Chapter One: Introduction

Overview on the History of Social Work

From Volunteers to an Occupation (prior to 1915)

Volunteerism is the origin of social work. Social work has its roots in the struggle of society to deal with poverty and the resultant problems. Therefore, social work is intricately linked with the idea of *charity work*; but must be understood in broader terms. The concept of charity goes back to ancient times, and the practice of providing for the poor has roots in all major world religions. Social work as a profession grew chiefly out of the development of social welfare policies and programs in the United States, Europe, and Muslim countries. Judeo-Christian and Muslim practices and beliefs underlie many of the early attempts to provide help to the poor, the sick, widows, orphans, the -insane and- imbeciles (as those with problems of mental illness and developmental disability used to be called) and the elderly.

The words '***philanthropy'*** and '***charity'*** and the concepts, which they stand for be love of mankind, love of humanity, brotherhood be care, have the Greek and Latin origins. It is also emphasized on the importance of Jewish tradition in the development of modern philanthropy. Ancient Jewish doctrines teach the duty of giving and equally important, the *right* of those in need to receive. Throughout the Old Testament, we find commandments to give to others, particularly the old, the sick, those with handicaps, and the poor. This giving is not a matter of charity but a matter of justice. Not only do the Scriptures state that one might break off his iniquities (or acts of wickedness) by showing a compassionate face to the poor, but they also go on to command than not harden thy heart nor shut thy hand to the unfortunate. It is forbidden, according to the Scriptures, to turn away a poor man empty-handed. And in a phrase that social workers would appreciate, people should give such aid with a friendly countenance, with joy, and with a good heart.

Christianity carried on the charitable tradition, adding a particular emphasis on love and compassion. The basic principle underlying early Christian approaches to social welfare was similar to the Hebraic idea that poverty was not a crime. Even though discretion should be observed in giving aid, and rules set up for discriminating between the various classes of poor people, evidence of need was still the paramount factor in offering help. It was assumed that need came about as a result of misfortune for which society should take responsibility.

At first, charity was an informal system of help, but as Christianity became more established as a religion, Church fathers felt it was important to set up a more formal system of charities. Beginning in the sixth century, monasteries began to serve as basic agencies of relief, particularly in rural areas. Some monastic orders were organized with a particular mission of serving the needy. These orders received income from donations, legacies, and collections, and used this to provide help to the poor who came to their doors. They also, in a forecasting of what we might now call community outreach, carried food and other provisions to the sick and needy in their communities.

The Arab world has also contributed to charitable traditions. Islamic thought draws a distinction between social justice and charity. The faith has a strong tradition of social reform, based on the Prophet Muhammad‘s advocacy on behalf of women, children, and the disadvantaged. This tradition is operationalized through the requirement that all Muslims who are financially able shall contribute 2.5% of their net wealth each year for support of the needy. This practice, called *zakah*, is not considered to be charity but rather an act of social justice through the redistribution of wealth. Any contributions in addition are seen as charity, or *sadaqa*, which is one of the five pillars of Islam. The Koran lists eight categories of uses to which charitable contributions can be put: aid to the poor, the needy, those who collect the contributions, those whose hearts must be reconciled, debtors, wayfarers, the redemption of captives, and for God‘s cause.

Simply stated, the profession of social work owes its existence to ***volunteerism***. Volunteers founded relief societies, children's homes, day care programs, recreation services, family and child welfare associations, and mental health associations. In other words, volunteers preceded social work in almost every field of practice. Many introductory texts on social work and social welfare recognize the profession's origin in volunteerism. For example, Morales and Sheafor (2004) describe the beginning of social work as being found in the extensive volunteer movement during the formative years of the United States. In the colonial period, for example, it was assumed that individuals and families could care for themselves, but if further difficulties existed, one could depend on *mutual aid*. Friends, neighbors or other representatives of the community could be counted on to help out when needed. Volunteer activities involved interaction with the poor, the ill, and those experiencing other social problems. As social agencies began to develop, they soon learned how to train volunteers in constructive ways to relate to clients and improved their ability to be helpful. Developing out of this background came social work as an *occupation.*

Modern History of Social Work

Professional Emergence (1915-1950)

With social work firmly established as an occupation, attention then turned to its development as a profession. The practice and profession of social work has a relatively modern (19th century) and scientific origin. Social work is a phenomenon of the late 18th century and the early 19th century. The movement began primarily in the United States and England. After the end of feudalism, the poor were seen as a more direct threat to the social order, and so the state formed an organized system to care for them. In England, the Poor Law served this purpose. This system of laws sorted the poor into different categories, such as the able bodied poor, the impotent poor, and the idle poor. This system developed different responses to these different groups.

