical matters and do not want to burden their loved ones. Social workers can help patients and families plan for future care

needs as well as preferences for burial and associated financial arrangements. These help persons who are at the end of their life feel some control and ensure that their wishes are honored.

### DISENFRACTISED GRIEF

Doka (2002) defined disenfranchised grief as the grief experienced in connection with a loss that is not socially acknowledged, publicly shared, or supported through usual rituals. The significance of the loss is either not recognized or the relationship between the deceased and the bereaved is not socially sanctioned, the person suffering the loss is given little or no opportunity to mourn publicly. It is experienced when the relationship is not recognized (lovers, ex-spouses, same-sex partners, close friends), when the loss itself is not recognized (stillbirth, miscarriage, abortion, adoption, pet loss), when the griever is not recognized (very young, very old, developmentally disabled). The manner of death itself can be disenfranchising (murder, suicide, AIDS). When such deaths are treated as less than significant losses, the process of grieving becomes more difficult. Social workers who become close to patients who die can also be disenfranchised mourners. Their own grief experiences should be acknowledged and dealt with. Often social workers in the same area form support groups or hold brief ceremonies to recognize all of their patients who have died in a period of time.

### COMPLICATED GRIEF

It is sometimes difficult to differentiate uncomplicated from complicated grief. Worden (2001) outlined four complicated grief reactions:

1. *Chronic grief*: One that is prolonged, is excessive in duration, and never comes to a satisfactory conclusion.
2. *Delayed grief*: Emotion that has been “inhibited, suppressed, or postponed.” A subsequent loss may elicit an exaggerated reaction because the bereaved is grieving for two losses.
3. *Exaggerated grief*: Occurs when feelings of fear, hopelessness, depression, or other symptoms become so excessive that they interfere with the daily existence of the bereaved.
4. *Masked grief*: Symptoms and behaviors experienced by a person who does not recognize the fact that these are related to a loss.

The task of a social worker is to recognize symptoms or responses that may indicate complicated grief, including an excessive degree of guilt, remorse, self-blame, a delay of up to 6 months in beginning the grief process, a prolonged grief process, hostility against the deceased’s caregivers, avoidance of the loss through overactivity, avoidance of emotional expression and severe depression or insomnia, or self-destructive behaviors (Worden, 2001).

### SOCIAL WORK IN PALLIATIVE CARE

Reese and Raymer (2004) provided evidence that social work involvement in hospice operations is correlated significantly with reduced patient care costs. Their survey about social work involvement on hospice outcomes included social workers

and hospice directors in 66 randomly selected hospices across the United States who completed questionnaires and reviewed 330 patient charts. The survey clearly indicated consistent benefits of social work involvement in all aspects of hospice care, to the patients and families as well as to the hospice administration itself. The qualifications of the social work staff and hospice staffing and budget policies were also important variables. Better outcomes were correlated with more experienced social workers, higher social work salaries and higher social work staffing ratios. The authors recommended that social work participation take place from intake and assessment through continuing care in order to prevent crises, reduce the severity of anticipated problems, promote effective pain and symptom management, provide expert psychosocial interventions and maximize the opportunities for patients and families to maintain a good quality of life at the end of life.

The Open Society Institute's Project on Death in America (PDIA) began the Social Work Leadership Development Awards Program to identify and support outstanding social work faculty and clinicians committed to improving the care of the dying and the bereaved. The program promoted innovative research and training projects that reflected collaborations between schools of social work and practice sites that would advance the ongoing development of social work practice, education, and training in the care of the dying. These awards promoted the visibility and prestige of social workers committed to end-of-life care and enhance their effectiveness as academic leaders, role models, and mentors for future generations of social workers. Between 2000 and 2004, 42 social workers were given the award (for a list of PDIA social workers, please visit <http://www.soros.org/initiatives/pdia>).

The Social Work Summit on End-of-Life and Palliative Care took place in March 2002. Social work and end-of-life care experts met for a 3-day summit to design a social work agenda to improve care for the dying and their families. The agenda called for organized professional leadership, standards of practice, and increased preparation at all levels of social work education. Leaders from national social work organizations, social work schools, hospices, hospitals, government agencies, and end-of-life care advocacy groups attended the meeting, representing more than 30 organizations. Social workers take the lead in providing essential emotional and social services to the dying and the bereaved, including guidance on advance directives, emotional support to patients and their families, and assistance in locating health-care and financial resources. There are long-standing gaps, however, in end-of-life care education at the undergraduate, graduate, and postgraduate levels and a general lack of access to leadership in practice, teaching, advocacy, and research. The summit was co-sponsored by Last Acts, the Duke Institute on Care at the End of Life, and the Soros Foundation's Project on Death in America.

The Social Work Summit on End-of-Life and Palliative Care was held again in June 2005. Participants continue their work through the Social Work Hospice/Palliative Care Network, an emerging network of social work organizations and leaders who seek to enhance end-of-life and hospice/palliative care in social work (<http://www.swhpn.org>).

As an outgrowth of the National Social Work Leadership Summit, the National Association of Social Workers (NASW) began an initiative in 2003 to increase social workers' awareness of end-of-life issues, to create and advocate for more edu-

cation and training opportunities in the field, and to promote the value of social work in palliative care, hospice care and other end-of-life practice areas. NASW received a grant from the Project on Death in America to develop practice standards on palliative care, end-of-life care, and grief work to provide social workers with guidance for ethical and effective practice (NASW, 2004), develop a comprehensive policy statement on and develop a web-based course on the standards with pre- and posttesting to document knowledge gains. This initiative complements other NASW policy statements on client self-determination in end-of-life decisions, health care, hospice care, long-term care, and managed care.

### COMPASSION FATIGUE

Social workers and other health-care professionals who work in end-of-life care experience a great deal of trauma of illness and death. Those who work in end-of-life care can experience short- and long-term effects that can be profoundly disruptive, both professionally and personally. Social workers develop and nurture a therapeutic alliance with patients and families; in that process, they can be seriously affected as a result of listening to stories of suffering and pain. Compassion fatigue, also referred to as secondary trauma, is the natural, predictable, treatable, and preventable stress resulting from helping a traumatized or suffering person (Figley, 1994).

Some professionals may be more vulnerable than others to compassion fatigue due to, for example, multiple losses, unresolved personal trauma, or insufficient recovery time. Social workers also grieve and need support. Each social worker has her own professional style and ways of coping that may mask symptoms and interfere with coping. They need effective self-care strategies and stress management techniques to treat the symptoms of compassion fatigue. Strategies to prevent or cope with compassion fatigue include supervision, personal psychotherapy, grief support for staff, stress management, and maintaining a balance between personal and professional responsibilities.

### CONCLUSION

Many issues in end-of-life care are beyond the scope of this chapter: pain management in palliative care and ethical issues such as medical futility, withholding or withdrawing medical therapy, assisted suicide, euthanasia, and terminal sedation, for example (see chapters elsewhere in this *Handbook* regarding pain management and social work ethics for more details). It is difficult for social workers and health-care professionals to use their considerable skills in situation that ultimately will not change the final outcome of a life-limiting illness. Experience tells us that as patients and families approach the end of life, social workers often feel they no longer have a role to play. They may want to withdraw from the patient and family. One of the hardest tasks is to be emotionally present during moments when there is nothing that one can do. Having a social worker be a physical and emotional witness to their suffering is often all that is needed by patients and families. Accepting the limits of what we are able to do and sitting with a patient and family who are trying to cope with the end of life can be an important and meaningful experience, for the patient and family as

well as the social worker. Cultivating the ability to be present in the moment with patients and families and be a witness to their personal struggles at the end of life is one of the most difficult, but important and rewarding skills a social worker can possess.

## SUGGESTED LEARNING EXERCISE

### LEARNING EXERCISE 20.1

Maria was a Puerto Rican woman who was diagnosed with breast cancer at age 35 years. During the three and a half years that she lived after diagnosis, she received a variety of services from a cancer support organization, including weekly individual supportive counseling with a social worker and group therapy. At the time of her diagnosis, Maria had been married to Joseph for 13 years. They experienced fertility problems secondary to her treatment. Maria reported to her social worker that this was a major source of conflict in the relationship and that she did not feel emotionally supported by Joseph.

Maria began working in a bank at age 17 and by age 30 had attained a middle management position. For 2 years after diagnosis, she worked full-time while receiving chemotherapy every 3 weeks, refusing to take time off for her cancer treatments. She reported significant depression, anger, and apprehension about recurrence. Within 6 months of diagnosis, she had begun to reexperience previous losses, most significantly the loss of her mother to breast cancer when Maria was 10 years of age. She reported consistent faith that the chemotherapy would cure her mother and hopeless betrayal by God when her mother died. Her oncology social worker suggested a referral to a psychiatrist for Maria's worsening depression, which Maria declined, saying that she did not wish to take antidepressant medication.

Ultimately, Maria agreed to a stem cell transplant and left her job after a year of disability leave. She agreed to see a psychiatrist for a one-time consultation, yet continued to refuse antidepressant medication. The social worker reported that she became increasingly fatigued, depressed, and agoraphobic (e.g., she stopped going out alone secondary to panic attacks). Her cancer recurred after 1 year and she died 18 months later.

Please answer the following questions based on your interpretation of Maria's case:

1. How do you think that Maria defined good quality of life?
2. What do you see as the social worker's role in providing support to clients like Maria that would help them to achieve good quality of life as well as good quality of death?
3. Arthur Kleinman (1988b) offers an explanatory model of illness that fosters a sensitive approach to helping clients like Maria. How might you have used his approach to elicit information from Maria to maximize your ability to help her? Recall that Kleinman suggested using the following questions:
  - What do you call the problem?
  - What do you think caused the problem?
  - Why do you think it started when it did?



- What do you think the sickness does? How does it work? How does it affect your body?
  - How severe is the sickness? Will it have a long or short course?
  - What care do you desire? What are the most important results you hope to get from your care?
  - What are the chief problems the sickness has caused?
  - What do you fear most about the sickness?
4. What do you consider to be the most pressing medical, psychosocial, and spiritual concerns that Maria faced? How would you prioritize these concerns in devising your approach to treatment?
  5. How would you go about developing a plan of care for Maria that took into account her cultural and spiritual perspectives and emphasized her definition of good quality of life?

## SUGGESTED RESOURCES

### WEB SITES

Aging with Dignity (Five Wishes; <http://www.agingwithdignity.org>)

The Aging with Dignity web site contains the Five Wishes, a document that is an advance directive addressing the dying patient's holistic needs.

American Pain Foundation (<http://www.painfoundation.org>)

The APF is a nonprofit information, advocacy and support organization serving all people affected by pain. Their mission is to improve the quality of life of those affected by pain by providing practical information, raising public awareness and understanding of pain, and advocating against barriers to effective treatment.

Americans for Better Care of the Dying (ABCD; <http://www.abcd-caring.org>)

Features the latest on policy reform efforts, with discussion groups, resources, and community outreach.

Association for Death Education and Counseling (<http://www.adec.org>)

ADEC is dedicated to improving the quality of death education; promoting the development and interchange of related theory and research; and providing support, stimulation, and encouragement to its members and those studying and working in death-related fields.

Cancer Care, Inc. (<http://www.cancercare.org>)

Cancer Care is the largest national social service agency providing free emotional support, information, and practical assistance to people with cancer, their loved ones, and caregivers. Their web site features a special section on End-of-Life and Bereavement Concerns and includes educational information and resources for patients, caregivers, and professionals.

Center to Advance Palliative Care (<http://www.capc.org>)

CAPC is a resource to hospitals and other health-care settings interested in developing palliative care programs.

Center to Improve Care of the Dying (<http://www.gwu.edu/~cicd>)

The Center to Improve Care of the Dying promotes research, public advocacy, and education activities to improve end-of-life care.

End-of-life Physician Education Resource Center (<http://www.eperc.mcw.edu>)

Assists physician educators and others in locating high quality, peer-reviewed training materials. Includes a comprehensive links section.

Finding Our Way: Living With Dying in America (<http://www.findingourway.net>)

The Finding Our Way national public education initiative focuses on bringing practical information to the American public regarding end of life and its surrounding issues.

Growth House (<http://www.growthhouse.org>)

Growth House is an international gateway to resources for life-threatening illness and end-of-life care, and its primary mission is to improve the quality of end-of-life care through public education and professional collaboration.

National Hospice and Palliative Care Organization (<http://www.nhpc.org>)

The official web site representing the national interests of hospice professionals. It includes information about local programs, legislative actions, and resources.

Precepts of Palliative Care ([https://www.aacn.org/AACN/practice.nsf/Files/ep/\\$file/2001Precep.pdf](https://www.aacn.org/AACN/practice.nsf/Files/ep/$file/2001Precep.pdf))

This document was designed to give health-care professionals a framework for palliative care and identifies the broad areas that palliative care covers, including the development of palliative care services, educational programs and policy initiatives.

Project on Death in America (PDIA; <http://www.soros.org/initiatives/pdia>)

This site provides PDIA's mission statement, funding initiatives, media and publications, online newsletter, and information about the Social Work Leadership Development Awards, Faculty Scholars program and arts and humanities initiatives.

Social Work in Palliative Care Listserv—to join, contact listserv co-coordinator Terry Altilio, ACSW [http://www.stoppain.org/for\\_professionals/content/information/listserv.asp](http://www.stoppain.org/for_professionals/content/information/listserv.asp).

Hosted by the Beth Israel Department of Pain and Palliative Care, this listserv provides an opportunity for social workers in such fields as oncology, geriatrics, HIV, hospice, nephrology, and pediatrics to network and discuss multi-dimensional aspects and issues related to palliative and end-of-life care.

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## CHAPTER 21

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# Pain Management and Palliative Care

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**T**HE UNIQUE VALUES that inform the purpose and perspective of social work practice are essential to the provision of quality palliative care and comprehensive pain management. Social workers have historically seen the alleviation of suffering as part of their mission, and this is reflected in a code of ethics that supports service, social justice, respect for the dignity and worth of the person, a belief in the central importance of human relationships, integrity, and competence (National Association of Social Workers [NASW] Code of Ethics, 1999). These ideals are woven through the twin fields of palliative care and pain management, yet social work has not been fully present or engaged in these areas of practice. In addition to shared values, a certain knowledge and expertise is necessary if social work is to strengthen its voice in these practice arenas. In this chapter, we discuss the interface of values and knowledge and detail the richness of opportunity presented to social work in palliative care and comprehensive pain management through the integration of patient-family narratives.

The purpose of this chapter is to discuss the integration of social work values with the principles and practice of palliative care and pain management.

### CHAPTER OBJECTIVES

- Define palliative care.
- Define and distinguish pain and symptom management as both a focus of palliative care as well as an independent focus of social work practice.
- Provide an historical perspective that confirms social work values as core components of palliative care and pain management principles.
- Confirm the unique opportunity for social work in this area of practice and explore the obstacles to realizing the opportunity.

- Discuss domains of care and guidelines as defined by the National Consensus Project for Quality Palliative Care.
- Discuss aspects of a biopsychosocial and spiritual assessment that inform a plan of care.
- Define interventions and illustrate their usefulness through patient narratives.
- Discuss ethical principles that relate to palliative care and the management of pain.
- Discuss various models of team collaboration.
- Explore the importance of work-related stress and its etiology and opportunities for professional self-care.

### PALLIATIVE CARE AND PAIN MANAGEMENT—AN OVERVIEW

The chapter first focuses on palliative care and its comprehensive approach to the care of patients with life-threatening illness. While pain and symptom management is included as a core palliative care skill, a separate section discusses pain management as an independent subspecialty. Underlying both practice areas is a multidimensional focus on the unique experience of the patient and family, which includes biological, emotional, cognitive, socioeconomic, cultural, and spiritual aspects. It is at this powerful and vibrant interface that social work expertise is essential.

#### PALLIATIVE CARE

According to the *American Heritage Dictionary*, palliate means “to alleviate without cure.” The World Health Organization has adapted this basic definition stating that palliative care improves the quality of life of patients and families who are facing life-threatening illness through prevention and relief of suffering, which might include assessment and treatment of pain as well as other physical, psychosocial, and spiritual distress. Palliative care is applicable throughout the course of illness and may be integrated with disease modifying therapies that are intended to prolong life. For example, palliative care may be incorporated with chemotherapy and radiation therapy in an oncology setting. In chronic renal disease, it may be provided along with dialysis. Interventions are adapted to the changing course of illnesses, such as when disease-modifying therapies lose their benefit or appropriateness. When this occurs, palliative care may become the primary focus of intervention. Palliative interventions affirm life but regard dying as a normal process. Clinicians generally work as a team to assist patients and families, including children, to live as actively as possible with an enhanced quality of life. Families who may be biologically or emotionally related are helped to cope during the illness and through their own bereavement (World Health Organization, 2002). Pain and symptom management are essential components of palliative care because uncontrolled pain and symptoms not only shape the lived experience of the patient, family, and staff but also influence bereavement and the legacy of the illness as it is integrated into the family narrative. Families express this through comments such as “my mother suffered terrible pain; I cannot bear to think that my husband will suffer in the same way.”

Palliative care may be provided throughout the course of illness and be complemented and enhanced by referral to a hospice program (i.e., an interdiscipli-



nary program of care, support, and bereavement services for persons whose life expectancy is believed to be 6 months or less).

## PAIN MANAGEMENT

While pain and symptom management are essential foci of palliative care, pain management as a specialty extends beyond life-limiting illness to chronic conditions such as migraine headaches, fibromyalgia, arthritis, and back pain. An estimated 9% of the U.S. adult population suffers from moderate to severe pain at any one time (Roper Starch Worldwide Inc., 1999). While not necessarily life limiting, these conditions can compel major life adaptation and, as in palliative care, assessment and treatment is often based in a biopsychosocial and spiritual model that engages the patient and his or her family. As a generic concept, pain management refers to both chronic and acute pain. The populations that are highlighted in this chapter include persons who experience pain as a consequence of a life-limiting illness and those who are affected by chronic pain.

The International Association for the Study of Pain defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. While it is unquestionably a sensation in part or parts of the body, it is always unpleasant and, therefore, an emotional experience” (Mersky & Bogduk, 1994). It is clear from this definition that pain involves the physical and emotional self at a very basic level. Acute pain differs from chronic pain in that it has a clear onset and has either persisted for a short time (seconds to weeks) or is expected to end during this time frame. It is usually associated with tissue injury and roughly parallels the healing of the injury. An example might be a toothache or a fractured bone. Chronic pain is largely defined temporally. Because it is often associated with tissue injury, the absence of objective injury may confound inexperienced clinicians. They may challenge the credibility of patients’ reports of pain. This can be distressing for patients who are hoping for a cause that can be cured. One definition says that chronic pain is any pain that outlasts the healing of an acute injury by a month, recurs frequently over a period of months, or has any duration but is associated with a lesion that is not expected to heal.

A key characteristic of chronic pain from the patient’s perspective is that it becomes like any other chronic illness (Portenoy, 2005). That is, as opposed to acute pain, the focus often changes from searching for the cause and cure to managing the pain itself. While objective physical signs such as hypertension and rapid heart rate often accompany acute pain, chronic pain is rarely associated with such signs. The absence of objective signs may lead inexperienced clinicians to wrongly conclude that the patient isn’t experiencing the pain he reports (American Pain Society, 2003). Assessment and interventions encompass biological, psychological, social, cultural, and spiritual aspects. Their goals include minimizing suffering and the negative effects of chronic pain and enhancing functioning and quality of life.

## CHALLENGES AND OPPORTUNITIES

Principles and values underlying palliative care and pain treatment have much in common with those of social work. In both, comprehensive quality assessment is individualized, patient- and family-centered, and multidimensional and includes biological, social, emotional, spiritual, and environmental factors that interact

and contribute to an understanding of the patient and family experience. Underlying values that inform this process are a respect for the central importance of human relationships and an affirmation of the person-in-environment paradigm in all of its manifestations (Roy, 1981). Consideration of patient and family values, needs, beliefs, and goals is implicit in the principle of respect for the dignity and worth of the person. Historically, health social workers have championed the idea that context, community, and family are critical components of the illness experience of patients. Ida M. Cannon, who led the first social work department at Massachusetts General Hospital (see Chapter 1 in this *Handbook*), saw the task of helping physicians understand the impact of the community and social context as essential to social work. This is a unique perspective that is a core element of both palliative care and pain management. This role's potential is enhanced by the plethora of interventions, ethical concerns, and policy issues that invite the participation of compassionate and competent social work clinicians to these two specialty areas of practice (Roff, 2001).