Social work involves ameliorating social problems such as poverty and homelessness. The 19th century ushered in the Industrial Revolution. There was a great leap in technological and scientific achievement, but there was also a great migration to urban areas throughout the Western world. This led to many social problems, which in turn led to an increase in social activism. Jane Addams (1860–1935) a founder of the U.S. Settlement House movement and is considered one of the early influences on professional social work in the United States. In America, the various approaches to social work led to a fundamental question is social work a profession?

Even as many schools of social work opened and formalized processes for social work began to be developed, the question lingered. In 1915, at the National Conference of Charities and Corrections, Dr. Abraham Flexner spoke on the topic "Is Social Work a Profession?" He contended that it was not because it lacked specialized knowledge and specific application of theoretical and intellectual knowledge to solve human and social problems. Following Flexner's admonition to go forth and build itself a profession social workers busily worked on it. In 1957, Ernest Greenwood using the five critical attributes of the profession: a systematic body of knowledge, professional authority, sanction of the community, a regulative code of ethics and a professional culture. These criteria enabled to conclude that social work was a profession. This led to the professionalization of social work, concentrating on case work and the scientific method, by developing a code of ethics, knowledge, skill and value base of the profession.

The Conceptual Underpinnings (foundations) of Social Work in Health Care

Social work in health care owes it origins due to the following 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 emigrated to U.S.A. between 1820 and 1924 from Germen, Ireland, Italy, Poland, Russia (particularly Jewish) and other eastern European countries. The major reasons for European migration were the economic and political reasons. Moreover, the Gold Rush, and the

Homestead Act attracted the European migrants. In these circumstance, the United States struggled to adapt to the challenge of migration. The massive waves of migrants presented new health-care challenges, especially in the Northeastern New York City where most of the new arrivals settled. These resulted in as accidents were common, sanitation primitive, and food supplies were in poor condition in the city. Infants' mortality also became highly prevalence phenomena in New York City, particularly those died prior to their first birthday. 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. 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.

Besides, the various medical services in different hospitals, home visiting was increased with an adequate attention to social conditions. For many years, home visits were part of the education of nurses and physicians in training. Later in, it is established as a program in which volunteers visited the homes of ill patients (mothers and children) to report on conditions and ensure that medical instructions had been understood and implemented. A close partnership between the Johns Hopkins Hospital and Baltimore's Charity Organization Society are 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 were actively involved in the application of social work to medicine. The first social worker, called a *hospital almoner.* Through time, institutions such as the Hospital Almoners' Council (later the Institute of Hospital Almoners) took over the training of almoners. These almoners were responsible for the prevention of illness.

Methods were simple because social work in hospitals "*the only one who carried the responsibility for bringing the social viewpoint into the hospital*". In many hospitals, 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. Social workers, however, controlled access to medical records by physicians and nurses and had to approve all free medical care and prescriptions for medicine. The social service departments in many hospitals of United States provided a range of services, all focused on the provision of assistance to the patient.

The Professionalization of Social Work in Health Care

The first training course in medical social work was held in 1912. However, 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 twofold purpose: (a) to foster and coordinate the training of social workers in hospitals and (b) to enhance communication between schools of social work and practitioners. The American Association of Hospital Social Workers was the first national organization of social workers in health care.

The American Association of Hospital Social Workers (1928) reported 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 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. Formal courses in medical social work was offered in various U.S Universities and medical social work was considered to be graduate-level work. The major six activities of medical social workers were:

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.

Defining Medical Social Work

The American Association of Medical Social Workers (1934) defined medical social work as a specific form of social case work that focuses on the relationship between disease and social maladjustment. It is an important part of the social worker's function to concern the social problems arising directly out of the nature of the medical treatment. In this way, social workers facilitate and extend the medical treatment. Emphasis was placed on surmounting social impediments to health i.e. providing some occupation or experience for the person pushed out of his/her regular plan of life by chronic disease; to balance what he/she has lost and to make him/her feel that he/she has still a useful place in the world. Some of problems highlighted by the Association 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.

The competition for attention between personality and social environment gained salience with the advent (coming) of psychiatry and psychoanalysis in the United States. 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. The 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 focus on personality allows the social worker to get at the client's problem with ease, thus saving time for treatment.