Rich opportunities appear at the same time as significant challenges for health social workers in palliative care and pain management. Although there are likely myriad reasons for social work's lack of involvement in the two fields, lack of adequate training is perhaps the most salient. Few social workers are mentored in sophisticated palliative or end-of-life counseling. Schools of social work make difficult, complex decisions about curriculum content, and even though death is a universal experience, the topic is typically only taught as an elective course. Pain has largely been viewed as a physical problem, and the biopsychosocial-spiritual focus has come primarily from the fields of psychiatry and psychology. Few social workers practice in pain management programs in which their person-in-environment and strengths perspective can be utilized. Many social workers in health-care settings struggle with the impact of shortened stays, competing priorities, and increasing caseloads. End-of-life counseling and pain management interventions may not seem sustainable in understaffed, managed care environments (see Chapter 5 in this *Handbook* for an explanation of managed care). Social workers have been less accountable for providing evidence-based interventions than their colleagues in nursing and medicine. Likewise, standardization of practice does not exist across settings and specialties and as a result, many social workers may not be expected to maintain and enhance their skills over time. At the same time, regulatory agencies such as the Joint Commission on Accreditation of Healthcare Organizations include pain, palliative, and end-of-life care in their standards, creating opportunities for skilled social workers to participate in and lead institutional initiatives, expand their scope of service, and improve patient care. The aging of the population means that an ever-increasing number of people will require these services, creating a mandate for trained social work clinicians across practice settings.

Social workers who work in any venue—hospitals, public agencies, hospices, methadone maintenance programs, prisons, nursing homes, private practices, or government programs, for example—have the opportunity to enhance the care of patients and the coping of patients and families affected by chronic or life-limiting illness. This broad range of practice settings allows this critical work to be transferred from formal health-care institutions to the community. While these settings may impose specific challenges, generic competencies and values underlie the social work approach. Understanding how community, culture, and institutional and family dynamics impact palliative care issues or pain ex-

periences informs and guides intervention. For example, in a rural community in which pain often accompanies physical labor and is thus expected, it is important to recognize that a new pain may be ignored or minimized until it interferes with work. In the prison population, tolerating pain may be a sign of strength and a defense against vulnerability. Expression of need or a request for care, even in cases of life-limiting illness, may be seen as weakness. Inmates might avoid any medication that would impact their alertness and awareness of their surroundings. In a prison environment, in which lack of control pervades, coping skills that utilize internal processes such as relaxation, imagery, and focused breathing have the potential to restore some control and enhance internal comfort, thus minimizing suffering (Enders, 2004).

### A HISTORICAL PERSPECTIVE

Principles and behaviors that inform the work of palliative care and the treatment of pain have their roots in human antiquity and serve a vital social function. A historic tension exists between society's desire to flee from the ill, injured, or dead and our recognition that the vulnerable need assistance in order to survive. The need to flee is based on the fear that others' misfortune may befall us. At the same time, helping the vulnerable and suffering is derived from an empathic understanding that we potentially need the other for our own optimal survival. Caring for those who suffer reinforces important social bonds and the capacity to be empathic. Each society throughout history has evolved special ways of caring for its suffering, dying, and bereaved members.

For example, shamans or healers proscribed behavior and offered guidance in times of crisis. Those who "know what to do" offer comfort, and such healers might be considered our earliest social work ancestors as they provided what might be thought of as early psychoeducational and spiritual support and expertise. From the origin of human life until the advent of antibiotics and other treatments in the mid-1900s, only limited interventions were available to influence the course of illness, so the alleviation of pain and suffering often was the most one could hope for. Palliative care was the only means of medical intervention for the seriously ill. These earliest healers offered integrated spiritual, herbal, and behavioral interventions to normalize concerns and support the dying and their families. Compassionate support during illness or injury was the imperative, although the outcome was understood to be outside of the healer's control.

The origin of the words *hospice* and *hospital* date back to the fourth century. During the Middle Ages, hospices were established at key crossroads on the ways to religious shrines. These shelters helped pilgrims, many of whom were traveling to shrines in search of cures and many of whom died while on their pilgrimage. Returning crusaders, often ill or wounded, also died at these hospices, strengthening the association of hospices as places for the dying and destitute (Koppelman, 2003).

In addition to linguistic history, philosophical perspectives infused the evolution of medicine and the care of the sick. For example, the seventeenth-century lawyer and mathematician, Renee Descartes popularized the dualistic-mechanistic model, which suggested that the body belonged to the realm of science and the spirit to the realm of religion (Koppelman, 2003). This began the "medicalizing" of dying and, by the mid-twentieth century, almost 80% of people in the United States

died in a hospital or nursing home. This changing death trajectory coincided with the widespread use of antibiotics. With the discovery of penicillin and other medical advances, such as anesthesia that made more daring surgery possible, the medical field began to focus on expanding possibilities for cure. Attention to the traditional concerns of palliative care and pain management somewhat paradoxically became less important to the providers of mainstream medicine.

Prior to this time, pain medications typically had been herbal in nature, with reliance upon alcohol and morphine as the most potent remedies for serious discomfort. In the mid-nineteenth century, laudanum (the synthetic form of morphine) was widely available and became immensely popular. Easy access to these remedies allowed individuals to self-medicate and addiction became a societal evil associated with stigma. Legislative regulations subsequently were enacted to protect the public. This fear of addiction to pain medications and the stigma associated with addiction and opioid medication use continues to influence professional behavior, patient and family perceptions of illness and its treatment, and public policy.

In London in the 1960s, Cicely Saunders, a physician previously trained as a nurse and social worker, developed the first modern hospice (Saunders, 1996). She pioneered the concept of "total pain" which recognized pain as a social, psychological, spiritual, and physical experience that required intervention provided by an interdisciplinary care team. She revolutionized the treatment of pain by the regular use of opioids instead of only when the patient was experiencing pain, with the goal of containing persistent pain. She was instrumental in encouraging patients to self-assess pain and incorporated the family in care (Forman, 1998; Saunders, 2001). In 1969, Elisabeth Kübler-Ross's book *On Death and Dying* set the stage in the United States for a revolution in the provision of end-of-life care, the development of palliative care as a medical specialty, and the renewal of interest in more sophisticated pain and symptom management strategies. More recently, pioneers like physician Jimmie Holland have championed the development of psycho-oncology as a unique specialization that seeks to integrate the biopsychosocial and spiritual factors of illness. This model is exemplified by the decision of the National Comprehensive Cancer Network to encourage the use of "distress thermometers" as standardized screening tools to measure physical pain as well as psychological suffering in cancer patients.

Social workers have failed to add their expertise to these specialties, leaving a vacuum that is being filled by psychologists, chaplains, nurses, and physicians sensitive to psychosocial issues. The conspicuous absence of social work leaders in palliative care and pain management is true for all aspects of care: policy, research, education, and clinical practice.

#### NATIONAL CONSENSUS PROJECT ON PALLIATIVE CARE

Palliative care programs are increasing in number at a rapid pace in response to the growing population of persons with debilitating and life-limiting illnesses. In addition, reports such as the Institute of Medicine's *Approaching Death, When Children Die* (2003) and *Crossing the Quality Chasm* (2001) called for improving access to palliative care during all stages of illness along the continuum of care. The purpose of the National Consensus Project for Quality Palliative Care was to estab-

lish clinical practice guidelines to promote consistent and high-quality care that can serve to guide the development of palliative care services. The project's participants included professionals, health-care organizations, policy and standard setting bodies, consumers, and payers.

The consensus document describes palliative care as interventions that may accompany life-prolonging treatments and be practiced at both the generalist and specialist levels. The implication that primary health-care providers learn basic palliative care invites all health-care providers, including social workers, to learn core skills. The integration of palliative care into generalist practice has great potential to impact care for patients and families along the continuum of illness to the end of life.

The domains and guidelines in Box 21.1 operationalize the following objectives:

Palliative care services aim to support patients of all ages with debilitating and life-threatening illness and their families, through the full course of illness, regardless of its duration, until cure or until death, and through the bereavement period. Palliative care is delivered through skilled and interdisciplinary attention to pain and other distressing symptoms; emotional, spiritual, and practical support; assistance with complex medical decision making; and coordination across the continuum of health-care settings. The goal is to help the patient and family achieve the best possible quality of life in accordance with their values, needs, and preferences. These guidelines for quality palliative care programs represent a consensus opinion of the major palliative care organizations and leaders in the United States, and are based both on the available scientific evidence and expert professional opinion. (National Consensus Project, Executive Summary, 2004, p. 21)

The guidelines are followed by criteria that further define and clarify the domains. The document, while acknowledging that some central tenets have not been validated in experimental studies, provides health-care professionals with a framework for excellence in practice (National Consensus Project, 2004, p. 42). Although the guidelines delineate general aspects of practice, specific issues for the patient and family are unique to social work. They are at the core of social work assessment, which has always been based on respect for the individual experiences of patients and families. The following section discusses aspects of social work assessment.

## BIOPSYCHOSOCIAL AND SPIRITUAL ASSESSMENT

Comprehensive and ongoing biopsychosocial and spiritual assessment is a key function of social workers in health-care settings and is the basis of effective treatment planning. The process of assessment in many ways forms a beginning intervention because our approach to patients and the questions that we ask frame the potential quality of the clinical relationship and prioritize its content. As in any clinical situation, the scope of the assessment is modified according to context and the immediate needs and goals of the patient. The assessment of an individual with chronic pain or a life-limiting illness involves gathering in-depth information about the physiological or biological aspects of the symptoms and illness, addresses treatment, and complements competent medical management. A family history should include previous experiences with pain and illness, remote and immediate loss experiences, and pain- and illness-related behaviors, as

**Box 21.1**  
**National Consensus Project for Quality Palliative  
Care Domains and Guidelines**

**Domain 1: Structure and Processes of Care**

Guideline 1.1: The plan of care is based on a comprehensive interdisciplinary assessment of the patient and family.

Guideline 1.2: The care plan is based on the identified and expressed values, goals and needs of patient and family, and is developed with professional guidance and support for decision making.

Guideline 1.3: An interdisciplinary team provides services to the patient and family consistent with the care plan.

Guideline 1.4: The interdisciplinary team may include appropriately trained and supervised volunteers.

Guideline 1.5: Support for education and training is available to the interdisciplinary team.

Guideline 1.6: The palliative care program is committed to quality improvement in clinical and management practice.

Guideline 1.7: The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families.

Guideline 1.8: Palliative care programs should have a relationship with one or more hospices and other community resources in order to ensure continuity of the highest quality palliative care across the illness trajectory.

Guideline 1.9: The physical environment in which care is provided should meet the preferences, needs, and circumstances of the patient and family to the extent possible.

**Domain 2: Physical Aspects of Care**

Guideline 2.1: Pain, other symptoms, and side effects are managed based on the best available evidence, which is skillfully and systematically applied.

**Domain 3: Psychological and Psychiatric Aspects of Care**

Guideline 3.1: Psychological and psychiatric issues are assessed and managed based on the best available evidence, which is skillfully and systematically applied.

Guideline 3.2: A grief and bereavement program is available to patients and families, based on the assessed need for services.

**Domain 4: Social Aspects of Care**

Guideline 4.1: Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed in order to respond to these needs as effectively as possible.

**Domain 5: Spiritual, Religious, and Existential Aspects of Care**

Guideline 5.1: Spiritual and existential dimensions are assessed and responded to based on the best available evidence, which is skillfully and systematically applied.

**Domain 6: Cultural Aspects of Care**

Guideline 6.1: The palliative care program assesses and attempts to meet the culture-specific needs of the patient and family.



**Domain 7: Care of the Imminently Dying Patient**

Guideline 7.1: Signs and symptoms of impending death are recognized and communicated, and care appropriate for this phase of illness is provided to patient and family.

**Domain 8: Ethical and Legal Aspects of Care**

Guideline 8.1: The patient's goals, preferences, and choices are respected within the limits of applicable state and federal law, and form the basis for the plan of care.

Guideline 8.2: The palliative care program is aware of and addresses the complex ethical issues arising in the care of persons with life-threatening debilitating illness.

Guideline 8.3: The palliative care program is knowledgeable about legal and regulatory aspects of palliative care.

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well as information about family roles, structure, functioning, communication and conflicts, social supports and resources, and cultural and spiritual values and networks.

Unique family factors and illness variables impact family function and response. Did the illness evolve over time or appear suddenly? What is the role of the patient? Is the family a cohesive unit? How adaptable and flexible are they? Is extended family or social network support available? What life cycle issues are present? Is the family experiencing stressors such as financial worries, preexisting conflicts, or illness? What might interfere with the family's ability to adapt, support each other, or use community resources?

Numerous needs and challenges arise when pain or life-limiting illness presents itself in the ongoing life of a family. Such needs and challenges include: understanding the disease, its treatment, and potential prognosis; developing strategies to manage the impact of pain or illness; coping with and learning the language of professional caregivers and institutions; maintaining stability while restructuring to meet the changing individual needs of the patient and her family members; dealing with family responses as well as the individual emotions, grief, and adaptation of specific family members; planning for the continuation of family life through periods of change and uncertainty and possible death; and finding meaning as a family and as individuals.

Persons with chronic pain or chronic progressive illnesses and their loved ones may experience grief as they come to terms with the myriad losses associated with pain and illness. The pervasive impact of these loss experiences is outlined by Monica McGoldrick, who describes loss as an event in time as well as a structural modifier which extends backward and forward in time, changing the family forever (McGoldrick, 2003). Many chronic pain sufferers face similar loss experiences that are not related to life-limiting illness but similarly evoke grief and demand multiple levels of change and adaptation (MacDonald, 2000).

Illness-related behaviors and responses arise in the context of specific family, cultural, social, health care, and political systems that may influence the suffering component of the illness experience. Suffering, as defined by *Webster's Dictionary*, is "to submit to or be forced to endure, to tolerate as inevitable, to sustain loss or damage, to endure death, pain or distress." Suffering is a subjective experience viewed through the lens of an individual's life, values, perspectives, and priorities

and is closely tied to a search for meaning. It may include pain but can exist in the absence of physical symptoms (Cassell, 1991). In the absence of meaning and a reframed vision of hope that extends beyond cure of a condition, suffering may continue despite excellent management of pain and treatment of disease (Barkwell, 1999). Viktor Frankl, in his book *Man's Search for Meaning*, develops "Logotherapy," a therapeutic concept based in the belief that finding meaning allows one to transcend loss and suffering (Frankl, 1984). The construct is useful when working with persons whose lives have been derailed by life-limiting illness or chronic pain. Clinicians can create a supportive space within which patients can gently and respectfully explore alternate sources of meaning (Otis-Green, Sherman, Perez, & Baird, 2002).

Chronically ill people may experience sadness and some symptoms of depression. When symptoms interfere with function and quality of life and are pervasive and persistent, aggressive treatment, including pharmacology and counseling, should be considered. Likewise, caregivers and other family members may become overwhelmed and exhausted over time and be at risk for physical and psychological effects (Schulz & Beach, 1999). In the palliative care model, the unit of care is the patient and those identified as family, and consequently clinicians attend to the needs of caregivers and family as a necessary part of ongoing assessment and treatment. Comprehensive care of persons with chronic pain should also involve those family members who are observers and often participants in the chronic pain experience (Glajchen, 2003).

The perceptions, evaluation, and experiences of the patient, family, and health-care professional are unique. As a result, discrepancies in observations and assessment may occur that should be addressed. For example, the clinician or family caregiver's appraisal of pain may not agree with that of the patient (Lobchuk & Degner, 2002; Miaskowski, Zimmer, Barrett, Dibble, & Wallhagen, 1997). Evidence suggests that clinicians underrate pain, especially when it is severe (Cleeland et al., 1994; Grossman, Sheidler, Swedeen, Mucenski, & Piantadosi, 1991; Von Roenn, Cleeland, Gonin, Hatfield, & Pandya, 1993). Appraisals are filtered through the experience, suffering, and cognitive and emotional distress of the appraiser, thus assessment is crucial to insure that appropriate interventions are directed to the right persons (Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002). For example, a family caregiver may perceive his loved one's pain to be out of control while the patient reports a reasonable level of comfort. The caregiver's perception may be affected by fatigue, fear, and feelings of helplessness. The intervention might therefore be for the social worker and team to reevaluate the plan of care and increase support through practical and psychological interventions rather than an increase in medication for the patient.

Individual and family attitudes and behaviors related to pain, illness, and death must be considered within a cultural context. Societal attitudes toward health, illness, and death have been influenced by a variety of ethical, religious, and philosophical beliefs in addition to changing medical practices through the past century. While the standard medical approach to illness and health care is largely based on the Western bioethical model of autonomy, self-determination, and informed consent, the United States is a multicultural society in which beliefs and behaviors are informed by a range of values. The assumption that patients and families work from a model of self-determination, accept the values implicit in advance directives, and become informed self-advocates may repre-

sent a clinician-driven focus that does not necessarily reflect the unique and individualized experiences of patients and their families. Psychosocial assessment should recognize that cultural values and nuances inform patient and family understanding and adaptation to pain and symptoms, illness, and death and that care should be adapted accordingly (Crawley, Marshall, Lo, & Koenig, 2002; Kagawa-Singer & Blackhall, 2001; Koenig & Gates-Williams, 1995). The following case example captures some of the complexity that is involved when the health-care team is faced with cultural beliefs that differ from the traditional Western bioethical model.

### **Case Example**

Mrs. M is a 33-year-old Muslim woman from Nigeria diagnosed with ovarian cancer and hospitalized with symptoms of pain, nausea, and weakness. She speaks little English and communicates through her husband or through an AT&T language line interpreter. Although she is a competent adult, she requests that information be given to her husband, who will make the health-care decisions. This request is troubling to the health-care team who are more comfortable with the traditional Western model of informed, self-determined decision making. The social worker from the palliative care consult service asks the primary team to consider that one can retain autonomy while giving decision-making power to another individual. She acts as cultural mediator throughout the hospital stay. A discussion ensues about the harm that may result if staff's pressure to inform the patient of her prognosis is experienced as an assault to the beliefs that sustain the couple in times of crisis. The situation escalates when the possibility of surgery is raised. The patient, her husband, and the health-care team explore the interface of cultural, institutional, and legal issues and negotiate an agreement whereby the husband will consent with the patient assenting by marking an X on a witnessed consent form. The social worker assists the team with the following interventions and adaptations that were required in order to provide respectful care to this couple: (a) A visual pain assessment tool is combined with observation of nonverbal behaviors to help staff assess and manage Mrs. M's pain. Mr. M is reassured that when he is not available, his wife's pain can be assessed and managed in spite of the language difference; (b) Issues related to prognosis, as per cultural and religious beliefs, are not discussed with the patient because both the husband and the AT& T interpreter report that discussing the possibility of death will be distressing, may impact her adversely, and be interpreted by her as a challenge to the will of Allah; (c) Postdeath needs and rituals are researched, discussed with an Imam, and shared with nursing staff so that all will be prepared to provide respectful care.

The scope of a palliative care assessment (see Box 21.2) has much in common with a comprehensive pain assessment in that it can include physical, emotional, socioeconomic, cognitive, cultural, behavioral, spiritual or existential, and environmental realms. Quality palliative care will also focus on advance care planning and risk factors for complicated bereavement.

Given the essential impact on family and caregivers, a comprehensive assessment involves the individual as well as significant others and seeks to identify needs and any discrepancies in perceptions and understanding.

**Box 21.2**  
**Assessment in Palliative Care**

*Physical:* Diagnosis and prognosis; history of disease or pain; symptoms; and impact on function, sleep, mood, and intimacy.

*Emotional:* Depression, anxiety, demoralization, fear, anger, grief, sadness, acceptance, guilt, shame, loss of control, helplessness, hopelessness, preexisting or comorbid psychiatric issues, and coping skills.

*Socioeconomic:* Sources and stability of income; access to care; entitlements; insurance issues; potential issues related to economic disadvantage or ethnic minority status; impact and symbolic significance of disability status; and litigation.

*Cognitive:* Attitudes, beliefs, and values; expectations that inform responses to pain and illness; internal dialogue and symbolic significance of pain, disease, and treatment; attributed meaning; impact on self-efficacy, self-image, and locus of control.

*Cultural:* Communication, gender, and language issues; degree of acculturation, assimilation, or generational differences; beliefs related to illness, pain, decision making, truth telling, death; use of folk remedies, and native healers.

*Behavioral:* Verbal and nonverbal communication; conscious and unconscious bodily responses such as grimacing, restlessness, or crying; regression, dependence, and acting out; and problematic handling of medications and inability to cooperate with treatment plans.

*Existential/spiritual:* Issues of meaning, despair, faith, and spiritual comfort; life review, hopes, and goals for the future; legacy building opportunities, illness, pain, and suffering as related to beliefs such as redemption, endurance, forgiveness; religious or spiritual beliefs that impact treatment decisions and peaceful dying.

*Environmental:* Emotional significance of the physical environment, including alterations that need to be made consequent to pain or disease-related issues, such as need for equipment, medical personnel at home; and behaviors of staff, friends, or family that may increase distress.

## INTERVENTIONS

For social work, the fields of pain management and palliative care present an emerging opportunity to apply skill sets that are a routine part of our training and to learn other skills that enhance the care and outcomes of patients and their families. Social work interventions may be focused in the arena of policy or public advocacy work or in the clinical realm of the patient's family experience.

### ADVOCACY

Advocacy is an ongoing task; needs change, distress varies, and skills of self-advocacy may fade as the patient and family deal with protracted illness, symptoms such as pain and fatigue, and associated feelings of helplessness and hopelessness. Unrecognized and unrelieved pain and misunderstandings within families or with staff require social work advocacy skills. Patients and families often need assistance in advocating for adequate discharge plans and negotiating with insurance companies. When patients and families are less overwhelmed, ad-

vocacy skills can be taught with the goal of increasing self-efficacy (McCaffery & Pasero, 1999). Additionally, there are multiples opportunities for systems change within an institution as well as at a political and policy level.

#### SUPPORTIVE COUNSELING INTERVENTIONS

Supportive counseling interventions include techniques of clarifying, exploring, partializing, validating, and problem solving. Patients and family members may be overwhelmed by many illness-related issues such as pain and crucial medical decision making. These interventions, along with aggressive medical management of symptoms, establish a basis for trust as they explore immediate needs and concerns and help the patient and family feel understood while the social work clinician identifies patient and family strengths and coping abilities.

#### EDUCATION AND ANTICIPATORY GUIDANCE

Education is an essential part of helping people master circumstances. In the health-care environment, this often means learning the language of medicine in the setting of pain, illness, and anxiety. The health-care community is responsible for accommodating and adapting to the needs of patients and providing information in a way that supports competence. Health-care clinicians need to anticipate future challenges and offer preemptive education and support to patients and their loved ones, including exploring the use of advance directives.

#### **Case Example**

Maria introduced herself as the family's social worker by explaining that she was there to offer them support through Mr. S's upcoming hospitalization for cardiac surgery. In addition to inquiring about their immediate questions and needs, she provided a folder of information and suggested that they might find the material helpful as treatment evolved. She acknowledged that people had different ways of coping and discussed some of the resources such as support groups and counseling opportunities that others had found helpful. Maria closed by saying that she would be available to discuss concerns, such as the impact of treatment on the family and its side effects, sexual functioning, finances, and spirituality.

The affective and cognitive components of pain described earlier in this chapter can be impacted by providing education and information about pain, pain management techniques, and strategies for coping. Many people are familiar with acute pain, and the transition to a chronic pain condition is often gradual and subtle. Consequently, the necessary emotional and cognitive adaptation to a chronic condition may be delayed. In the absence of clear education, expectation for cure may continue with the result that the patient and family have repeated experiences of failure and disappointment. Education helps patients and families distinguish between the preventive use of medications and addiction, physical dependence, and tolerance. Information should be customized to the needs of individual patients and families, because learning styles differ.

### Case Example

Mr. W is a 33-year-old unmarried male living at home with his parents who came to America from Trinidad. He hurt his back while stocking shelves in the supermarket. He has been out of work for 2 years and, as a result of his ongoing struggle with worker's compensation insurance, he has become defensive and interprets pain-related assessment questions as a challenge to his credibility and the validity of his pain experience. His mother has searched for curative treatment. When his pain continued, she began to wonder if he had a psychiatric as well as a physical problem. She sought a chronic pain program where, over time, educational interventions addressed the following interrelated issues: (a) Mr. W's pain experience includes physical, psychological, cultural, and systemic components. Multidimensional assessment of his pain is not intended to diminish his pain but rather an acknowledgment of him as a whole person, including but not limited to his physical self. Diagnostic and medical evaluation indicates that pain is no longer a signal that he is doing further harm to his body. (b) His mother's behaviors, based in her culture and role, need to be refocused on supporting independence and recovery rather than "taking care of her son." His back pain is re-framed from an acute to a chronic condition, requiring a care-giving approach that encourages efficacy and maximum functioning. (c) Medications are prescribed to diminish his pain and also serve to symbolically validate the clinician's belief in his reports of pain. (d) Mr. W need not wait for the pain to go away to consider participating in a vocational rehabilitation program.

### COGNITIVE BEHAVIORAL INTERVENTIONS

Cognitive behavioral techniques recognize that the biological, cognitive, behavioral, and emotional aspects of experience are related and that interventions at any one aspect have the potential to modify the entire experience. The internal dialogue of the patient or family member becomes a source of rich diagnostic information and the relationship of body, mind, and emotion becomes an avenue for helping to maximize feelings of control and self-efficacy and modify symptoms. Cognitive behavioral interventions may be adjuncts to the medical management of symptoms. They often are used in combination and may be the primary interventions in chronic pain situations. They can be helpful to patients during procedures and diagnostic tests that often create distress and feelings of lack of control.

The strategies selected relate to the goals, condition, and ability of the patient. For those who are overwhelmed or physically or mentally exhausted, the clinician works to build a successful experience by selecting interventions that require less effort, such as audiotapes and music. These interventions can be taught to individuals and families or can be incorporated into group experiences. Education is often a basic component of these techniques. Normalizing aspects of cognitive behavioral interventions helps patients and families integrate them more easily. To that end, comparing imagery to controlled daydreaming or distraction to being engaged in an exciting movie reinforces the familiar at the same time that new skills are being introduced. It can be helpful to introduce these techniques as an extension of natural abilities to distract from the painful stimuli, which does not mean that the pain is either nonexistent or psychological in origin



(Altilio, 2004; Berlin, 2001; Devine, 2003; Jacobsen & Hann, 1998; Loscalzo & Jacobson, 1990).

#### COGNITIVE RESTRUCTURING

Cognitive restructuring involves monitoring and evaluating a person's interpretation of events in order to reduce feelings of distress, helplessness, and hopelessness. Exploring a patient's internal dialogue can help to identify thoughts and feelings that worsen pain, symptom intensity, and distress. The technique provides an opportunity both to explore fears and misconceptions and to reinterpret thoughts to enhance comfort and control (Bradley, 1996; Syrjala, Donaldson, Davis, Kippes, & Carr, 1995).

#### Case Example

Mr. K is a 51-year-old Latino, married father of two adult children who was admitted to the hospital with back pain. Within a 5-day period, he was diagnosed with lung cancer, with metastasis to his liver and bones. His sister is an assertive, informed advocate who speaks English and was the primary spokesperson for the family with the health-care team. Mrs. K, who speaks only Spanish, was frightened and tearful, which distressed the patient who had seen himself as protector and provider. Mr. K's respiratory condition worsened precipitously, and before he made a decision to appoint a health-care agent, he was placed on a ventilator and became unable to communicate. Diagnostic work continued and antibiotics were prescribed for his respiratory symptoms. The social worker and palliative care team continued to provide service to the patient and family to provide continuity throughout the crisis. Supportive counseling techniques were used to assist Mr. K and his family to integrate the quickly changing medical situation. They included education about diagnosis and treatment, validation of the range of emotions, concerns, and questions associated with the medical and family crises, and clarification of the intent and goals of the medical team. In family meetings, Mrs. K was determined to be the surrogate decision maker although the process of decision making was one of family consensus. The social worker assured that Mrs. K had a staff interpreter to ensure that information was interpreted directly to her rather than through distressed family members and to validate the importance of her role and participation. In addition to current circumstances, the social worker and doctor explored the patient's prior articulated beliefs and values that might inform the decisions made on his behalf. This is especially important consequent to the family's perception that they would be "killing" Mr. K if they agreed to have the ventilator removed. The family indicated that Mr. K had said he would not want to be sustained by machines. He had also told the team chaplain that he had a good life and that quality of life was more important to him than quantity. Using the technique of cognitive reframing, the family was asked to consider discontinuing the ventilator respectful of Mr. K's values and that, rather than "killing him," they were allowing death to occur, consistent with the guidance he had given. Family members allowed the medical team to remove the ventilator. The social worker provided anticipatory guidance to assist family members with their individual decisions to be present as the ventilator was removed, educating them about this unfamiliar process, using breathing and

imagery techniques both to prepare them for his death and to enhance coping with the actual experience.

#### COPING STATEMENTS

Coping statements are internal or spoken statements designed to distract, enhance coping, or diminish the threatening aspect of a situation or experience (McCaul & Malott, 1984; Syrjala et al., 1995).

Catastrophic and defeating self-statements about pain can be replaced with internal dialogues that enhance coping and competence.

#### DISTRACTION

Distraction involves refocusing attention to stimuli other than pain and to other aspects of self that might include mental activity (internal) such as prayer and reading or physical activity (external) such as breathing, rhythm, or engaging in conversation (American Pain Society, 2005; Broome, Rehwaldt, & Fogg, 1998). Activities such as telling stories, music, life-review, prayer, and reading silently or aloud can have therapeutic value while at the same time distracting from pain and other sources of distress (Altilio, 2002; McCaffrey & Pasero, 1999).

#### SELF-MONITORING TECHNIQUES

Self-monitoring techniques such as diaries or journals externalize and objectify thoughts, behaviors, and feelings and create a personal history. The identification of attitudes, thoughts, and beliefs allows redefinition of the threatening aspects of experience toward the goal of decreasing distressing feelings and reactions. The techniques are adaptable to different personalities and goals, can be kept for a week or for months, written in telegram format or in paragraphs, and provide a link to the clinician (Altilio, 2004; American Pain Society, 2005). At times, diaries and audiotapes serve an additional purpose because they come to symbolically represent the therapeutic relationship, thereby extending the therapeutic benefit and comfort implicit of that relationship (Winnicott, 1971).

Diaries can be useful in understanding the multidimensional aspects of many symptoms including pain, insomnia, anxiety, and depression and thereby guide interventions (Kelly & Clifford, 1997).

#### Case Example

11:00 A.M.: I had a relatively good nights sleep. When I woke up, instead of turning on the TV, I tried to go back to sleep. I told myself that if I tried for 15 to 20 minutes to go to sleep, I could get up or watch TV. I fell back to sleep both times. [Coping statement integrated with sleep hygiene techniques empower and diminish helplessness regarding sleep.]

2:00 P.M.: Feeling very depressed because I was supposed to go out to dinner in the city, but I cancelled because I feel so horrible. I'm also afraid that I'd be in miserable pain . . . that's why I cancelled. But now I'm feeling depressed be-

cause I feel like this pain has control over my entire life. [Patient's catastrophic thinking and anticipation of pain controls behavior, exacerbating his helplessness and distress.]

April 8, 4:30 P.M.: Feel really depressed about everything. The pain is making me feel like I'm dying [attributed meaning]. Not that it's that bad—it's not—it's actually pretty mild, but I just feel overwhelmed by everything; the decisions I have to make. [Patient differentiating pain, symbolic meaning of pain and feelings and distress generated by pending decisions.] (Altilio, 2004).

#### RELAXATION TECHNIQUES

In the 1970s, a research cardiologist named Herbert Benson developed a simple relaxation technique that incorporates muscle relaxation and rhythmic breathing. Its goal is to elicit a relaxation response that counteracts "fight-or-flight," the internal adaptive response to threat during which the body secretes catecholamines, or stress hormones, that prepare a person to fight or flee. This response is essential when facing acute threats, such as a frightening diagnostic test, but is not helpful when stress is chronic, such as when the threat is an internal experience (e.g., pain or dyspnea; Benson, 1975).

Many patients use breathing techniques with or without muscle relaxation to reverse their physiologic, emotional, and behavioral reactions to stress and pain. The choice of technique is based on a clinical evaluation. Most exercises combine repetition of a word, phrase, or breath, with or without imagery, and are enhanced by a quiet environment and a secure comfortable physical position. Audiotapes of personalized relaxation exercises and imagery are often made by clinicians for use by their clients after practice within the therapeutic setting because they have the potential to extend the therapeutic benefit to home (Gallo-Silver & Pollack, 2000; Loscalzo & Jacobson, 1990).

#### IMAGERY

Imagery is the use of mental representations to assist in the control of symptoms, to enhance relaxation and comfort, or to distance oneself from a problem or gain insight into it. Imagery often incorporates a relaxation exercise. While visualization is the most common form, many exercises are enriched by involving the senses of taste, smell, hearing, and touch. Imagery can be used to mentally rehearse upcoming activities or feelings that are threatening (Graffam & Johnson, 1987; Luebbert, Dahme, & Hasenbring, 2001; Sheikh, 1983). Images elicited from the client may represent personal memories or imaginary places and have the potential to enhance the therapeutic impact of intervention.

#### HYPNOSIS

Hypnosis is a technique for inducing a state of heightened awareness, increased suggestibility, and focused concentration that can be used to alter the perception of pain, reduce associated fear and anxiety, and sometimes control pain itself (Kirsch, Montgomery, & Sapirstein, 1995; Montgomery, David, Winkel, Silverstein, & Bovbjerg, 2002). Autogenic self-hypnosis uses self-suggestions of warmth, heaviness, and relaxation in sequence throughout the body. It can be associated

with decrease of pain and enhanced relaxation (Sternbach, 1987). Clinicians who choose to add hypnosis to their skill sets should seek specialized training.

#### LIFE REVIEW AND LEGACY BUILDING

The diagnosis of an advanced illness is often associated with an increased awareness that one is indeed mortal. Erikson (1963) speculated that those facing death attempted to resolve the conflict between “ego integrity” and “despair.” Assisting patients with life review by focusing on generativity (continuing to be engaged in meaningful activities) offers a foundation for positive reflection at this vulnerable stage of life. New attention to existential “meaning of life” concerns may begin to take precedence as the individual considers the possibility of a limited life span or living with chronic pain. Social workers can assist during this period by normalizing these concerns, sharing time for review, and offering resources to assist in the life review process. Tools are available that offer guidance in recording life history on video or audiotapes, in journals or scrapbooks, or through other artistic strategies (Babcock, 1997; McPhelimy, 1997; Otis-Green & Rutland, 2004). These efforts can be tremendously cathartic for the patient and of great value to loved ones as part of an intentional legacy-building exercise. With chronic pain, life review may happen as a natural part of integrating the impact of chronic pain as patients and families reflect on changes in their present lives as well as their future hopes.

#### Case Example

Tanisha had been reluctant to come to the Detours group that met monthly at the hospital. When her doctor told her that it was for those with recurrent disease, she summoned her courage and came to a meeting. She was relieved to see so many others already grabbing snacks and finding seats. The social work facilitator invited the participants to share what “detours” life had thrown each of them. Tanisha found herself relaxing as she listened to so many stories similar to her own. She had been feeling “stuck” and unsure of what to do since learning of her recurrence. The social worker encouraged each member of the group to think about what was most important to her and to consider how to ensure that what is most essential to her was not lost. Tanisha raised her hand and told the group that her three children were what mattered the most to her and asked the group for suggestions to help her “protect them from all of this.” Later, Tanisha told her doctor that the group helped her to see that, although she might not be able to protect them, she now was thinking more clearly about how she would be able to better prepare them for whatever they might have to face. In subsequent meetings, Tanisha developed a guardianship plan and worked on recording and creating memories through videotape and preparing a book of reminiscences and memories for her children.

#### INTEGRATIVE STRATEGIES: THE USE OF THE EXPRESSIVE ARTS

The expressive arts offer the social worker enormous opportunities for culturally sensitive interactions with those they serve. Integrative interventions are especially useful as a distraction technique for those suffering pain. Although many

pediatric units recognize the benefits of expressive art interventions, fewer adult units incorporate art, music, or play strategies into routine care. Health social workers are well positioned to recommend and coordinate integrative programs (Otis-Green, 2003). For example, hand or foot massage programs may fit well into a skilled nursing environment, the introduction of a music program may be appropriate for an ICU setting, or the use of the visual arts may be incorporated into existing support groups. Developing a mind-set that looks for ways to integrate the expressive arts into conventional settings is all that is necessary for success.

### **Case Example**

Hsing had chronic renal disease and significant diabetic neuropathy, yet came regularly to the Hands on Harps concerts and workshops sponsored by the clinical social work department. When queried about what made these meetings so important to him, he always beamed and said that when listening to the music all of his pain disappeared and that although he lacked digital dexterity, "playing with the harp always sounded so sweet." When he became too ill to attend the workshops, his social worker arranged for the harpist to visit his hospital room. Hsing's family later reported that they played harp music to him while they sat vigil awaiting his death and planned to play the CD at his funeral, since it always brought such comfort to him.

### CHILD/ADOLESCENT SPECIFIC INTERVENTIONS

In years past, children were often excluded from participation and interaction with the illness experiences of their family members. This well-meaning exclusion was intended to protect children from distress and confusion. It is now understood that providing children with age-appropriate information, and allowing them to participate as appropriate, can enhance their adjustment to a changed family experience and to the losses and adaptations that accompany chronic pain, progressive illness, and death (Harpham, 2004).

Most children are very perceptive but may lack both the cognitive and developmental abilities to understand what is happening in their family and the language to talk about it. While cultural variation may influence how families engage children and adolescents, clinicians can focus attention to child and adolescent coping by asking relevant questions as part of an overall assessment not only about the immediate or nuclear family members, but also of grandchildren, nieces, and nephews who are emotionally connected to the patient. Age-appropriate information provided by significant adults can enhance understanding, dispel myths, fears, and anxieties, and help children make sense of their own feelings as well as those of others. Many children worry that they have caused the pain or illness of loved ones because of magical thinking that may accompany their stage of development. They may have fears about their own health, overreact to comparable symptoms such as pain, and worry about how they will be cared for if income is lost or a parent becomes disabled or dies. Giving children permission to ask questions and express feelings and fears helps them feel secure and cared for. Techniques such as play therapy, art therapy, storytelling, and journaling can be especially helpful. Signs of regression or disinterest, while common for children,

can be disconcerting for adults who may already be overwhelmed. Reassurance and maintenance of routine is often helpful (Heiney, Hermann, Bruss, & Fincannon, 2000).

Adolescents are at a particularly vulnerable stage of development that can be complicated when an adult is ill or affected by chronic pain. The need to be aligned with peers, to regulate uncertainty and anxiety, and the desire to achieve some degree of emancipation and independence may become more difficult when medical issues and role changes create additional anxiety and require the adolescent to limit peer activity and assume more responsibility at home. Resulting behaviors may include withdrawal, silence, or anger, and reflect a myriad of feelings such as embarrassment, sadness, guilt, depression, and anxiety. Social work interventions may include:

- Educating the family about adolescent-specific issues
- Engaging and educating adolescents about medical situations in age appropriate ways
- Encouraging adults to continue to talk even in monologue, about what is occurring, reinforcing stability as well as changes that may occur
- Monitoring unobtrusively the teen's school work and interactions with peers and significant adults
- Assessing the pros and cons of alerting school personnel—teachers, counselors—about what is occurring in the family, ensuring that they respect the teen's confidentiality while offering additional support
- Encouraging opportunities for contact with significant adults in the teen's life, such as aunts, uncles, and coaches
- Evaluating for depression, anxiety, and changes in sleep and appetite

#### FAMILY MEETINGS

Family meetings can be used as therapeutic tools for providing family-oriented clinical, palliative, and end-of-life care. In the hospital setting, such meetings, also called family conferences, may be defined as "a meeting which involves a number of family members, the patient, and hospital personnel in discussions concerning the patient's illness, treatment and plans for their discharge or their care outside the hospital" (Hansen, Cornish, & Kayser, 1998, p. 58). Family conferences are not the same as family therapy (Meyer, Schneid, & Craigie, 1989). They can, however, enhance and enrich therapeutic work. Effective communication with families is particularly challenging, because family members are often the "hidden patients" in palliative care, both providing and needing care (Kristjanson & Aoun, 2004). By advancing a family systems theoretical perspective, family conferences bring a holistic approach that is emphasized in palliative and end-of-life care, but largely absent in medical systems (Erstling & Devlin, 1989).

Family conferences often address emotionally intense topics such as advance care planning, pain and symptom management, and ethical issues. They are important forums for decision in hospitals, intensive care units, and clinics (Atkinson, Stewart, & Gardner, 1980; Curtis et al., 2001; Hansen et al., 1998; Kushner, Meyer, & Hansen, 1989; Meyer et al., 1989). Furthermore, they provide opportunities for collective patient, family, and health-care provider discussions (Ambuel, 2000; Liebman, Silbergleit, & Farber, 1975) that promote the inclusion of patients



and families, invite family members to be active participants in care (Atkinson et al., 1980), allow for collaborative dissemination of information and clarification of misinformation, and increase coordination of health-care providers to reduce conflicting information to patients and families. This is especially important in chronic pain care, because many times families need education and encouragement to emotionally and cognitively accept the transition from an acute care model that focuses on waiting for pain to dissipate to a recognition and acceptance that what one is experiencing is chronic. Varying combinations of patients, family members, and health-care providers may participate in family conferences, making these interventions adaptable for a broad range of family configurations and cultural traditions.

### ETHICAL ISSUES RELATED TO PAIN AND PALLIATIVE CARE

Medical ethics was remarkably continuous and consistent from the time of Hippocrates until the mid-twentieth century. In recent years scientific, technological, and social developments have produced rapid changes in the many traditional conceptions of ethical practice and obligations in health-care practice. Medical care, living with chronic illness, and in many instances, dying, have become more complex than in previous generations as a result of our highly technical and disjointed systems of care. At times, it seems that our medical technology has surpassed the ability to make ethical decisions about its use. Ethics is a branch of philosophy that seeks to determine how human actions may be judged right or wrong. The study of ethics implies that the human mind is the fundamental means by which actions can be judged (Beauchamp, & Childress, 1989). Thus, ethics is not the same as moral theology or religious ethics since ethics uses reason alone and does not invoke religious beliefs as the source of its conclusions. Nor is ethics the same as the law. While the law is largely concerned with the public good and the protection of individual rights, ethics goes further to look at the obligations of individuals to themselves as well as to others and to society.