Social Work in Health Care: ***Beyond the Hospital***

After World War II and the passage of the Social Security Act, social work in healthcare 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 of Medicare and Medicaid provided coverage for persons who might otherwise not have been treated. These programs further increased the need for social work services. The number of social workers in health care increased with the variety of work settings. In United States, 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 US federal government began to institute measures to control costs.

The cost containment efforts in health service provision impacted that the 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, 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. New techniques have been developed in response to time limits on treatment. Task-centered case work emphasizes the goals of treatment, and a number of brief treatment techniques have been developed. Social workers have helped to adapt intervention theories for use in health settings, such as stress inoculation from cognitive theory. The new role for social workers defined 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". These teams often operate across facilities. Social workers were seen as key members of disease management teams due to their ability to work across health systems and managed care settings.

Changes in Technique and Approach through Time

The settings in which social work is practiced in health care have changed through time. In the beginning, medical social workers practiced almost entirely in hospitals. During the course of change, in the earlier periods, it described 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 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 health care and its failure to define a niche that was exclusively its own since that time, prepared social workers to remain viable in a changing health-care environment. They have adapted well to these changing environments.

At a time when the changing demographics pose problems of communication in health care, social workers used as a translator or interpreter seems modern and as salient today. 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 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. Clearly, the translator or interpreter role first defined 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.

The more scientific and systematic social workers was become evidenced with the advent of research in social work. The success of evidence-based practice and the active incorporation of research in social work practice in health care heartened many of the professional social workers. Social workers with health-care backgrounds now head research teams and serve as program director. Social work in health care has been through a great deal over more than 100 years and has weathered seemingly insurmountable challenges through time. Nevertheless, its guiding principles remain in force and are strong even today.

Introduction to Health Care System

The *spectrum of health care delivery* refers to the various types of care within this spectrum; four levels of practice have emerged:

1. Population-based public health practice,
2. Medical practice,
3. Long-term practice, and
4. End-of-life practice.

1. Population-Based Public Health Practice

Population-based public health practice incorporates interventions aimed at disease prevention and health promotion, specific protection, and a good share of case findings. A primary component of population-based public health practice is education. If people are going to behave in a way that will promote their health and the health of their community, they first must know how to do so. Health education not only provides such information but also attempts to empower and motivate people to put this information to use by discontinuing unhealthy behaviors and adopting healthy ones. Though much of public health practice takes place in governmental health agencies, it also takes place in a variety of other settings (such as voluntary health agencies, social service agencies, schools, businesses and industry, and even in some traditional medical care settings).

2. Medical Practice

Medical practice means "those services usually provided by or under the supervision of a physician or other traditional health care provider." Such services are offered at several different levels. We used the terms *primary, secondary,* and *tertiary* as they related to levels of prevention. These terms have a similar meaning here, but they are now applied to health care delivery rather than prevention.

A. ***Primary Medical Care:*** Primary care is "front-line" or "first-contact" care. The unique characteristic of primary care is the role it plays as a regular or usual source of care for patients and their families. Formally, primary care has been defined as the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.

Primary care includes routine medical care to treat common illnesses or to detect health problems in their early stages. Primary care usually is provided in practitioners' offices, clinics, and other outpatient facilities by physicians, nurse practitioners, physician assistants, and an array of other individuals on the primary care team. Primary care is the most difficult for the poor and uninsured to obtain.

The World Health Organization has stated that primary health care rests on the following eight elements:

- Education concerning prevailing health problems and the methods of preventing and controlling them.
- Promotion of food supply and proper nutrition.
- An adequate supply of safe water and basic sanitation.
- Maternal and child health care, including family planning.
- Immunization against the major infectious diseases.
- Prevention and control of locally endemic diseases.
- Appropriate treatment of common diseases and injuries.
- Provision of essential drugs.

B. ***Secondary Medical Care:*** Secondary medical care is specialized attention and ongoing management for common and less frequently encountered medical conditions, including support services for people with special challenges due to chronic or long-term conditions. This type of care is usually provided by physicians, ideally upon referral from a primary care source. Secondary medical care can be further divided into acute and sub-acute care. *Acute care* is short-term, intense medical care for an illness or injury usually requiring hospitalization. *Sub-acute care* provides specialty services for patients “who no longer need acute care but require more nursing intervention than nursing homes have traditionally provided,” such as for the patient who is on a respirator.

C. ***Tertiary Medical Care:*** Tertiary medical care is even more highly specialized and technologically sophisticated medical and surgical care than secondary medical care. It is care for those with unusual or complex conditions (generally no more than a few percent of the need in any service category). This care is not usually performed in smaller hospitals; however, it is provided in specialty hospitals, academic health centers, or on specialized floors of general hospitals. Such facilities are equipped and staffed to provide advanced care for people with illnesses such as AIDS, cancer, and heart disease, and procedures such as gall bladder removal and heart bypass surgery.