In the practice of medicine these obligations are intimately related to purpose. Pellegrino (1979) asserted that purpose in medicine is a right and good healing action taken in the interest of a particular patient. Kass (1983) emphasized healing as the primary purpose of medicine, while acknowledging that the pursuit of health, the prevention of death, and the alleviation of suffering were secondary to healing. The dialogue which attempts to explore and expand these values and concepts needs to be based in a common understanding of the language used.

The four principles that underlie and guide ethical decision making are autonomy, beneficence, nonmaleficence, and justice. The following definitions establish a common language as a basis for collaboration and discussion:

*Autonomy* Derived from the Greek *autos* (self) and *nomos*, (rule, governance, or law). The health-care formulation of the principle of autonomy is expressed as follows: *You shall not treat a patient without the informed consent of the patient or his lawful surrogate, except in narrowly defined emergencies.* Closely tied to the principle of autonomy are the values of respect for persons, the right of self-determination, and informed consent.

Respect for persons is based on the tacit belief in the value of each person and considers social, economic, and cultural variables. Respect for persons includes the right to self-determination. This is the right of competent clients to determine the appropriate level, if any, of medical intervention and the right to change their wishes about treatment as their condition changes, a right that underscores the need for informed consent.

*Beneficence and Nonmaleficence* At its most basic, beneficence means no more than “do good.” Similarly, the principle of *nonmaleficence* tells us to avoid evil. Ethical medical decision making is complex and it is not always possible to know clearly what is “doing good” in the face of ambivalent and nonspecific potential outcomes. Additionally, the concept of doing good may differ based on individual opinions, cultural and spiritual beliefs, and social preferences as evidenced in the case example describing the care of Mrs. M.

Ethicists have created specific guidelines for challenging situations. As an example, a guideline that informs the use of palliative sedation for the management of intractable symptoms is the principle of *double effect*. This principle holds that a single intervention (giving medication for symptom relief or sedation) with one intention (symptom management) may have two effects: (1) pain relief and (2) possible respiratory depression. The foreseen beneficial effect (symptom relief) must be intended and be equal to or greater than the foreseen harmful effect (possible respiratory depression; Coyle, 1992; Lo, 2000). The principle of double-effect provides that a person may perform an act that has risks if all four of the following conditions are verified: (1) the action must be good or morally indifferent in itself; (2) the agent must intend only the good effect, not the harmful effect; (3) the harmful effect cannot be a means to the good effect; and (4) there must be proportionality between the good and harmful effects.

This same principle applies in the treatment of a disease such as cancer in which the intended good of disease remission or cure is often achieved through chemotherapies or procedures such as hematopoietic cell transplants. These treatments cause foreseen harmful toxic side effects that are considered acceptable secondary effects when balanced against the intended good (proportionality). While the principle of double effect informs the management of intractable symptoms at the end of life, euthanasia and physician assisted suicide or hastened death are more difficult to consider.

*Euthanasia* The deliberate action by a physician or another individual other than the patient to end the patient’s life for benevolent motives, such as the relief of suffering. The act is performed with the explicit consent of a competent adult who is the patient. *Involuntary Euthanasia* is the intentional administration of medications or other interventions to cause the death of a competent patient without the patient’s explicit request and full informed consent. *Nonvoluntary Euthanasia* is the intentional administration of medications or other interventions to cause the patient’s death while the patient is incompetent and incapable of explicitly requesting it (Emanuel & Emanuel, 1992). All forms of euthanasia are illegal in the United States.

*Physician-Assisted Suicide* The provision by a physician of medications or advice that enables the patient to end his life. It is the ingestion of medications by a terminally ill, competent adult intended to hasten death. The patient takes her own

life and is thus the direct agent of death through means provided by another. The only state in which this is allowed, under specific conditions, is Oregon, in which the Death with Dignity Act, which provides for this option, has been in effect since 1998 (<http://ohsu.ethics.edu>).

*Justice* An important ethical principle that involves provision of health care as related to the availability and distribution of goods and services. Society is called on to determine a just, or at least reasonable, distribution of goods necessary to protect the dignity of the individual person. When we expand the construct of “distribution of goods” to include pain management skills and medications, it becomes a violation of the principle of justice as well as beneficence, when the elderly, women, and minorities are not provided competent pain management equal to that provided other groups (Bonham, 2001; Cleeland et al., 1994; Tarzian & Hoffman, 2004). Distribution is concerned with scarce resources. Demand at times outstrips supply, a reality that becomes particularly complex in the American health-care system, in which supply is also influenced by availability of services and access as determined by geography, finances, and socioeconomic status.

*Medical Futility* Refers to the judgment that no desirable benefit can be achieved by a specific treatment. Medical futility conveys extremely poor prognosis, unilateral and negative judgment about a patient’s quality of life. The interpretation of futility is not universal and state-specific variations exist. It is a complex and important area, because the judgment of futility moves decision making from the patient, surrogate, or agent to the physician who also needs to consider the values, beliefs, and perceived quality of life as defined by the patient. At the same time, physicians are not required to violate their own ethical and moral values by providing treatments that they consider to be futile or harmful (Lynn, 1989).

## PAIN MANAGEMENT—AN OVERVIEW

In addition to the opportunity presented in palliative care, many persons who live with chronic pain have needs that fall well within the purview of social work practice. In 2003, a national telephone survey of 1004 adults revealed 57% of respondents to have reported chronic or recurring pain during the past year (Hart, 2003; [www.painfoundation.org](http://www.painfoundation.org)). The survey considered chronic pain conditions such as back and knee pain, arthritis, headache, and migraine. Of those surveyed, 76% had experienced pain, either directly or through a connection to a family member or friend. Chronic pain had led to changes in employment, residence, personal freedom, or mobility. Steps taken to cope with pain included applying for disability and seeking help with activities of daily living. These findings reflect adaptation and experiences of loss that have the potential to affect self-esteem, identity, role function, and social and economic stability both for the person suffering and for close family members and friends. In addition to the personal and family impact, data from an American Productivity Audit in 2001 estimated that over half (52.7%) of the workforce reported pain conditions in the 2 weeks prior to the survey. In that 2-week period, 12.7% of respondents lost productive time, with an average loss of 4.6 hours per week, at a cost of \$61.2 billion a year. This points to a health and economic concern of major proportions (Stewart, Ricci, Chee, Morgenstein, & Lipton, 2003).

Pain is necessary to survival and generally, but not always, signals physical injury or disease and alerts one to take some kind of action. Although pain arguably is a truly universal experience, at the same time individuals, including clinicians, relate to pain through a kaleidoscope of cultural, familial, sociopolitical, and spiritual values. For example, pain can be viewed as a misfortune, as a weakness, a path to redemption, or a form of punishment. Some believe the appropriate response is to bear pain stoically, while others view pain as a signal to seek medical attention and expect to receive help and care from family and friends. While many expect to be healed through medical intervention, others believe that pain can best be controlled through prayer or psychological or complementary interventions. Patients with chronic pain that may or may not be associated with observable tissue damage are sometimes accused of exaggerating pain and disability for secondary gain; yet, many feel ashamed and or diminished by dependence on others and the need to apply for disability in a system that often challenges the integrity of applicants. We begin to see the complexity and importance of comprehensive clinical assessment and interventions to assist persons with pain that has the potential to profoundly impact their identity and the quality of their lives and the lives of their family and friends. This is true for chronic pain or for pain that accompanies incurable progressive illness.

Pain is also unique as a symptom in that it is a subjective experience and unlike other somatic experiences, such as high blood pressure, body temperature, or blood glucose levels, cannot be measured objectively (American Pain Society, 2003). Clinicians and family members must rely on the person's report of pain severity and its impact. Social work's emphasis on starting where the client is and assessing persons in their environment serve as frames of reference that imply a respect for individuals' perceptions of their experiences and a valuing of the whole person, including but not limited to the body. In the management of pain, an analogous principle is to believe the report of pain; in palliative care, a comparable mandate is an understanding of the holistic experience including values, beliefs, and culture that inform the life of the patient and family. The task for social work clinicians is to complement values such as respect for the dignity and worth of the person with pain and palliative expertise that empower the profession to intervene on a clinical, institutional, policy, and research level.

#### PAIN IN LIFE-LIMITING AND CHRONIC INCURABLE ILLNESS

In palliative care settings, the experience and management of pain is impacted by the multiple challenges presented by diseases such as cancer, multiple sclerosis, and AIDS. The following statistics provide a sampling of the diseases for which compassionate care demands that pain and palliative care needs are addressed.

Pain occurs in:

- 50 % of patients with multiple sclerosis (Moulin, Foley, & Ebers, 1988; Vaney, 1990; Warnell, 1991)
- 40 % of patients with Parkinsons disease (Ford, 1998; Goetz, Tanner, Levy, Wilson, & Garron, 1986)
- 65% of patients with spinal cord injury (Siddall & Loeser, 2001)
- 49% of pediatric cancer patients (Collins et al., 2000)

- 30% to 90% of patients with AIDS (Breitbart et al., 1995; Vogl et al., 1999)
- 30% to 40% of cancer patients in active therapy (Greenwald, Bonica, & Bergner, 1987; Larue, Colleae, Brasseu, & Cleeland, 1995)
- 70% to 90% of cancer patients with advanced disease (Greenwald et al., 1987; Larue et al., 1995)

Pain and symptoms such as shortness of breath, cognitive impairment, and anorexia present challenges to patients, their families, and caregivers that intensify the suffering and feelings of helplessness often associated with life-threatening and incurable progressive illnesses. The following case example illustrates the impact of pain, fatigue, and cognitive impairment that extends beyond the direct experience of the patient.

### **Case Example**

Mrs. D is a 65-year-old widowed African American woman diagnosed with chronic renal disease. She has been the emotional and administrative center of a large extended family and is becoming increasingly fatigued, spends more time in bed, and is less able to engage with and direct her family. Her pain is being managed aggressively and the medications prescribed have caused cognitive impairment. It is expected that as her body becomes tolerant to the medication, her cognition will improve. Her family is becoming increasingly distressed; wanting her to be more awake, physically active, and cognitively clear. They are angry with the palliative care doctor, because they perceive his lack of expertise in prescribing as the reason for her cognitive impairment. Diagnostic assessment indicates that the symptom of fatigue reflects irreversible, progressive kidney failure. Social work interventions include (a) reviewing the family's perception and understanding of the status of disease; (b) exploring various factors that might inform the anger expressed at the physician, including a lack of understanding of the process of trialing and adjusting pain medications, racial tensions or misunderstandings, and fear that patient is being harmed rather than helped; (c) exploring the symbolic significance for this family of viewing their mother as confused and unavailable to them; (d) assisting the family to integrate medical information by organizing a family meeting with team and by exploring their own observations of the changes in the patient's condition; (e) working with medical staff to prepare the family for the probability that Mrs. D will become increasingly sleepy and that as she clears cognitively, they will need to value and maximize the time that she is awake and able to interact; (f) acknowledging and exploring the individual and family response to this potential loss and reinforcing community and spiritual supports that might be helpful to them; and (g) acknowledging the changing family structure as a loss experience and assisting the family to consider how to move forward with roles and responsibilities.

Mrs. D's case example portrays how a multidimensional view of symptoms can be at the core of the assessment and intervention process. A unique individual and family experience the symptoms in the context of either a chronic or potentially life-threatening illness. The following case example takes the same symptoms—pain, fatigue, and cognitive impairment—but demonstrates how the etiology, impact, symbolic significance, and resulting interventions may differ.

### Case Example

Mrs. J is a 35-year-old married Italian mother of three children, ages 3 to 8. She has back pain that is often debilitating and interferes with her ability to parent, work, and participate in an intimate relationship with her husband. She is engaged in a multimodal treatment plan that includes medication trials, physical therapy, and cognitive behavioral therapy. As directed by her doctor, she has gradually raised the dose of opioid medications and experiences increased side effects of fatigue, sleepiness, and cognitive slowing. Her husband and extended family worry that she is too impaired to care for her children, who appear to be increasingly “out of control.” Her sister-in-law, who is not aware that she is receiving opioids for pain, interpreted her behaviors as symptoms of drug addiction and reported the family to child protective services (CPS).

In this context, Mrs. J’s symptoms, which were actually medication side effects, precipitated an emergency situation that stemmed from her decreased ability to function, compromised the safety of her family, and resulted in trauma and family conflict consequent to the charge of child endangerment. A proactive and preventative approach from the pain management team might have prevented the deleterious outcome. The social work plan included (1) assessment of the relationship between the children’s behaviors, Mrs. J’s symptoms and side effects, and the increased family tensions; (2) work with the family and CPS to address the needs of the children and ensure the family’s ability to provide support and supervision as medications are stabilized; (3) meet with family members, including the sister-in-law, to educate them about the difference between addiction, tolerance, physical dependence, and behaviors related to medication side effects; (4) engage family members as informed supports and participants in a plan of care that would involve multimodal treatments, including ongoing trials and adjustment of medications.

## VULNERABLE POPULATIONS AND DIVERSE SETTINGS

Undertreatment of pain is a multifaceted problem that involves educational, regulatory, and reimbursement barriers, as well as beliefs, values, and behaviors that impact the individual’s relationship to pain, medications, and health-care professionals. Poorly controlled pain causes unnecessary suffering for many and particular groups have been identified as more vulnerable. When assessment of pain becomes more of a challenge, for example in the case of language or cultural difference, babies, children, elders, and demented and mentally ill patients—the risk of undertreatment increases (American Pain Society, 2003). Social work’s heritage of service, commitment to justice, and advocacy for oppressed groups demands that we develop the ability to recognize and advocate for populations whose vulnerability and feelings of powerlessness may be intensified by pain, illness, and the inherent and growing difficulty implicit in accessing care from an increasingly unresponsive health-care system (Mendenhall, 2003).

### GERIATRICS

Geriatric social work clinicians share responsibility for highlighting and solving the problem of unnecessary suffering in older persons caused by unrecognized



and uncontrolled symptoms, including pain and depression (Beekman, Geerlings, & Deeg, 2002; Bernabei et al., 1998; Fox, Raina, & Jadad, 1999; Jerant, Azari, Nesbitt, & Meyers, 2004; Liao & Ferrell, 2000). Elders may experience multiple chronic illnesses over time that impact their quality of life as well as the lives of their family and caregivers. Uncontrolled pain can lead to depression and other mood disorders, agitation, sleeplessness, decreased function, appetite, increase isolation, and risk of falls (American Geriatric Society Panel on Persistent Pain in Older Persons, 2002; Stein, 2001; World Health Organization, 2004). Elders often believe that pain is to be expected and when asked may deny "pain" but acknowledge "aches" or "soreness." Additional barriers include myths and misunderstanding regarding addiction, worry about cost, and side effects of medications. The focus of assessment often extends beyond physical pain to existential issues such as the mortality of self and friends and the meaning and purpose of life. In this vulnerable population, cognitive impairment can complicate the expression, assessment, and management of pain and increase the clinical team's responsibility to adapt assessment and treatment for chronic conditions like osteoporosis or for life-threatening illnesses (Sachs, Shega, & Cox-Hayley, 2004; Stein, 2001).

Palliative care and chronic pain interventions need to accommodate to the particular needs of elders, both at the individual level, by adapting assessment to functional limitations such vision or hearing limitations, and at the level of the group, community, or society, by constructing alternate palliative care models to respond to the needs of those who require care over the course of chronic, slowly progressing illnesses (Jerant et al., 2004).

#### GENDER ISSUES

A person's experience with and response to pain is influenced by multiple factors, including those that are biological, cultural, emotional, and cognitive. Evidence exists to support that men and women experience pain differently and that women are more likely to be inadequately treated both in chronic pain settings (Hoffman & Tarzian, 2001) and in the case of illnesses such as cancer and AIDS (Breitbart et al., 1995; Cleeland et al., 1994). The study of gender-based difference in pain includes consideration of such complex areas as:

- Biological factors, such as mechanisms related to opioid receptors, sympathetic nervous system function, and hormonal influence.
- Psychological factors, such as cognitive appraisal and attributed meaning.
- Behavioral responses, such as coping mechanisms, communication styles, and health related activities, such as seeking care and taking medications.
- Cultural and socialization factors that impact reactions, perceptions, thoughts, and behaviors on both the part of the patient and health-care practitioners (Unruh, 1996).

Although etiology and causation are not well understood, current research suggests that the pain reports of women are taken less seriously than those of men, that women's pain is more likely to be discounted as emotional or psychogenic, and that women receive less aggressive treatment. This disparity violates the ethical principles of justice and respect for the dignity and worth of the individual (Hoffman & Tarzian, 2001).

## MINORITY POPULATIONS

In 2001, Bonham reviewed multiple studies documenting disparities in pain treatment by race, ethnicity, and socioeconomic status. While reports are somewhat inconsistent, substantial evidence exists to support the troubling conclusion that persons belonging to racial and ethnic minority groups are less likely to receive adequate treatment for acute and chronic pain (Anderson et al., 2000; Bonham, 2001; Cleeland et al., 1994; Dannemiller Memorial Educational Foundation, 2004). Variables that underlie these disparities are multifactorial and may exist on the clinician, patient, family, or institutional level. They range from poor communication, mistrust, racism, and economic or educational disadvantage to a health-care system that supports disengagement, lack of continuity of care, and fails to allow sufficient time in clinical encounters to bridge differences and enhance trust.

In addition, language differences can intensify misunderstanding and increase anxiety consequent to the patient's inability to comfortably communicate his or her needs to health-care professionals. Research exists to support the notion that living in disadvantaged neighborhoods is further compounded by the reality that inner-city pharmacies often do not stock opioids used to treat moderate to severe pain creating an additional challenge for an already stressed group. Informed social workers can assist their patients and colleagues to prevent crises by encouraging patients to contact their pharmacies to ensure that prescribed medications are available or to make alternate plans to secure them (Morrison, Wallenstein, Natale, Senzel, & Huang, 2000).

## SUBSTANCE ABUSE

It is estimated that between 6% and 15% of the U.S. population has a substance use disorder that may involve the abuse of illicit drugs or misuse of prescription medications (Collier & Kopstein, 1991; Groerer & Brodsky, 1992; Zachny et al., 2003). Some medications used in the management of chronic pain and in palliative care are controlled substances. These and other classes of medications have the potential for abuse and diversion. This causes heightened vigilance when pain medications are prescribed for patients known to abuse drugs. Treatment of patients with a current or remote history of addiction is impacted by clinical, social, regulatory, and policy challenges such as:

- Confusion and lack of understanding about addiction, physical dependence, tolerance, and pseudo-addiction. The latter are behaviors that can mimic addiction and be interpreted as drug-seeking rather than relief-seeking behavior. These behaviors cease when pain is adequately treated (Weissman & Haddox, 1989).
- Providers' fear of the processes and consequences of prescribing opioid analgesics, which has been referred to as opiophobia (Morgan, 1986; Shine & Demas, 1984).
- Fear of regulatory, law enforcement, and medical board scrutiny.
- Patient's, family's, and clinician's fears of causing relapse or activating a latent addictive disease.

- Worry about potential diversion.
- Lack of the time, skill, and interdisciplinary support needed to assess, treat, and monitor the care of persons with pain and problematic drug use behaviors.

Many addicted persons have multiple medical problems and consequently can be quite symptomatic. They are often marginalized, with few advocates. They require expert and respectful treatment of their addiction or problematic drug-use behaviors as well as symptom management that maximizes benefit and diminishes harmful outcomes. Care should include assessment of both issues. While experts in these dual fields are few, guidance is available through web resources such as [www.stoppain.org](http://www.stoppain.org) (Portenoy, 2005). A treatment program should provide structure, consistency, and psychosocial interventions to maximize the opportunity for successful treatment of both pain and addictive disease.

#### POLICY ISSUES—OPPORTUNITY FOR ADVOCACY AND LEADERSHIP

In 1998, the National Institutes of Health (NIH) estimated the financial impact of poorly treated pain was estimated to be in excess of \$100 billion a year, including the costs of health care, compensation, and litigation. Above and beyond the multilevel impact of poorly treated pain on the quality of life of individuals and their families lie the financial implications of a public health problem of significant proportions.

For example, while the standard of care in both pain and palliative care is a multidimensional approach with a strong emphasis on psychosocial needs, reimbursement is insufficient to support this level of the quality of care. There is a need to collaborate with insurers and legislators to advocate for research funding and to document the potential impact of palliative care interventions on the quality and cost of care for patients, families, and caregivers who provide care to patients. This care often is provided at considerable physical, financial, and emotional cost to caregivers and ultimately to the health-care system (Levine, 2004). Public discussion of euthanasia and physician-assisted suicide invite thoughtful and comprehensive social work analysis because they are reflective of profound and complicated ethical and moral issues. Legislative efforts range from pain management bills that mandate professional education to bills that recommend monitoring programs that require prescribers to submit patient prescription information to a central database. While the goal is to decrease abuse and diversion of prescription medications, this program challenges core social work and human values, such as privacy, self-determination, autonomy, and confidentiality. These legislative efforts are rich areas for social work involvement. Whether as clinicians, advocates, community organizers, policy planners, or researchers, the need for a social work presence in these areas is critical.

#### INTERDISCIPLINARY AND TRANSDISCIPLINARY TEAM

An interdisciplinary team approach involving health-care providers from a number of professions is central to optimal palliative care practice (Lickiss, Turner, & Pollock, 2004; World Health Organization, 1990) and is at the core of chronic pain care.

In contrast to a multidisciplinary approach in which different professionals independently provide care, “interdisciplinary practice refers to people with distinct disciplinary training working together for a common purpose, as they make different, complementary contributions to patient-focused care” (McCallin, 2001, p. 419). A team addresses patients’ and family members’ needs—biological, psychological, emotional, social, and spiritual—by providing the dual benefit of specialized knowledge and skills from multiple professionals delivered in combination rather in isolation. Characterized by a collaborative effort that includes information exchange and coordinated care planning, it places the patient and family at the center of team deliberations and maximizes the unique contributions of each member (Connor, Egan, Kwilosz, Larson, & Reese, 2002). Intervention techniques, such as family conferences that include patients, family members, and health-care team members, promote such coordinated interdisciplinary practice.

Some highly coordinated interdisciplinary palliative care teams may be using a transdisciplinary approach. The transdisciplinary team is characterized by substantial overlap in functions such that members share roles in addition to providing their discipline-specific contributions to the team. Although team professionals are not interchangeable, they share responsibilities for assessing and addressing patient and family care issues. “In transdisciplinary work . . . roles of the individual team members are blurred as their professional functions overlap. Each team member must become sufficiently familiar with the concepts and approaches of his or her colleagues to be able to assume significant portions of the others’ roles” (Hall & Weaver, 2001, p. 868).

The team approach requires professionals to act both as unique contributors and as team members. This dual role may be very challenging to health-care providers, but offers a very powerful form of care. Team members should be able to verbalize and explain their roles both to team members and to patients and families. At the same time, team members should be flexible in practicing their professional roles and careful not to compromise patient and family care due to overly guarded application of their professional “turf.” Turf issues should be openly discussed so that they can be disarmed and minimized. In the setting of economic strains in health care, team members may be especially guarded about their “turf” in service of job security.

Teams that function well develop effective communication and mutual trust. Coordinated function is important for minimizing the conflicting and confusing transmission of information to patients and families, especially in the sensitive context of palliative and end-of-life care. Teams should engage in team-building efforts, such as becoming more familiar with each other, acknowledging differences and similarities in perspectives, addressing conflict respectfully and openly, and developing nonhierarchical patterns of communication. The latter activity is especially challenging in the health-care setting in which the biomedical model imposes a hierarchical perspective.

#### SELF-CARE

Practitioners working in the arena of palliative care and pain management often witness the anger, sadness, and suffering of those for whom they care, especially in situations in which patients are facing chronic pain or the end of life.

Social workers who remain with patients when treatments have failed can experience heavy emotional burdens when, instead, intensive and compassionate comfort care is provided to patients. The emotional, existential, and spiritual depth of social work practice is characterized by the profession's use of self and the capacity to witness and "sit with" people's pain. This intensely personal and deep involvement on the part of the clinician demands conscious and candid attention to how practitioners are preventing compassion fatigue, especially in the long-term. Challenges for all practitioners include maintaining delicate professional boundaries, in which investment and attachment to patients and family members is genuine but not overly consuming. This balance of closeness and distance allows clinicians to provide sincere, meaningful skilled care that is not so depleting that it causes practitioner burnout or compassion fatigue. Social workers experiencing burnout and compassion fatigue have experienced unbalanced practice over the long term that has worn away their internal emotional resources to the point of apathy and inability to provide empathic dedicated care.

Self-care requires maintaining balance between personal and professional life in the larger context of a social worker's life. Clinicians must develop and preserve boundaries between their professional and personal lives. This does not suggest an artificial separation, but rather a concerted effort to develop a rich personal life of relationships, interests, hobbies, and activities that are not related to work and an ability to enjoy one's personal life without having frequent intruding thoughts about work. Engagement in such a personal life, subtly full of life-affirming activities, becomes important for the rejuvenation of the self and the ability to continue practice over time.

## CONCLUSION

The research of Sieppert (1996) and the work of Christ and Sormanti (1999) and Raymer and Csikai (2005) has demonstrated the need for education, research, and leadership in both chronic pain and palliative care. The Social Work Summit on End-of-Life and Palliative Care, held in 2002 and again in 2005, addressed the need for collaboration between practitioners, educators, and researchers. The inclusion of palliative care and pain management in the present *Handbook* is an important step toward expanding the presence and influence of social work in these specialties. Palliative care has been a professional focus in England since the 1960s as evidenced by the writings of Monroe (2004), Saunders (2001), and Sheldon (1999, 2000), but in the United States, social work progress in these specialties has followed in the footsteps of physicians and nurses. The formalized curricula represented by Education of Physicians in End-of-Life Care (EPEC, 1999) and End-of-Life Nursing Education Consortium (ELNEC, 2001) have recently been joined by the Social Work End-of-Life Curriculum Project (Raymer & Csikai, 2003), a continuing education project originally supported by the Soros Foundation. The Leadership Development Award, offered to social workers by the Soros Foundation Project on Death in America, focused on end-of-life and palliative care and included pain and symptom management as core skills for social work clinicians. In addition to the postgraduate curricula of some social work schools, organizations such as Cancer Care, the National Association of Social Workers, and the Association of Oncology Social Workers have created additional

comprehensive continuing education courses. Since the 1970s, social work authors (e.g., Glajchen, Blum, & Calder, 1995; Hudgens, 1977; Loscalzo & Amendola, 1990; Roy, 1981; Subramanian & Rose, 1988) have championed and encouraged social work expertise in pain management. The inclusion of these specialties in the present *Handbook* further validates the role, responsibility, and opportunity for social work clinicians in these areas of practice.

Since its inception, social work has championed important values such as justice, commitment to the underserved and the vulnerable, and respect for the integrity and worth of a human being. The fields of pain management and palliative care are like a tapestry in which these values are woven through every aspect of the work. Persons who are living with life-limiting illness and or chronic pain struggle with a health-care system that is essentially broken. They are vulnerable and often underserved. We hope that this chapter helps to alert social workers to the myriad of possibilities and opportunities to make a difference in the lives of these populations.

## SUGGESTED LEARNING EXERCISES

### LEARNING EXERCISE 21.1

Provide an example of how the skills of a generalist social worker can be translated to pain and palliative care social work practice.

### LEARNING EXERCISE 21.2

Select a teammate and conduct a role-play, with one person as an in-patient and the other as a health social worker called to assess why the patient is “so upset.” The patient informs the social worker that she has just learned that the treatment seems no longer to be effective and that the her prognosis is now grim. Consider what concerns a comprehensive biopsychosocial and spiritual assessment might address.

### LEARNING EXERCISE 21.3

Identify a social worker working in pain management or palliative care to interview. Questions might include:

- How did you select this line of work?
- How do you manage self-care?
- What motivates you to do the work that you do?

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## CHAPTER 22

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# Alternative, Complementary, and Integrative Medicine in a Conventional Setting

PENNY BLOCK

**T**HE USE OF alternative medicine in this country represents neither a passing trend nor a marginal sociological phenomenon. National surveys conducted in the 1990s (Astin, 1998a; Eisenberg et al., 1993; Eisenberg et al., 1998) trumpeted the substantial and escalating use of alternative treatments among Americans, but profiled the typical user of such care drawing from a limited population sampling, thus, misidentifying the adults who seek such therapies as primarily White, middle-aged females with higher education and income. A later corrective report, relying on data that was representative of wider demographics, came up with a different conclusion: Use of at least one alternative therapy was prevalent across all ethnic groups, income levels, and age ranges (MacKenzie, Taylor, Bloom, Hufford, & Johnson, 2003). Only the patterns of preferred healing modalities varied among different ethnic groups. To be truly effective, therefore, in our professional role with ethnically and socially diverse clients—to respond with genuine respect and helpful sensitivity to individuals from many cultural backgrounds presenting in a medical setting—it is essential to reach beyond our own biomedical indoctrination and augment our understanding of divergent health philosophies and practices. Knowing about and demonstrating regard for nonconventional modalities of importance to clients is a precondition to developing confidence, trust, and mutual respect. Doing so should help engage clients/patients in the cooperative planning of their treatment strategy by bridging conventional thinking with individual health beliefs and strengthen therapeutic alliances that enhance adherence to comprehensive and individually meaningful medical treatments. Moreover, when informed about beneficial synergies or problematic interactions among therapies, social workers can more completely coordinate services for optimal health care.

## CHAPTER OBJECTIVES

- Learn about the patterns and prevalence of alternative/complementary use among different populations.
- Distinguish alternative, complementary, and integrative categories.
- Discuss divergent health models and therapies grouped under the alternative umbrella.
- Understand the rationale for use, examples of supporting research, and effective applications.
- Learn about potentials for engaging a client in an open discussion about his or her personal health practices.
- Identify appropriate applications of mind-body strategies as stress mitigating tools.
- Provide resources for more detailed information and evaluation of nonallopathic therapies.

ALTERNATIVE AND COMPLEMENTARY  
PRACTICES IN THE UNITED STATES

While some experts have predicted that the popularity of unconventional practices might fade, instead increasing numbers of Americans are seeking health treatments outside modern Western medicine. Adults across the United States schedule more sessions with nonconventional providers (600 million annually) than medical visits with physicians. In the 1998 follow-up to their eye-opening 1993 report, Eisenberg and colleagues documented a 25% increase in the use of alternatives among Americans—expanding from 33% in 1990 to 42.1% in 1997. During this same period, the number of estimated annual visits to unconventional practitioners swelled from 427 million to 629 million, an upsurge of 47.3% or a projected 243 million more visits than to all U.S. primary care physicians in that year. Moreover, by 1997, those Americans using alternative care were spending approximately 27 billion unreimbursed dollars on unconventional therapies—up 45.2% from 1990—a total that slightly topped out-of-pocket expenditure on total physician services (Eisenberg et al., 1998). In a sample of 453 patients with different cancer diagnoses, 69% reported using at least one type of nonstandard practice or product (within previous year; Sparber et al., 2000). Variant rates appear in the records for pediatric use, with some surveys showing approximately 21% of parents treating their children with alternative or complementary practices (to be defined in following section), but seeking unconventional modalities for 73% of children diagnosed with cancer (Noonan, 2002).

Represented in these surveys were a range of relaxation techniques, herbal treatments, massage therapies, chiropractic practices, spiritual healing, megavitamins, self-help groups, imagery, dietary plans and other lifestyle programs, folk remedies, energy healing, homeopathy, hypnosis, biofeedback, and acupuncture (Eisenberg et al., 1998). While biofeedback, hypnosis, guided imagery, relaxation techniques, lifestyle, diet, and vitamin supplementation fall closer to conventional medicine on a continuum—seem more readily absorbed and accepted by mainstream medicine for specific chronic conditions—these therapies accounted for less than 10% of alternative practitioner visits (Eisenberg et al., 1998). What usually propels people toward modalities outside the conventional armamentar-

ium are chronic disorders, unrelieved by allopathic methods (e.g., back problems, allergies, fatigue, arthritis, headaches, neck problems, high blood pressure, insomnia, skin problems, digestive difficulties, depression, and anxiety). But it is unremitting back pain or annoying allergies that top the list as the most commonly treated with unconventional techniques (Eskinazi, 1998).

These combined data reflect a consumer-driven revolution in the health-care system that seems to be gaining momentum—not a simple fascination with exotic practices or passing fad, but a reflection of the growing public demand for a broader medical armamentarium than the limited inventory in the conventional medicine cabinet. In response to rather startling survey data and certain political pressures, in 1998 by a Congressional mandate, the National Institutes of Health (NIH) redesigned its Office of Alternative Medicine (OAM) as the National Center for Complementary and Alternative Medicine (NCCAM) with a budget that leaped from an initial \$2 million—the 1992 total—to more than \$100 million allocated to research the efficacy of alternative treatments and develop a public clearinghouse of information (Goldberg, Anderson, & Trivieri, 2002).

Yet, even with a surge in patient use of nonconventional therapies in conjunction with a continuation of conventional treatments, only a small proportion of patients actually divulged or discussed their use of these alternatives with their medical doctor: The 1998 report revealed that one in three adults consulting a conventional doctor for a principal condition simultaneously utilized an alternative therapy, but less than 40% of those patients ever mentioned such therapies to their physicians, specifically, 39.8% of alternative therapies were disclosed to physician in 1990, with a slight downward trend to 38.5% in 1997 (see Table 22.1; Eisenberg et al., 2001). Perhaps even more problematic, according to a 1994 assessment (Brown, Cassileth, Lewis, & Renner, 1994), 83% of those diagnosed with a serious medical condition combined unconventional along with conventional treatment but often did so surreptitiously, that is, 72% of these patients withheld this information from their doctor. Believing that their primary care physician would not be interested nor approve and thus dismiss complementary and alternative medicine (CAM) practices summarily, or feeling too embarrassed and deeming their traditional or alternative practices irrelevant to medical dialogue, many patients won't broach the subject in medical consultations (Brown et al., 1994; Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000).

Accompanying this picture of nondisclosure and contributing to legitimate medical worry are statistics showing soaring herbal use. The percentage of

**Table 22.1**  
Nondisclosure Reasons

Not important for doctor to know	61%
Doctor never asked	60%
None of doctor's business	31%
Doctor wouldn't understand	20%
Doctor would disapprove or discourage use of alternatives	14%

*Source:* "Perceptions about Complementary Therapies Relative to Conventional Therapies among Adults Who Use Both: Results from a National Survey," by D. M. Eisenberg et al., 2001, *Annals Internal Medicine*, 135(5), pp. 344–351.

Americans taking herbal remedies almost quadrupled in the years described above, and growth in high-dose vitamin supplementation has surged 130%, which Sullivan (2000) speculates places an estimated 15 million adults, taking prescription medicines concurrently with supplemental agents, at risk for possible adverse interactions. Specific supplements could possibly produce drug action inhibition, substantial interference with efficacy, or magnification of the bio-availability of certain pharmaceuticals, producing serious complications (examples discussed later in chapter) that demand attention. But too often, contraindicated practices remain unknown and unaccounted for in the medical setting. It is here—at the nexus of alternative use and medical implications—that the professional role of the social worker, intervening on behalf of the patient as liaison/coordinating presence with the medical provider, is so critical to the larger health needs of individual clients.

*Alternative Use among Ethnic Minorities* One finding echoed in several surveys, but inconsistent with expectations, is that alternative use is uncommon among ethnic minorities. Although Eisenberg's data (1993, 1998) described the typical CAM user as White, female, of higher educational and socioeconomic status, this belies what we know from ethnomedicine, contradicted by data in medical anthropology research (Becerra & Iglehart, 1995; MacKenzie et al., 2003), and experience with populations using traditional healing techniques (Culliton & Kiresuk, 1996). The Eisenberg team acknowledged that their database was neither sufficiently large enough nor adequately inclusive of different ethnicities to reflect minority use (MacKenzie et al., 2003). Plus, the three earlier national surveys of alternative and complementary trends (Astin, 1998; Eisenberg et al., 1993; Eisenberg et al., 1998) were conducted only in English, whereas MacKenzie's data (2003) relied on surveys conducted in multiple languages besides English (e.g., Spanish, Mandarin, Cantonese, Vietnamese, Korean). Analyzing the 1995 National Comparative Survey of Minority Health Care, the MacKenzie team found use of nonstandard approaches did not differ by ethnicity, that 43.1% of adults surveyed used at least one such therapy, with no statistically significant difference in percentage of use among African Americans, Hispanic Americans, Asian Americans, Native Americans and non-Hispanic-Whites. With their analysis, they concluded that earlier prevalence studies that reported that CAM practices were not medically significant among ethnic minorities, and especially among lower SES populations, were as a result inaccurate. Only preferences for specific alternatives—categorized as herbal medicines, acupuncture, chiropractic, traditional healer, and home remedies—were found to vary among ethnic populations (e.g., using herbal formulations more common or popular among Asian and Native Americans, whereas White Americans were found to be more frequent users of chiropractic services).

The MacKenzie investigation thus asserts that aggregate statistics of alternative and complementary use, ignoring divergent modalities, obscures actual usage among different minorities. For data to mirror the true profile of utilizers, surveys must distinguish divergent practices lumped summarily under the alternative/complementary umbrella (as shown in Table 22.2).

CAM use, they conclude, does not belong to any single demographic—neither ethnicity, income, age, nor being foreign-born predicted use—so understanding these various practices and their true prevalence is essential to the delivery of culturally competent medical care. Even with their more complete detailing, the

**Table 22.2**  
Patterns of Alternative Use among Racial Groups

Categories of Practice	Prevalence of Use
Herbal medicines	Asian Americans 3 times more likely than White Americans to use Latino Americans 2 times more likely than White Americans African Americans 1.5 times more likely than White Americans
Acupuncture	Asian Americans 12.84 times more likely than White American counterparts Uninsured respondents 2-fold higher rate than insured
Traditional healer <sup>a</sup>	Beyond high school education—about 3 times more likely
Home remedy	African Americans 1.24 times more likely to use than White Americans Women 1.24 times more likely to use than men Uninsured 1.5 times more likely to use than insured

<sup>a</sup>This label more academic than commonly used and understood terms such as curandero, medicine man, or root-worker which if used would likely have altered findings.

Source: From “Ethnic Minority Use of Complementary and Alternative Medicine (CAM): A National Probability Survey of Cam Utilizers,” by E. R. MacKenzie, L. Taylor, B. S. Bloom, D. J. Hufford, and J. C. Johnson, 2003, *Alternative Therapies*, 9(4), pp. 50–56.

MacKenzie team noted certain deficits that skewed their accounting: They did not survey religious or spiritual healing practices—keystones of most traditional medicines—nor home remedies and special diets. Also, the label “traditional healer,” more an academic reference than the common terms used in different ethnic circles such as *curandero*, “medicine man,” or “root-worker,” might not have elicited true numbers of followers because of the unfamiliar terminology. But beyond its particulars, the MacKenzie message is a compelling reminder that medicine is always a cultural construct, that the biomedical model is but one paradigm that originated in European science, and that many Americans continue to follow health-care approaches that emerged from nonallopathic medical philosophies. As a final caution, having data on ethnic patterns of medical preferences is essential but should not blind the social worker to individual divergences from cultural norms, which can only be identified with appropriate questions through supportive inquiry (Becerra & Iglehart, 1995; Krajewski-Jaime, 1991).

DEFINITION OF TERMS: DISTINCTIONS BETWEEN ALTERNATIVE, COMPLEMENTARY, AND INTEGRATIVE

Alternative, complementary, and integrative are labels often used loosely and interchangeably to refer to nonstandard medical practices. But this changing, elusive, and overlapping terminology perpetuates confusion and imprecision in efforts to distinguish the merits of different practices. Surprisingly, despite the swelling proportion of Americans seeking nonconventional therapies in the past decade, plus a governmental agency dedicated to studying such treatments with vast expansion in federal funding for this purpose, coupled with significant

growth of insurance coverage, no clear or consistent definition of alternative medicine has yet emerged. Experts still fumble with negative conceptualizations, the most prominent example of which is what is *not* taught in U.S. medical schools and what is *not* insurance reimbursed (Eisenberg et al., 1993). Yet by 1997, alternative coursework appeared in the curriculum of 75 medical schools and several insurance carriers had initiated cost coverage of alternative practices (Wetzel, Eisenberg, & Kapchuk, 1998).

Using terminology such as *alternative*, *unconventional*, and *unproven* to indicate practices outside the armamentarium of Western medicine implicitly censures such therapies (Scholten & Van Rompay, 2000). What words connote can subtly but effectively sabotage or substantially influence acceptance and credibility. For example, using the label "orthodox" to identify the currently dominant medical system in the United States confers automatic authority since the words "accepted," "approved," "established," and "standard" are understood as synonyms for orthodox. Even "biomedical" presumes that all practices under this umbrella are based on scientific confirmation, obscuring other evidence that the human organism is more than a biochemical entity, thus obviating the value of mind-body approaches (MacIntosh, 1999). The following discussion is offered to help unravel the tangled meanings of alternative, complementary, and integrative so that professional dialogue with colleagues and conversations with clients will be less susceptible to misinterpretation.

*Alternative medicine* is not a singular practice or tradition but divergent systems and practices of health care that emerge from widely disparate medical philosophies. Alternative medical *systems* are complete diagnostic and treatment approaches with distinctive theoretical foundations such as those traditional to non-Western cultures (e.g., Traditional Chinese Medicine [TCM] and Ayurveda) and those developed in Western cultures, for example, homeopathy and naturopathic medicine. In distinction, alternative *practices*, are specific discrete treatments or modalities independent of comprehensive or coherent medical schema (MacIntosh, 1999). The chief commonality connecting disparate alternative practices and systems is that they differ in some obvious respect from modern biomedicine and therefore are seen as challenges to the prevailing medical paradigm. Indeed, "alternative" is often used to indicate medical practices used *in place of* modern medical treatments, for example, iridology used as diagnostic technique instead of conventional blood assays.

Beyond the defining characteristic of alternatives just mentioned, there are several more positive, shared premises: (a) The human organism seen as an indivisible system, an ecological whole. This is the fundamental assumption that body, mind, and spirit are not separable but dynamically interconnected—stimulating the healing process as a unified system. In distinction, the Western medical model presumes that the psyche and soma are separate entities to be treated independently, believing a disorder of one organ is not interrelated with the dysfunction of another. Also, in biomedicine, the body as a machine with interworking but semi-independent anatomic parts is assumed and reflected in specialties of medicine that commonly function without intercourse among each other; (b) A core belief in the body's inherent potential for self-healing, with medical regimens designed to encourage/support that process; (c) Optimal health and total healing as the primary objective, rather than elimination of symptoms and signs of the presenting complaint. Western medicine maintains a fixation on physical



sickness; disease and restoring health, however, are not synonymous. Jonas (1998) refers to this nonallopathic emphasis on health as “salutogenesis,” rather than a biomedical fixation on “pathogenesis”; (d) Among many traditional systems, a presupposition that ill health results from a disturbance or imbalance in life force or energy (e.g., *Qi*, pronounced “chee,” in China, *Ki* in Korea and Japan, *Prana* in India, and “vital force” in homeopathy or other traditional Western systems)—for which there is no Western anatomical equivalent. Restoring that balance will reestablish health in all dimensions of being; (e) The principle of the patient’s active engagement or partnership in the healing process; (f) An assumption that spirituality is inseparable from physical and psychological health and critical to a full resolution of what Western physicians diagnose and treat solely as a biological disorder. (See full discussion in Chapter 6.) This spiritual underpinning of alternative practices is reflective of each culture’s dominant religious and cosmological beliefs, for example TCM connected to Taoism, Ayurveda rests on the Hindu belief system, Tibetan medicine is congruent with Buddhist precepts (Eskinazi, 1998).

In some cases, what is casually labeled as alternative may actually mesh effectively with the dominant model of medicine (e.g., hydrazine sulfate treatments for cancer) and therefore be more accurately considered a complementary adjunct. The same allopathic paradigm still determines the architecture of care—with an herbal or botanical medicament substituted or added alongside a conventionally prescribed drug—but the diagnostic categories and therefore essential treatment planning is consistent with orthodox Western medicine (Pietroni, 1994).

*Complementary Approaches* As certain alternatives (e.g., acupuncture, mind/body techniques including meditation, relaxation and biofeedback, chiropractic, and massage therapies) gained entrée to modern medical centers/medical mainstream, new status brought new nomenclature (Brown et al., 1994). Complementary medicine—actually a misnomer—is not a comprehensive system of health care but a heterogeneous assortment of hundreds of treatment modalities lumped under one categorical label. These therapies are used in conjunction with, rather than in lieu of conventional treatments and are often implemented to relieve discomfort or secondary consequences of modern medical interventions (i.e., specific herbals used with prescriptive drug therapies to help mitigate untoward effects, or relaxation strategies to accompany and alleviate symptomatic distress of surgery or chemotherapy). When applied, the model that prevails over the implementation of complementary treatments is still the Western medical paradigm (Pietroni, 1994). Although many times used interchangeably with alternative, *complementary* by definition means something that completes or provides what is lacking (Merriam-Webster, 2003), whereas alternative indicates something that is mutually exclusive of, “offering a choice between two incompatible courses.” If what was judged alternative is brought in-house—joined to mainstream medicine protocols—and institutionalized, it is assigned a peripheral or ancillary role and, therefore, no longer eyed as competitive or challenging the dominant medical model. Thus, complementary is more a designation that identifies the relationship of diverse treatments to the prevailing health system than one that is actually descriptive of different healing techniques. Placed in the company of alternative approaches being evaluated as useful adjuncts to

medical protocols, a new amalgam label has repositioned such unrelated practices as CAM, diminishing the outsider status of alternatives.

In records of CAM usage, the most common health complaints have been disorders that seem unremitting, such as chronic back pain, insomnia, arthritic problems, headaches, musculo-skeletal difficulties, and psychological distress (Campion, 1993). Among those who do seek CAM therapies for more severe health concerns, a large majority (83%) continued treatment with their standard provider. But 72% of those using nonstandard therapies chose not to inform their physicians they had done so (Eisenberg et al., 1993). Surprisingly, at the time of the earlier Cassileth paper, 60% of CAM practitioners were physicians—that is, those providing unorthodox therapies were not stereotypical untrained “charlatans”—and this proportion has been on a steady incline, but few are oncologists (Cassileth & Chapman, 1996; Cassileth, Luck, Strouse, & Bodenheimer, 1984). It is under these conditions—when conventional and nonstandard remain uncoordinated—that CAM can prove most harmful.

CAM practices are a frequent choice for patients diagnosed with cancer; yet such patients seldom discontinue their conventional treatments (Campion, 1993). And according to Campion’s report, a full 58% held the conviction that such treatments would likely provide a cure. Even data from 1984 revealed that 54% of patients surveyed in a major U.S. cancer center were CAM adherents, but at least 40% of patients at that center at one point had abandoned their standard medical treatments to pursue CAM exclusively (Cassileth & Chapman, 1996). A major concern arises if a patient does desert potentially effective conventional care, using only alternatives—even ones that as complements could prove truly helpful—since this person could lose his or her way on an unnecessarily perilous treatment path. Most analyses seem to concur that CAM applications for cancer issues represent a global phenomenon, including diet therapies; healing relaxation programs; metabolic therapies; acupuncture; homeopathy; manual and body therapies; vitamin, herbal, and botanicals or other supplemented compounds (such as, Iscador); and others, not easily dismissed. Eisenberg acknowledges CAM as an “invisible mainstream” within current health care (Cassileth, 1998a; Eisenberg, 1997).

*Integrative medicine*, a term in current parlance, designates an approach to health care which combines, in careful treatment programming, mainstream medical treatments and certain complementary therapies that have demonstrated safety and potential efficacy. Not a specific traditional system of health care based on a distinguishing philosophical or theoretical foundation, integrative exists with those providers who are formally trained in allopathic therapies and equally proficient in or knowledgeable about relevant alternative modalities. To produce a truly melded protocol of integrative care the practitioner must be fully versed in and able to anticipate positive synergies as well as problematic interactions that can occur when he or she combines previously unfused therapies. Even though a single system, there are certain consistent identifiable standards of care in this medical field: The integrative approach is a careful amalgam of conventional and alternative treatments intended to marshal the body’s own recovery processes; it maintains an openness to paradigms other than Western allopathy, focuses on the larger goal of optimal health beyond ameliorating specific disease issues, and begins by creating a partnership of provider and patient (according to

the University of Arizona Program in Integrative Medicine). This last principle echoes and is consistent with one of the key practice tenets of social work, reaffirming the true professional fit for the health-care social worker in the integrative sphere.

Proponents postulate therapeutic advantages if regimens are properly integrated and tailored to each individual's particular health needs. This means treatment plans for individual patients that rely on a sound coupling of therapies from both conventional protocols (e.g., prescription medications) and alternative practices (e.g., herbal/botanical agents), a melding guided by evidence-based information and a watchful eye to potentially problematic interactions (certain combinations contraindicated because of particulars about medical status of a patient or intervention). The totality of an integrative program can yield a "better-than-sum-of-its-parts" outcome, that is, a comprehensive and coherent treatment plan can produce full synergistic benefits beyond mere adjunctive add-ons of disconnected, exotic practices. Nevertheless, an unanswered conundrum hovers over the enthusiasm of integrative intentions: Can systems shaped by dissimilar, nonparallel paradigms of health and healing ever be fully blended?

#### REASONS FOR SEEKING ALTERNATIVE TREATMENTS

More than a decade after the Eisenberg's initial report (1993), the disagreement surrounding actual determinants of CAM still smolders. Discussing this dispute does not simply serve in the interest of debate or polemics but familiarizes us with proposed reasons in order to encourage an open but knowledgeable discussion with clients, to act as an informed liaison between patients being treated and the medical team, and to impact an administrative response to cultural and medical pluralism in effective programs.

There are those who argue from surveys that dissatisfaction with orthodox treatments is not a significant predictor of alternative usage. Astin (1998) cites data showing that 54% of those using alternatives reported feeling very satisfied with their conventional experience. Astin's conclusion supports a "philosophical congruence theory." That is, patients felt aligned with comprehensive treatments designed to promote health rather than oriented wholly on pathology and disease and with approaches that value dietary, mind-spirit, and lifestyle factors in self-care programs (Borins, 2002a). From this perspective, modern medicine represents a necessary but not sufficient response to health concerns.

Others contend that even philosophical congruence can be construed as an indicator of disappointment with orthodox care. Although most users of CAM are not distrustful of nor totally displeased with mainstream medical treatments, many would concur that electing to use an alternative implicitly signifies some dissatisfaction with results of the conventional armamentarium—that conventional therapies have not been fully effective, prompting the patient to seek other and more (Baldwin, 1998). From this perspective, electing CAM therapies suggests that even if not eschewing conventional interventions, patients doing so are not fully pleased with their experience in mainstream medical facilities. It has been argued that because Astin (1998a) did not include a direct question about perceived efficacy (i.e., "Has conventional treatment worked for you?"), and satisfaction with treatment is a primary determinant of each individual's medical choice, that Astin's conclusions are based on inadequate data. In Baldwin's

words, “patients in general would not part with good money unless they felt they were getting better results outside conventional health care” (1998, p. 1660).

While standard Western medicine is unparalleled at crisis intervention—trauma and emergency care—and battling microbial disease, it has been less successful at identifying how to achieve and maintain optimal health or how to respond to unabating chronic ailments—problems that fail to disappear. No doubt the drive toward CAM can be very idiosyncratic but certain recurring themes lead people to unorthodox practices: (a) discomfort with an impersonal quality pervasive in institutional settings, (b) discontent with technological procedures that presume a mechanistic and reductionistic model of human health (Borins, 2002a, 2002b); (c) unresolved chronic medical problems (e.g., arthritis and allergies often don’t respond to conventional interventions) and reduced faith in advent of medical breakthroughs to eliminate vexing health concerns (Jonas, 1998); (d) growing fascination in spiritual dimensions of health; (e) mounting unease about the toxic potential and adverse consequences of invasive medical practices (Jonas, 1998) combined with confidence in lower toxicity/greater safety of most alternative treatments; (f) the repeated experience of dispiriting or perfunctory communications from medical providers; and (g) the desire to regain a modicum of personal control over the direction and process of care.

This latter reason—the intent to reclaim responsibility for treatment decisions and medical care rather than remain as passive recipients of medical interventions and invasive technology—frequently propels cancer patients toward non-standard practices (Lerner & Kennedy, 1992). Beyond avoidance of dreaded side effects and iatrogenic consequences, many people diagnosed with a malignancy suspect that pollution, dietary patterns and stressors are implicated in the etiology of their disease, so the logical recovery strategy requires altering food intake and a personal regimen of lifestyle adjustments (Borins, 2002b). Although 43% of patients believed that their supplement program was a truly effective tactic in their cancer battle (Cassileth et al., 1984), when cancer patients elect alternative or complementary modalities, they usually do not limit CAM options to a singular practice. The likelihood of CAM use is heightened the longer a patient has been dealing with their cancer (Lerner & Kennedy, 1992). Plus, oncology patients choose these combination therapies because conventional treatments hold out poor cure and remission statistics—very bleak showings on desired outcomes—and seem unable to deliver desired outcome. All of which indicates, if not total disillusionment, dissatisfaction (Borins, 2002a; Lerner & Kennedy, 1992). Added to these issues is an increasing frustration among patients—and for substantial numbers of doctors—with their experience in standard medicine, perpetuated by a managed care economics that permits too little physician time and encourages a system that often feels impersonal (Weil, 2001). Therefore, although most users of alternatives may not be truly distrustful of mainstream medical treatment—in fact stay with conventional regimens simultaneous to alternative and complementary plans—nor are they fully satisfied with the results of their conventional modalities.

#### SYSTEMS AND PRACTICES

As critical as becoming familiar with names and types of single practices, agents, or therapies is learning the divergent cultural models of health and medicine that

are the philosophical underpinning of specific alternative interventions. (See Table 22.3 for categories.)

*Traditional or Indigenous Health-care Systems* Emerge from centuries-old philosophical principles and fundamentals of health care that differ appreciably from those undergirding the model of biomedicine. They developed from ancient texts and medical ideologies—embedded in and reflective of the specific traditions and societal and spiritual beliefs of each culture. Thus, TCM is connected to Taoism, Ayurveda rests on the Hindu belief system, and Tibetan medicine with Buddhist precepts (Eskinazi, 1998).

*Traditional Chinese Medicine* In this medical system, health is understood as the unimpeded flow of vital energy (Qi) traveling through a network of bioelectrical pathways, which have no exact correlate in the Western model of anatomy. Additionally, health implies a balance of opposed universal forces of yin and yang within all systems—body, mind, and spirit—and with the larger external environment. To reestablish balance and optimize health, traditional Chinese doctors prescribe a complex regimen of dietary adjustments, meditative physical exercises (e.g., tai chi and qi gong), specific massage treatments, herbal formulations, and acupuncture. These recommendations are tailored to match the individual’s diagnosis (e.g., hot liver excess)—TCM diagnoses bear no exact correspondence to Western disease categories—determined by pulse evaluations (again, unlike Western pulse taking or blood pressure readings) and other signature indicators (e.g., tongue signs, vocal tone, skin quality). In diagnosis, the practitioner identifies the underlying cause of body’s pattern of disharmony that is unique to that individual and at that time. For example, an individual diagnosed as suffering from cold-deficiency disease will be placed on a regimen of specific foods known as body-heating (not synonymous with temperature, but a quality believed to strengthen the blood).

*Acupuncture* Since disrupted energy flow is understood as the basis of disease, this treatment involves the insertion of very thin needles at blockage junctures or

**Table 22.3**  
Deaths from Ingestion in United States  
(1982 to 1993)

	1-Year Average	11-Year Total
Herbs	0	0
Dietary supplements <sup>a</sup>	3	3
Over the counter drugs	320	3,520
Food-borne illnesses	9,000	99,000
Prescription drugs	110,000	1,210,000

<sup>a</sup> Including 1989 contaminated L-tryptophan and iron poisonings.  
*Sources:* American Association of Poison Control Centers, Food and Drug Administration, U.S. Department of Agriculture, *Journal of the American Medical Association*, and *New England Journal of Medicine*.

specific meridian points to release or restore flow of energy through channels or meridians. It is theorized that there are more than 2000 points connected to particular organ systems. While deemed alternative in the United States, acupuncture is a traditional, standard healing practice in China, with origins in the classic text of Chinese medicine, the *Nei Ching* (circa, 2500 B.C.). Currently, it is the most commonly used medical practice worldwide, applied as a full diagnostic and healing treatment among Asian cultures (NCCAM, 2000; Gerber, 1988).

A report published in 1998 calculated more than five million visits were made to acupuncture practitioners annually in the United States (Eisenberg et al., 1998). With research primarily on its effectiveness at alleviating different degrees and types of discomfort, acupuncture has earned gradual medical acceptance for certain pain syndromes (NIH, 1972). Even though its specific mechanisms continue to elude scientific explanations, compelling evidence has found acupuncture efficacious beyond placebo in: relieving chronic and acute pain (Jackson, 1997; Takeda & Wessel, 1994), easing the severity of drug withdrawal (Ghandi, 1996), diminishing chemotherapy induced nausea and vomiting (Beinfeld & Korngold, 2003). Beyond analgesic and anesthetic applications, when administered as an adjunct for cerebral vascular episodes, acupuncture reduced recovery time by 50% and per-patient cost by \$26,000 (Johansson, Lindgren, Widner, Wiklund, & Johansson, 1993). In broader medical settings, acupuncture has been gaining favor as a therapy for asthma and gastrointestinal problems, chronic fatigue (Sullivan, 2000), as an effective treatment for night sweats, diarrhea, vomiting, digestive difficulty, insomnia and other debilitating AIDS symptoms, particularly when combined with moxibustion (specially heated herbs applied to acupoints) and herbal formulas (Hudson, 1996). But for those who are truly needle phobic, resistance to acupuncture might interfere with and obstruct anticipated benefits (Lu, Lu, & Kleinman, 2001).

*Ayurvedic Medicine (or Ayurveda)* This traditional medical system has roots in 4,000 year-old Indian texts that, similar to TCM, explain illness as disruption of harmony and balance in the vital life force or *prana*. Restoration of health—reestablishing balance—depends on individualized dietary, herbal, massage, and meditative therapies that correspond to the individual's predominant constitutional or metabolic body type, known as a *dosha*, for example, *kapha*, *pitta*, and *vatta* (Chopra, 1989). Rather than an exclusive focus on disease particulars and their specific treatment, Aurvedic plans of care are equally directed at systematic preventative care and optimization of health.

#### ALTERNATIVE HEALTH-CARE SYSTEMS

*Homeopathy* This complete system of medicine originated during the latter 1790s and early 1800s in Germany and is founded on the theory that "like cures like," also spoken of as *similia similibus curantur* or "law of similars," (Moore & Schmais, 2000). In this country, homeopathy was not only popular but was highly regarded professionally as a full medical approach during 1800s and early twentieth century. By 1900, homeopathic institutions included 22 medical schools, approximately 200 hospitals, and 15% of physicians were homeopathic doctors. The advent of allopathic standards, the pervasive impact of our cultural ideal of empiricism and the ascendancy of the American Medical Association—its domina-



tion and determination of acceptable practices (Wharton, 1999)—diminished homeopathy's stature, another manifestation of cultural and social configuration of medical models. However, homeopathy is more widely used globally than any other system of medical care, is still commonly applied in Western Europe (Sullivan, 2000), and has been attracting research interest and gaining advocacy once again in the United States.

The principles of homeopathy seem paradoxical and defy conventional pharmacological explanations. That is, homeopathy treats health disorders by administering tiny, dilute doses of natural substances—mineral, plant extracts, even disease-producing germs, diluted in pure water or alcohol (Goldberg et al., 2002), which, if given in a larger quantity, could produce the undesired symptoms or medical complaint. This doctrine of practice is referred to “The Law of Infinitesimal Doses”: The more highly dilute doses (30 successive dilutions) are considered more potent than less dilute (6x) formulations (Moore & Schmais, 2000). The basic assumption is that these precisely formulated microdoses target the root causes of disease by initiating the body's inherent healing mechanisms. In this system of care, symptoms are viewed as a functional attempt of the organism to right or heal itself (Taylor, 1995), and therefore, not the primary focus of treatment. For instance, two patients presenting with the very same Western medical disease diagnosis might exhibit very different symptoms. After careful analysis of other subtly related indicators, pointing to noncomparable origins of their malady, the practitioner would recommend entirely different homeopathic remedies (choosing among hundreds)—in contradistinction to the precise algorithms of Western medicine that would identify a singular protocol for a single diagnosis.

Even though homeopathic assumptions contradict Western medical precepts, more than 80 randomized trials show homeopathic efficacy for disorders such as severe diarrhea among young children (Jacobs et al., 1994), asthma, dermatitis, and otitis media (Sullivan, 2000). A meta-analysis (a comprehensive analysis of published empirical studies) found measurable benefits for disorders as various as hay fever, asthma, and influenza (Kleijnen, Knipschild, & Riet, 1991).

*Naturopathic Medicine* With an ebb and flow history, naturopathy is now regaining popular interest and recognition and is formally licensed in 11 states. Originating in the United States in the early 1900s (first with Benjamin Lust and later systemized in Henry Lindlahr's texts on natural therapeutics), this is a medical discipline of nontoxic regimens derived from worldwide healing systems. Treatment plans are designed to enhance the body's inherent healing capacity (*vis medicatrix naturae*) and are based on a meticulous composite of therapeutic diet, the naturopathic cornerstone, herbal medicine, homeopathic remedies, acupuncture, detoxification therapies (colonic irrigation, salt-water baths, and fasting), hydrotherapy, physical therapies, spinal/soft tissue manipulation, and hyperthermia—the compendium derived from various traditional healing systems. The most common application of naturopathy is treatment of chronic and degenerative problems, rather than acute or trauma conditions.

A basic principle of naturopathy (*primum no nocere*) holds that disease symptoms are the body's innate mechanism for correcting unhealthy imbalances. It is believed, for example, that reducing a fever or medicating inflammation—simple manifestations of imbalance—rather than eliminating the root cause (*tolle causam*) of an elevated temperature or the inflammatory condition, will perpetuate the

disorder and result in chronic disease. Often during the therapeutic regimen to remove causative factors, a patient will experience an acute episode or a “healing crisis” which according to naturopathic thinking indicates an expected reaction to treatment and a signal that the therapy is on track. It is assumed that subsequent to this amplification of symptoms, the adverse condition will naturally subside (Goldberg et al., 2002).

#### FOLK MEDICINES

In dictionary terms, folk medicine (or lay medicine) refers to a tradition of health beliefs and illness treatments transmitted orally and by imitation among a group of people with a common cultural and/or ethnic identity (Hurdle, 2002; Merriam-Webster, 2003). What this term seems to conjure inaccurately is a notion of folk medicine as a set of quaint practices predominant among rural or nonacculturated populations. Yet, in a 1995 paper, Becerra and Iglehart report the common practice of folk medicine, particularly for minor disorders or as preventative, among diverse urban populations who do have access to modern scientific interventions. Thus, Chinese Americans may selectively apply traditional Chinese practices while continuing to follow modern medical recommendations, deeming each differentially effective with particular health problems. Surprisingly, from surveying parents from different ethnic groups (Chinese American, African American, Mexican American, and non-Hispanic Whites), Becerra and Iglehart (1995) observed that level of assimilation was not predictive of reliance on folk medicine, but personal injury or illness of children during the prior 6 months was. Why these medicines still attract loyal adherents and are resilient even in modern urban societies can be attributed first and foremost to their effectiveness for specific problems, alongside an unwillingness to abandon heritage and tradition, a desire to preserve self-determination in personal health, affordability, and congruence with spiritual belief systems (Neff, 2004).

Although specific remedies or “cures” embraced by folk medicines are often used in combination with conventional medicine, these practices are not easily tagged as complementary. That is, folk practices might not fit the allopathic model—their theoretical underpinnings and thus diagnostic and healing categories can be incompatible with biomedical thinking. Folk medicines represent consistent and coherent patterns of practice, not disconnected assortments of remedies and preventatives. Each folk system reflects its cultural source with a distinct explanatory model of sickness (see Chapter 9 for a full discussion of health belief models), appreciably different from that of Western biomedicine that divorces spiritual and religious meaning from disease etiology and treatment.

These folk diagnostics and curatives, seem to share the belief that a patient’s disorder and subsequent health are embedded in environment that is simultaneously social, ecological, and spiritual. (A tenet that echoes and coheres with the person-in-environment fundamental of professional social work.) Another important distinction—unlike allopathic medicine that prescribes treatments even when disease causation is unknown or uncertain, folk systems do not proceed with curative therapies before identifying clear etiology (Krippner, 1995).

Since it is not feasible in this one chapter to present a full discussion of the complex topic of folk medicine, examples will be mentioned to highlight certain distinctions among systems and identify possible points of incongruity between

modern medical thinking and folk models—ones that reflect vastly different ways of construing health and sickness issues. For the health-care social worker, familiarity with folk practices helps to bridge separate cultures of medicine and engender mutual respect for a more effective delivery of services.

As an example, among Mexican Americans, *curanderismo* or folk healing is a continuing and stable presence in family health care (Becerra & Iglehart, 1995). Not an assortment of piecemeal remedies, this is a comprehensive tradition that holds religion as a core element with practices that derive from an elaborate classification of maladies. These have no exact corollary in orthodox medicine, thus may not be resolvable by Western medical techniques and, as a result, necessitate folk healer (*curandera* or *curandero*) interventions. While disease causation is not understood as God's punishment, the divine is viewed as the ultimate source of relief and recovery from illness (Becerra & Iglehart, 1995). Most often the *curandera* determines a diagnosis by reading the patient's aura or energy body, by questioning both patient and family about signs or symptoms and peculiar patterns of patient behavior, and ultimately by information from the spirit guide in dreams (Krippner, 1995). In *curandersimo* diagnostics, there are five principal folk sicknesses, four of which are deemed natural disorders ("males naturales"): *caida de la mullera* (fallen fontanel in infants due to mother's neglect), *empacho* (digestive disorder), *mal ojo* (the evil eye that occurs when stared at with envy or desire), *susto* (shock or fright)—and one with its source in witchcraft or sorcery—*mal puesto*, due to a hex (Becerra & Iglehart, 1995; Krippner, 1995). Symptom patterns can be complex including fever, headaches, vomiting, and drooping eyes for *mal ojo*, but do not in and of themselves define the problem. Depending on diagnosis, curatives can involve herbals, incantations, manipulations, and spiritual practices with the *curandera* ever-present to enlist divine assistance or the intercession of helpful spirits (Krippner, 1995).

Other folk practices persist in an urban setting. For example, without abandoning their modern medical care, African Americans may specifically seek herbal remedies ("root" work) or spiritual practices to cure sickness ("the misery") when illness is attributed to divine punishment, or natural or magical forces. In contradistinction, White non-Hispanics seem to rely more on specific food preparations and mechanical applications (e.g., poultices rather than herbals) as remedies; but parallel to modern medicine, Anglo popular medicines (as they are labeled by Becerra & Iglehart, 1995) separate spiritual rituals from physical health practices. These authors imply that although not as elaborate and codified as other folk medicines, continuity of Anglo healing measures is ensured because it enables and echoes values of independence and self-reliance.

Among many Native-American practices, a rigorous logic informs practice and, in fact, the sophistication of the Piman Indian model with its specialties and sub-specialties is seen by medical anthropologists as perhaps as highly developed as that of Western medical theories (Krippner, 1995). Comparisons, however, are not simple because many diagnostic categories are not comprehensible outside of a particular cultural perspective. The Piman model holds that one classification of disease responds to external treatment while other types may only heal with body's innate mechanisms or might not be remediable, for example, infant deformities (Krippner, 1995). According to Piman theory, the body of each patient reflects the accumulative repository of resources and weaknesses to be evaluated and analyzed by the shaman with the assistance of benevolent spirit guides before

the individual is assigned to the appropriate intervention of other practitioners. Specific behaviors inform the shaman's diagnostic conclusions. In this system, "wandering sickness" (impurities such as germs, pus, or heat that traverse the body) identified with signs such as fever, hives, piles, sores, is treated with herbals and spirit entreaties to bless curatives. Another category of maladies, "staying sickness" (manifestation of proscribed behavior toward power object from nature) persist in the body because the individual has violated sacred laws. This group includes "wind sickness," "deer sickness," and "rabbit sickness" and requires shamanic chanting, ritual removal of toxic substance from the ill person's body, often in conjunction with sand painting and/or special feasting (Krippner, 1995). In some instances, a disease is deemed untreatable—an intrinsic condition that is characterologically induced—obviating interventions that would interfere with a specific and necessary life lesson (Cohen, 1999).

*CAM Practices* As mentioned earlier, what is usually classified as complementary medicine is not a true medical system, but nonstandard practices that can be applied within the allopathic model, that is, where nonstandard treatments dovetail with, instead of supplanting, conventional plans of care. It is still the conventional biomedical model and theory that determine usage (MacIntosh, 1999). While the exhaustive listing of CAM modalities is far too extensive for full coverage in this chapter, some of the more common CAM categories of treatment are mentioned to increase familiarity (Loveland-Cook, Becvar, & Pontious, 2000).

**BODY AND MASSAGE THERAPIES (MANUAL THERAPIES)** This modality encompasses multiple distinctive therapies that primarily use physical touch for diagnostic and treatment plans (Loveland-Cook et al., 2000), which include the following as representative of such practices:

- *Chiropractic* is foremost a system of spinal adjustments. It is estimated that 23 to 38 million Americans visit chiropractors annually (Goldberg et al., 2002). While the primary chiropractic function remains treatment of back pain, one of the most common health complaints in the United States second only to the common cold, in some states (e.g., Illinois) chiropractors may be licensed to use certain noninvasive tools such as throat cultures and to treat minor health issues (Rattenbury, 1995). Therefore, chiropractors (DCs) are no longer perjoratively identified as "back crackers." According to the guiding premise in chiropractic, health is ultimately determined by the central nervous system; misalignment of the spine, referred to as "subluxation," engenders pain and other health problems, requiring spinal adjustments, achieved with varying methods and equipment, to restore healthier nerve functioning. Numerous studies have found chiropractic to effect better and longer maintained relief of back pain than that achieved by medical doctors (Meade, Dyer, Browne, Townsend, & Frank, 1990) and at significantly reduced cost (Jarvis, Phillips, & Morris, 1991).

- *Naprapathy* is a back/body modality related to chiropractic, but this practice treats musculo-skeletal pain by manipulating connective tissue and muscles rather than bones. Naprapaths (DNs) most commonly treat muscle spasms, joint pain, inflammation, and scar-tissue (Rattenbury, 1995).

- *Reflexology*, another manual therapy, is based on the premise that each body organ or system has one or several corresponding points on the feet and hands. By applying precise pressure to these points the practitioner can unlock disrupted pathways of energy which have produced pain or an unrelieved structural

disorder. Research has shown reflexology to be an effective treatment for chronic migraines and tension headaches (Launso, Brendstrup, & Amberg, 1999).

- *Therapeutic touch* has as its underlying rationale the theory that bioelectrical energy fields make up soma and psyche of each individual and these interact with environmental factors to produce health problems. This practice involves realigning or rebalancing disturbances in this energy field. Studies regarding efficacy have found that gentle therapeutic touch bolstered weight gain among premature neonatals (Harrison, Olivet, Cunningham, Bodin, & Hicks, 1996); helps calm children distressed during hospitalization (Kramer, 1990); other data suggest that TT aids factors that enhance immune response, particularly an increase in helper T4 cells and reduction of suppressor T8 cells (Quinn & Strelkuskas, 1993). Moreover TT has been associated with reduced pain of tension headaches (Keller & Bzdek, 1986) and has found applications in more than 200 hospitals (Goldberg et al., 2002).

- *Aromatherapy* uses essential oils, distilled from plant oils, to relieve and relax symptoms associated with disease and side-effects of treatment, and more generally to enhance overall well-being through the olfactory system. The usual routes of aromatherapy are through inhalation of oils dispensed by diffusers or when massaged directly on skin. The latter method requires knowledgeable professional guidance as certain oils such as cinnamon and clove can burn/irritate the skin. Another caution: Even the most purified oils should not be ingested because they can be quite toxic. But beneficial effects abound: Lavender induces calming, almost sedative benefits on brain wave activity (Birchall, 1990), and can be very helpful with sleep disorders, particularly sleep onset problems. During childbirth, lavender and lemon relieved tension in early stages of labor, whereas in later phases, peppermint was found to alleviate nausea and vomiting (Burns & Blarney, 1994); in an intensive care unit, aromatherapy combined with massage provided patients with greater observed ease and relaxation than massage alone (Dunn, Sleep, & Collett, 1995).

- *Therapeutic massage and bodywork*, with multiple practices—Swedish, deep tissue, sports, and lymphatic massage—fit under this classification, and estimates suggest they are used by a projected 20 million Americans annually (Goldberg et al., 2001). Research on various forms of manual therapy has produced substantial documentation that massage therapy can relieve psychological stress and lift mood (Corley, Ferriter, Zeh, & Gifford, 1995; Dunn et al., 1995; Sims, 1986). Physiologically, massage enhances blood and lymph circulation and parasympathetic response (e.g., decreased heart and respiratory rate, relieved muscle tension, and lowered blood pressure). It has been associated with better gastrointestinal functioning, diminished reliance on analgesics, and improved active functional levels (DeGood, 1996). In research with another focus, preterm infants have benefited, showing significantly improved weight gain and shortened hospitalization with daily massage (Field et al., 1986). Other physical manipulation therapies—too numerous for this chapter—include deep-tissue work to restructure the body such as Rolfing, or the gentler craniosacral therapy, pressure point techniques like acupressure, or health awareness through movement re-design of the Feldenkrais approach.

- *Mind/body* labels a broad category of techniques—meditation, hypnosis, biofeedback, autogenic training, relaxed abdominal breathing, guided imagery, progressive muscle relaxation—based on the understanding that psyche and soma are interconnected in a dynamic, unified system. The bidirectional communication



between autonomic, musculoskeletal, and psychoneuroendocrine systems via neurotransmitters means that stressors can exert a harmful impact on physiology and biochemistry, but inversely, relieving stressor impact can afford salutary effects on the body and total health.

Blumenthal and colleagues at Duke University (1997) assessing participation of angina patients in 16-week mind-body program found fewer subsequent episodes than among controls. Although stressors that initiate damaging physiological reactions may not be consciously perceived or processed, both acute and chronic psychological distress produce symptoms such as elevated pulse and blood pressure as well as respiratory rates, platelet aggregation, insulin levels, sodium retention, and decrements in immune response (Seaward, 1997; Wells-Federman et al., 1995). Techniques with empirical support of benefits offsetting damaging levels of stress include:

- *Guided imagery* techniques have demonstrated effectiveness, but guided imagery affords personal customization, for example, evoking a detailed mental image, using all senses—visual, auditory, olfactory, tactile—that represents for that individual a safe and healing setting. Strong associations were reported between such practices and mitigation of chronic pain as well as improvements in immune influenced diseases (Benson & Stuart, 1993; Hillhouse & Adler, 1991). In cancer settings, guided imagery combined with progressive muscle relaxation was more effective at reducing the experience of pain severity among women with stage II, III, and IV disease than simple supportive communications (Sloman, 1995); cancer patients trained in guided imagery were able to diminish the severe oral mucositis pain that followed chemotreatments (Pan, Morrison, Ness, Fugh-Berman, & Leipzig, 2000); in another study among women with breast cancer, a link was observed with improved killer cell activity along with mood enhancement (Fawzy et al., 1993; Newton, 1996); also with breast cancer patients enhanced interferon levels accompanied by improved stamina and well-being that was substantially greater than controls resulted with this mind-body technique (Justice, 1996); and a further application in oncology setting, relieved chemo-induced nausea and vomiting (Troesch, Rodehaver, Delaney, & Yanes, 1993).

- *Meditation* is a traditional practice in many cultures with technical variations, but when stripped of religious or cultural overlay, reveals substantial commonalities: Basic guidelines involve keeping the mind calmly focused on the present moment, diminishing painful ruminations about past and anxious preoccupations with future. In the concentrative approach of meditation, one is instructed to maintain attention on the breath, the repetition of a special word, phrase, sound (mantra), or image; alternatively, the mindfulness approach encourages observing thoughts as they enter the mindscape, but nonjudgmentally. The psycho-physiological benefits evidenced with mindfulness-based stress reduction (MBSR), a meditative discipline developed by John Kabat-Zinn and his team at University of Massachusetts and utilized in more than 100 U.S. hospitals include alleviation of chronic and heretofore unremitting pain (Cassileth, 1998; Hafner, 1982; Kabat-Zinn, Lipworth, & Burney, 1985); four times more rapid healing of psoriasis (Kabat-Zinn et al., 1998); documentation of anxiety and stress relief with accompanying physiological benefits (e.g., reduced hypertension).

- *Hypnosis* is a practice that uses selective attention to induce a specific altered state (trance) which enhances communication between conscious and un-



conscious processes (e.g., functioning of autonomic nervous system) for therapeutic benefit. All hypnosis is in effect self-hypnosis—that is, to produce a hypnotic state, the client/patient must be engaged actively as a willing participant with therapist as facilitator. While it is thought that the brain's limbic system—which influences emotions and controls what is believed to be involuntary body functions—responds to hypnotic suggestions, a precise understanding of how this intervention works still eludes scientific explanation. By 1991, at least 15,000 health professionals practiced hypnotherapy in combination with their conventional medicine to ameliorate many conditions (Goldberg et al., 2002). Hypnotherapy helps to: accelerate healing (Ginandes, Brooks, Sando, Jones, & Aker, 2003), triggering the release of endogenous anti-inflammatory chemistries; curb secretion of excess stomach acids among ulcer patients; soothe chronic and acute pain (Montgomery, DuHamel, & Redd, 2000); relieve side effects of chemotherapy such as, nausea and vomiting (Leviton, 1992; Lynch, 1998; Marchioro et al., 2000; Syrjala, Cummings, & Donaldson, 1992); speed return of intestinal motility, reduce blood loss and pain medication needs associated with surgery (Disbrow, Bennett, & Owings, 1993; Enqvist, 1991), assist in asthma relief (Hackman, 2000), and provide measurable relief with other difficult treatments (Goldberg et al., 2002). One study demonstrated that burn patients healed more rapidly and with less pain if a light trance was induced soon after the trauma (Findlay, Podolsky, & Silberner, 1991). In pediatrics, hypnosis was helpful with problems from recurrent migraines to sickle cell anemia (Goldberg et al., 2002). Contrary to earlier estimations, approximately 94% of patients experience some relief, and those more easily hypnotized benefit even more substantially (Podolsky, 1991).

- *Biofeedback* is a painless procedure in which sensors, attached to electrodes, are slipped on fingers or placed as upper arm cuffs while a patient/client observes signals on a computer monitor indicating that he or she is able to achieve a desired state, for example, reduced heart rate, relief of tension headaches, warmer peripheral temperature (Long, Machiran, & Betell, 1986). This technique involves a process of learning to control seemingly involuntary body functioning (e.g., skin temperature, brain wave patterns) when the patient practices relaxation tactics. It has been found useful with Reynaud's disease (fingers become painfully cold when in cooler, not necessarily frigid conditions). Numerous insurers reimburse the cost of this therapy (Goldberg et al., 2002).

Mind/body techniques are congruent with social work objectives of empowering patients/clients to implement positive changes through self-management, and with social work values of respecting and tailoring to individual needs since each of these techniques is amenable to individual adjustment. Moreover, through professional training programs and workshops, mind-body approaches can be added to clinical skills and incorporated into professional social work practice. By engaging patients/clients in these complementary techniques—training and treating individuals whose health can benefit from mind/body modalities—the social worker enlarges his or her clinical role beyond that of patient advocate and medical liaison, and in treatment ideals that echo social work fundamentals.

**NUTRITION AND LIFESTYLE REGIMENS** Traditional medical systems rely heavily on dietary adjustments to restore or maintain balance seen as the essence of health. Depending on environmental factors and the individual's energetic status, specific foods are to be eaten while deliberately avoiding and eliminating others.

*Macrobiotic Regimen* is a lifestyle and dietary discipline emerging from Japanese Zen practices that prescribes individualized regimens to restore yin-yang energy balance. Dietary guidelines are based on fresh whole foods such as whole cereal grains, fresh vegetables, legumes, seeds, nuts, fruits, and some fish with adjustments to match the individual's particular imbalanced energy—determined by evaluating condition and constitution—and to correspond to changing climate exigencies.

*Lifestyle Heart Trial* showed patients with substantial coronary artery disease had significant regression of atherosclerosis when following a specific low-fat diet combined with nonimpact exercise and relaxations strategies (Ornish et al., 1983; Ornish et al., 1998). Other dietary information from epidemiological and observational research suggests that vegetarian eating may relieve rheumatoid arthritis symptoms and may reduce arthritic incidence and allergy problems by cutting protein triggers (Adam, 1995). Furthermore, high fiber as well as other aspects of whole grain, vegetable, legume, and fresh fruit consumption is linked with healthier gastrointestinal functioning and diminished risk of specific cancers as well as cardiovascular problems (Block, 1999; Burkitt, Walker, & Painter, 1974).

*Nutritional Supplementation* has shown a continual and dramatic rise in use among Americans in recent decades, despite medical controversy (Murray & Pizzorno, 1996), reconfirms the public conviction that botanicals, herbals, and nutrients do make a significant difference and are generally less toxic than pharmaceutical drugs. Even in the midst of a media furor, there is little contest that specific agents can improve resistance to and duration of certain infectious sicknesses (Hemila, 1994), even among the elderly (Chandra, 1992). Supplements can augment preventive measures to counter severe disorders (e.g., protective against heart diseases as well as certain cancers), particularly vitamins E and C as well as carotenoids (Loveland-Cook et al., 2000). Preliminary evidence also supports the value of coenzyme Q10 for cardiovascular problems such as congestive heart failure (Gaby, 1999) and protects with cardiotoxic chemotherapies like adriamycin (Mortensen, Aabo, Jonsson, & Baandrup, 1986) and chromium helpful with type 2 diabetes (Sullivan, 2000).

*Bioelectronic Therapies* depend on the theoretical premise that all living organisms are affected by and exist within electromagnetic (EM) fields guides bioelectromagnetic (BEM) treatment. Therapeutic improvement of EM fields—altering the individual's BEM energy for physiological relief—is postulated by creating bodily contact of an individual's BEM field with a weak, nonthermal EM field to enhance blood and lymph circulation, cellular oxygenation, and detoxification thus relieving pain, hastening the healing process, and boosting energy. Enhanced healing of bone fractures was evidenced in studies reported in 1984 (Barker, Dixon, Sharrard, & Sutcliffe), accelerated wound healing (Basset, 1993; Lee, Canaday, & Doong, 1993) was conferred by this energy modality. But research to verify benefits of magnets applied on the body have not produced statistically significant results.

*Biological Treatments* refers to chemical formulations for injection or ingestion theorized to achieve very particularized physiological responses such as enhancing specific immune factors, but are not pharmaceutical drugs that target the elimination of disease-producing organisms or disease processes. *Chelation Therapy*, for example, involves an injectable substance (ethylene diamine tetracetic acid or EDTA) said to attach to toxic materials in the body (e.g., aluminum and

lead) that are then eliminated from the body through excretion rather than reabsorbed. Chelation has shown itself useful with cases of lead poisoning and is being assessed for other health problems (Chappell, 1995). EDTA has been added as an effective adjunct for atherosclerotic problems including strokes and peripheral vascular disease (Goldberg et al., 2002).

**HERBAL MEDICINES (BOTANICAL MEDICINE)** Medicinal herbal applications have a 60,000-year-old history, in fact the most ancient form of medical treatment, with evidence dating as far back as the Neanderthal era (Solecki, 1975). In Europe, herbal therapies hold a long-honored tradition and are more commonly incorporated into standard treatment plans than in American medicine. But even across the states, herbal regimens are inching into mainstream medical plans, with science verifying what medical folklore has long posited. Herbals are plant substances that can include the root, flower, stem, seeds, or leaves to enhance or correct improper functioning of organs and represent a core treatment component in TCM, Ayurvedic medicine, and naturopathy. One example, garlic (and its compounds), the herb most universally recognized for medicinal value (Blumenthal, Goldberg, & Brinckmann, 2000; Goldberg et al., 2002), takes a lead in varied applications: ingested to reduce problematic cholesterol and elevated blood pressure (Vorberg & Schneider, 1990; Warshafsky, Kramer, & Sivak, 2000), commonly taken for its antibiotic and antimicrobial properties (Sullivan, 2000), as a popular antidote for gout and rheumatism (Foster, 1991), to effectively reverse arterial plaqueing (Koscielny et al., 1999), and in large epidemiological studies modest intake was statistically linked with reduced intestinal cancer (Lawson, 1997). By 1998, garlic could boast 1,990 research papers on its beneficial activities often very impressive (Goldberg et al., 2002): in just one study among heart patients, six milligrams of garlic daily resulted in a 35% reduction of heart attacks and a 45% reduction in mortality as opposed to a placebo (Lawson, 1997).

#### RESEARCH DILEMMA

The best potential for increased respect and comprehension of CAM and integrative benefits is continuing controlled research. What impedes full investigation are issues of economics and real methodological conundrums. The bias against full studies can be huge, since unlike testing of single pharmaceutical drugs, the likelihood of financial gain from CAM is miniscule, yet the expense great. Plus, most alternative systems, CAM protocols, and integrative regimens are difficult to study because they usually involve complex, multifaceted programs that are difficult to evaluate against single therapies and which seem to defy unifocal investigative efforts, the most common scientific investigational approach. One additional puzzle—how to design a true double-blind study on certain practices such as meditation, that is, what can serve as a genuine placebo control? And finding groups that maintain as controls is a thorny task because surveys tell us the vast numbers of patients on their own initiative and in secret are receiving alternative treatments. Finally, even diagnostic categories among alternative systems do not always correspond to those of biomedicine so comparisons can be inexact.

*Problems/Concerns* What confuses a definitive evidence base is that specifics of treatment vary considerably (e.g., Chinese versus Korean acupuncture). This variance among practices can be very problematic if counseling a client, for example, on

the value of acupuncture for musculoskeletal pain based on documented randomized controlled trials (RCTs) due to uncertainty about real correspondence between the methodology used by the local acupuncturist and the precise approach tested in the research. Or, another example, it is not clear for migraines which precise acupuncture points are most effective, what duration for needle insertion, nor the necessary number of treatments (Vickers, 2003).

An unresolved quandary haunts a full melding of practices: Can different medical models be effectively and truly integrated; that is, when diagnostic and therapeutic systems are based on very different biological and philosophical premises, can treatment plans be successfully merged? For example, a single disease presentation, in Western medicine labeled as stomach cancer, can point to several very different maladies in the Chinese system, for example, stomach *yin* deficiency due to stomach heat, blood stagnation due to qi stagnation, or stomach *yang* deficiency (Beinfeld & Korngold, 2003), each demanding a disparate, even incongruent treatment. While an American physician would reasonably and almost automatically prescribe one chemotherapy protocol intended specifically for stomach cancer, the Chinese doctor might advise very dissimilar regimens for this same stomach cancer, determined by the different Chinese diagnostic categories.

Another continuing concern is that formal training, credentialing, and licensure of CAM practitioners remains inconsistently monitored or required across the 50 states (an exception is chiropractic, licensed in all states with specific training standards). Also, even though the risk of toxicity of most herbal preparations is usually very small, because many formulations incorporate multiple chemical substances believed to synergistically enhance their therapeutic potential, toxic consequences and adverse herb-drug interactions are possible. However, compared to prescriptive pharmaceuticals, supplements—whether herbal or nutraceuticals—carry fractional hazards (see Table 22.3 for a comparison of deaths due to supplements). Furthermore, experts acknowledge that at least 51% of prescriptive drugs can produce severe side effects that went undetected even in controlled testing prior to approved use (Moore, Psaty, & Furberg, 1998).

Because dietary supplements are sold as food compounds, they are unregulated by FDA standards. Quality issues are a continuing worry for an untutored public (De Smet, 1999; Marrone, 1999): Contamination and variation in content and processing. Some formulations hit the market with meaningless amounts of identified key ingredients, many don't even dissolve or disintegrate after ingested, most are not standardized, so even if positive research findings are available on one product (e.g., black cohosh) indicating safety and benefits, there is no assurance that a different cohosh product will produce the same effect because actual dosing might be inconsistent.

Certainly, some more aggressive alternative practices do carry the possibility of untoward consequences, but the potential for truly severe side effects of most CAM therapies seems dwarfed by that of pharmaceuticals or more invasive procedures; and when practiced skillfully and applied appropriately the likelihood of problematic effects is minimized (Jonas, 1998). This consideration does not deny limited but real concerns about problematic interactions between alternative practices and conventional drugs. One such example is the use of special grapefruit preparations (as reported informally from Jamaica, October 2003) to reduce symptoms of hypertension. Regular grapefruit juice consumption is known to increase blood volume of specific antihypertensives, antihistamines, and antidepressants by down-regulating cytochrome P450, an enzyme that functions in the body to metabolize drugs

(Beinfeld & Korngold, 2003). An example of possible herbal contraindication is the use of *Hypericum perforatum* (St. John's Wort)—available for purchase in health food stores, backed by scientific and popular literature as normally safe and effective with mild to moderate depressive symptoms. This usually benign herb is known to (a) augment the metabolism of protease inhibitors thus reducing blood levels of such medications; (b) elevate the body's serotonin to potentiate the impact of MAO and SSRI antidepressant drugs; (c) interfere with the full effectiveness of drugs such as cyclosporin and theophylline (Croom, 2000). Another undesired herb-drug complication, *Ginkgo biloba*—commonly used for memory and cognitive enhancement—can inhibit platelet aggregation (as does garlic), elevating anticoagulant effects of some prescription drugs. However, warnings such as these stem from scientific evaluations of each herb as a single agent. The impact observed is moderated when an herb or nutrient is one component in a multiple compound formulation, whereby, for instance, any anticoagulant concern is mitigated by the presence of other herbs. One recommendation for modifying posited drug-supplement problems is taking drugs separately from food consumption to avoid undesired digestive tract interactions (Blumenthal et al., 2000).

#### INSURANCE COVERAGE ISSUES

Several third-party insurance carriers are now reported to cover 25% of the cost for CAM treatments used by cancer patients (Campion, 1993). One of the appeals of alternative practices to American consumers is financial; many alternative treatments are less costly than conventional therapies; exceptions may be interventions such as antineoplastons (Ernst, 1994, 1995). In fact, in reporting use of alternatives among ethnic minorities, MacKenzie and her team (2003) noted that being uninsured, that is paying out of pocket, predicted greater likelihood of unconventional practices. Yet, managed care companies, confronted by fierce competition, are now chasing the very lucrative CAM market to attract new enrollees from a public enamored with these once obscure or seemingly exotic practices. One marketing strategy of managed care corporations to counter a growing disenchantment with HMO restrictions is to attach a rider to a general policy to include some alternative-care options. Other groups provide discounted access to nonconventional services—25% off practices such as chiropractic, acupuncture, and so on (Rauber, 1998). By 2000, 43 insurers covered alternative care, up from just two or three a few years earlier and some are marketing packages with a blend of benefits (Pelletier & Astin, 2002).

#### CONCLUSION

Today's health-care terrain is a *mélange* of medical preferences and practices mirroring the nation's cultural plurality. Encouraging evidence implies that deep-rooted prejudices may be gradually fading and a new consensus emerging, one that holds that distinctions between alternative and conventional medicine are detrimental (Fontanarosa & Lundberg, 1998). Advocates of a broader medical philosophy believe that there is only good or bad medicine, that all health professionals are mandated to actively maintain an open-mind to what might be most beneficial for each patient. On this principle, MacKenzie and her co-authors (2003) pointedly ask, "How well do the health systems we have created fit the persons we wish to serve?" (p. 56). One attempt to address this issue has been a



corrective response to linguistic problems—to untangle and rephrase complex medical terminology, and to improve how professionals communicate disease and treatment information to patients from diverse backgrounds. But this effort has been motivated largely by the medical need to persuade patient compliance to seemingly foreign and misunderstood protocols (MacKenzie et al., 2003). While medical professionals have initiated efforts at greater language congruence, the need to acknowledge and better integrate components of divergent medical practices and thinking into our biomedical paradigm is still unmet. To effectively serve and support individual clients who embrace culturally diverse or idiosyncratic health beliefs, but who might get lost in a labyrinth of technical and personally incongruent medical thinking, we as social workers are called on in our specialized professional role to build an expanding familiarity with divergent approaches as a bridge to better care. This chapter is an introduction and overview that urges each reader's further and continuing exploration.

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### SUGGESTED LEARNING EXERCISE

Using aspects from this chapter in conjunction with issues addressed in Chapter 6 on spirituality in health care and Chapter 9 on health beliefs, discuss how you would engage one of the following people in an open and supportive conversation of personal health practices to enable better care. A 40-year-old Mexican American (or Chinese American) woman diagnosed with stage II breast cancer, which can be effectively treated with chemotherapy, has not shown up for two of her scheduled appointments. Assume for this assignment that you have helped her find appropriate practical support and have communicated effectively the value of treatment and presence of pharmaceuticals to counteract side effects, but you wish to understand what other factors prevent her from continuing with the oncologist's recommendations. Understanding cultural health values while respecting individual predilections, and examining your own medical predispositions, describe your preparatory thinking and your interaction with her. What considerations before actually meeting with her, what questions, and what suggestions might you offer? Then, describe how you might present to her physician the rationale for why she has been using practices he or she might regard as problematic "alternatives," and how he or she can best create culturally and individually congruent recommendations.

As another project option, consider your advance thinking and subsequent conversations with a 50-year-old African American man whose hypertension seems either unresponsive to medications or, as his doctor implies, he is not adhering to his medical regimen, or a Native American man in a similar scenario but with diabetes. What alternative recommendations are worth consideration and investigation, what possible impediments to medical effects?

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- National Center for Complementary and Alternative Medicine (NCCAM)—within NIH Clearinghouse: Toll-free: (888) 644-6226; TTY (for deaf or hard-of-hearing callers): (866) 464-3615; e-mail: info@nccam.nih.gov; CAM on PubMed: www.nim.nih.gov/nccam/camonpubmed.html.
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# Afterword

CANDYCE S. BERGER

MUCH ATTENTION IN the literature has been devoted to the changes affecting the health-care arena. We are living in times that have been described as chaotic, tumultuous, and unstable (Berger, Robbins, Lewis, Mizrahi, & Fleit, 2003; Dombovy, 2002; Fairfield, Hunter, Mechanic, & Flemming, 1997; Ross, 1993). Many factors have contributed to this situation. The growing emphasis on fiscal constraint in health care, the technological explosion, ethical challenges, spiritual concerns and consumer expectations have all had a significant effect on health-care service delivery. While social work practice has been influenced by these changes, research has shown that we are not being differentially impacted, experiencing a greater proportion of the negative consequences, such as downsizing and decentralization (Berger et al., 2003). Chapter 1 traces the long history of 100 years of social work involvement in health, while Chapter 2 explores the factors that have shaped the evolving roles of social work. These chapters provide a context in which we examine our environments today. We struggle, more than ever, with the challenges of defining social work roles as the health-care environment responds to fiscal priorities, demands by payers for accountability, and consumerism. Today, many health social work programs are actually harnessing their creativity and skills to expand social work roles and secure social works position both in the present and for the future (Mizrahi & Berger, in press).

Much of our unease is in response to a health-care system that is facing runaway costs, without commensurate improvement in health outcomes. The United States has ranked poorly in international comparisons for all measures of health outcomes, in spite of our constant ranking as number one for health-care costs. While health care consumes almost 14% of the gross domestic product, over 45 million Americans are without health insurance, and many more struggle with intermittent or poor health-care coverage. Chapter 5 critically examines the financial, regulatory, and governance issues that shape health-care policy and the delivery of health-care services. Without radical changes to nation's health-care policy and systems of care, we will continue to see health-care systems struggle to maintain fiscal viability through a variety of cost-containment strategies, including hospital closures, mergers, restructuring, and resizing initiatives, and the push to community-based practice. All of these strategies will influence staffing mix in medical centers, service delivery, and social work roles (Berger et al., 2003; Globerman, Davies, & Walsh, 1996; Ross, 1993). Consequently, social workers in

health will continue to rely on clinical practice skills, but they will also need to expand their practice repertoires to incorporate community-based clinical interventions, macro practice skills that are essential to autonomous practice, and research techniques that enable us to use data to support our practice. Skills in advocacy will become even more critical to challenge policies and regulations that are driven by fiscal priorities that can compromise the quality of patient care.

### THE MOVE TO THE COMMUNITY

While these changes promote feelings of fear and insecurity, new opportunities have been and will continue to emerge for social work. In the twentieth century, acute care dominated health-care practice, moving the hospital to the central position within the health-care system. As we look to the twenty-first century, our emphasis is shifting to a new priority—the management of chronicity. This will promote expansion of community-based systems of care, where prevention strategies will assume a higher level of importance. Many scholars in the field of health social work believe, as in the past, that the future of the profession lies in our ability to work within the community, developing successful linkages across systems of care (Berkman, 1996; Davidson, 1990; Rehr, Rosenberg, & Blumenfield, 1998).

This book traces the changing roles for health-care social work, balancing acute care with the movement to community-based models of practice. This shift to the community will require a greater understanding of interventions aimed at health promotion and disease prevention (Berkman, 1996; Davidson, 1990), with a greater awareness of the critical role of individual, family, and community behavior in shaping health status. Chapter 7 provides the theoretical foundations needed to understand health behavior so that effective, community-based strategies can be designed and implemented. Chapters devoted to community-based practice and public health augment this learning by examining the spectrum of issues shaping social work practice at the community level. These chapters are rich with theory, skills and practical applications that will promote the development and expansion of social work community-based practice.

### AN EXPANDED CLINICAL BASE

As we move from managing acute episodes of care to the management of chronicity, our focus will shift to the identification of at-risk populations whose health status is compromised by poor health behaviors, environmental challenges, and genetic predispositions. Effective and efficient clinical interventions at the acute level will continue to be a priority for social work practitioners, but they will need to incorporate expanded clinical skills in such areas as brief assessments, short-term treatment, population-oriented care, case management, health promotion, and disease prevention. This expertise requires increased understanding of theories of health behavior, and the influence of risk factors, such as socioeconomic status, the environment, mental health, substance abuse, ethnicity, culture, spirituality, family systems, and sexuality, all of which are effectively addressed in this *Handbook*. Social work practice will be shaped by a growing emphasis on managing larger numbers of patients as their roles span the continuum of health care. This will call for social work practitioners who draw from a large

repertoire of knowledge and skills, and are able to broadly traverse larger systems devoted to service delivery. Part Two and Part Three capture many of these issues, demonstrating the critical impact of biopsychosocial factors on health behavior and health outcomes. What kind of practitioner will be needed to face the challenges ahead?

There is little debate about the need for clinical skills in the future, but debate still rages as to the most effective approach—generalist versus specialist. A generalist approach utilizes fundamental skills of social work that are transferable across settings and populations served. Generalist approaches may be more effective with community-based models of care or in acute, general medical, surgical, or pediatric settings where a broader understanding of illnesses, psychosocial implications of illness, and systems of care may be required. A generalist approach is particularly relevant to community-based practice, where a variety of skill sets are needed to effectively navigate a complex system of providers, payers, and clients (Ross, 1993). This does not mean that specialists will not also be needed.

Specialists models emerged in large, specialty hospitals where social workers were recognized and advanced professionally based on their expertise in a defined area of practice (e.g., disease or population expertise). To be successful, social workers needed to understand the details of specific diagnosis and their biopsychosocial ramifications for patients and families; they needed specific knowledge regarding the populations most likely to be affected and the resources and systems of care to be mobilized to address issues and problems related to the illness (Ross, 1993).

In an interview with recognized health-care leaders (“How Are Hospitals financing,” 2004) the importance of health-care systems delineating and promoting their unique competencies is addressed; they need to carve out their market niche. It was suggested that health-care systems should identify three to four service lines (e.g., cancer, cardiology, trauma) that will be priorities (i.e., Centers of Excellence) for the health-care system rather than equally distributing limited resources across all services. For social work to be a member of the health-care team in these specialty centers, they will require specialized knowledge and skills to effectively and efficiently provide psychosocial services so that they are capable of becoming an essential member of the team. Specialty content is often handled individually, through scholarly articles or books that address a specific disease or population. While a comprehensive analysis of all potential areas of specialization is not realistic within an overview book, the authors have done an outstanding job weaving in specialty content on key areas where a social worker is likely to be involved (see Part Three of the book).

## THE AUTONOMOUS PRACTITIONER

As social workers broaden their knowledge and skills, they will need to be as adept at macro level interventions as they are at clinical practice (Berger & Ai, 2000). Many health-care systems are moving away from “silo” organizational structures (i.e., centralized departments) to programmatic structures. Social workers may find themselves practicing in more autonomous, multidisciplinary settings where the leader may not be a social worker. Furthermore, as more seamless, comprehensive systems of care emerge, practitioners will need to rely on

skills that span both micro and macro practice in order to effectively navigate system complexity.

These changes will require social workers to have greater knowledge of fiscal arrangements and processes, and increased ability to assess organizational environments, as addressed in Part One of the book. This knowledge needs to be combined with increased skills in decision making, conflict management, planning, community organizing, marketing, and program management. Political acumen will be essential to survival in a politically volatile environment derived from constant change and limited access to health-care resources (e.g., money, staff, technology).

### EMBRACING RESEARCH AS A PRACTICE NECESSITY

As health care expands over the continuum of care, practitioners will need to draw on skills in research techniques. Four factors shape the need to embrace research as an essential element of practice. First, population interventions are dependent on population-based research—epidemiology (Berger & Ai, 2000; Berkman, 1996). This type of research will be essential to identifying population at-risk, and to understanding the health-care needs of diverse populations. Second, the ability to effectively assess and intervene in health-care organizations and community systems will be dependent on accurate and timely data. Third, social work practitioners and educators in health cannot continue to ignore the mandates for evidence-based practice. Many of the health disciplines have already embraced this philosophy, and social work will need to quickly move in this direction to maintain or expand its role. Social work has historically relied on documenting the process of their interventions rather than the outcome. Social work will not survive as a provider unless they can harness available empirical information to design and support our practice models and teach students the skills of evidence based decision-making. This will require the introduction of reliable and valid tools to do assessments and to measure outcomes (Berger & Ai, 2000; Berkman, 1996). Finally, empirical research is an essential ingredient to effective advocacy. While no single chapter is devoted to research approaches, this content is woven throughout the book, emphasizing its importance in relationship to specific settings, illnesses, and populations.

### THE ROLE OF ADVOCACY

Advocacy is another theme that permeates throughout the book, acknowledging its importance as a priority for social workers in health care. Social workers must act to effect changes in policies and regulations as fiscal priorities threaten to compromise quality of care. We must embrace social work values, priorities, and ethics, recognizing when fiscal priorities compromise these professional tenets of practice. As health-care professionals, we must join forces with those most affected by the changes—patients and families—and develop coalitions with other health-care disciplines and advocacy groups to mobilize changes in health-related policies.

In conclusion, health care can be described as a tumultuous and often chaotic setting where change is the constant. Preparing social workers for this new environment borrows from the old as well as the new. To be successful in the future of health care, our practice must be grounded in theory and data. We need to be

strategic, placing increased emphasis on documenting the results of our interventions. We need to free our creative energy to critically examine what we do, and design and implement innovative strategies that span the continuum of health care. We need to be willing and able to take calculated risks, venturing into new arenas of care and incorporating new roles. According to Cowles and Lefcowitz (1995), "If we don't actively work to create the future, then we leave the future solely to chance" (p. 14). We must build a reputation as creative and innovative practitioners and assume responsibility for shaping our professional destiny as health-care practitioners.

The authors of this *Handbook* have put together an excellent resource to prepare social workers for the contemporary and future challenges of social work practice in health care. We will need to be aware of our history, drawing strength from our longevity as practitioners in health care. Our historical emphasis on community-based interventions, combined with our strengths perspective and sensitivity to cultural competency positions us to succeed in this changing health-care environment. We draw on a strong base of values and ethics that will support our professional goals and directions as we face new challenges and ethical dilemmas.

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