3. Long-Term Practice

Long-term practice can be divided into two subcategories: - restorative care and long-term care.

I. ***Restorative Care:*** Restorative care is the health care provided to patients after surgery or other successful treatment, during remission in cases of an oncogenic (cancerous) disease, or when the progression of an incurable disease has been arrested. This level of care includes follow-up to secondary and tertiary care, rehabilitative care, therapy, and home care. Typical settings for this type of care include both inpatient and outpatient rehabilitation units, nursing homes, halfway houses, and private homes.

II. ***Long-Term Care:*** Long-term care includes the different kinds of help that people with chronic illnesses, disabilities, or other conditions that limit them physically or mentally need. In some situations, time-intensive skilled nursing care is needed, while some people just need help with basic daily tasks like bathing, dressing, and preparing meals. This type of care is provided in various settings such as nursing homes, facilities for the mentally and emotionally disturbed, and adult and senior day care centers, but often long-term care is used to help people live at home rather than in institutions.

4. End-of-Life Practice

The final level of practice in the health care delivery is end-of-life practice. End-of-life practice is usually thought of as those health care services provided to individuals shortly before death. The primary form of end-of-life practice is hospice care. *Hospice care* is a program of palliative and support care services providing physical, psychological, social, and spiritual care for dying persons, their families, and other loved ones by a hospice program or agency. The most common criterion for admission to hospice care is being terminally ill with a life expectancy of less than six months. The first hospice program in the United States was established in 1974. In most cases, the hospice services are available in home and inpatient settings.

Types of Health Care Providers

To discuss the different types of health care workers simply, they have been categorized into five different groups as Independent providers, Limited care providers, Nurses, Allied health care professionals, and Public health professionals.

1. ***Independent Providers***: Independent providers are those health care workers that have the specialized education and legal authority to treat any health problem or disease that an individual has. This group of workers can be further divided into allopathic, osteopathic, and non-allopathic providers. *Allopathic providers* are those who use a system of medical practice in which specific remedies for illnesses, often in the form of drugs or medication, are used to produce effects different from those of diseases. The practitioners who fall into this category are those who are referred to as Doctors of Medicine (MDs).

   Another group of physicians that provide services similar to those of MDs are *osteopathic Providers*-Doctors of Osteopathic Medicine (DOs). At one time, MDs and DOs would not have been grouped together because of differences in their formal education, methods, and philosophy of care. It is now based on a philosophy of health care that emphasizes the interrelationships of the body's systems in the prevention, diagnosis, and treatment of illness, disease, and injury. The distinctive feature of osteopathic medicine is the recognition of the reciprocal interrelationship between the structure and function of the body. The actual work of DOs and MDs is very similar today. Their differences are most notably the DOs' greater tendency to use more manipulation in treating health problems and the DOs' perception of themselves as being more holistically oriented than MDs.

   Non-allopathic Providers are identified by their nontraditional means of providing health care. Some have referred to much of the care provided by these providers as complementary/alternative medicine (CAM) or complementary/integrative medicine. Included in this group of providers are chiropractors, acupuncturists, naturopaths (those who use natural therapies), herbalists (those who use herbal brews for treating illness), and homeopaths (those who use small doses of herbs, minerals, and even poisons for therapy). Complementary/alternative medicine/ CAM has been defined as the diagnosis, treatment and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual framework of medicine. When used in addition to mainstream medical treatment, a therapy is most often identified as *complementary*. However, when a therapy is used instead of conventional treatment, it is labeled as *alternative* like chronic pain costs less and satisfies the patient, they will pay for it."

2. ***Limited (or restricted) Care Providers:*** Much health care is provided by limited (or restricted) care providers who have advanced training, usually a doctoral degree, in a health care specialty. Their specialty enables them to provide care for a specific part of the body. This group of providers includes but is not limited to dentists (teeth and oral cavity), optometrists (eyes, specifically refractory errors), podiatrists (feet and ankles), audiologists (hearing), and psychologists (mind).
3. ***Nurses***: We have categorized nurses into a group of their own because of their unique degree programs, the long-standing tradition of nursing as a profession, and their overall importance in the health care industry. It has been estimated that there are about 4 million individuals who work in the nursing profession. Non-physician Practitioners (NPP) This group typically includes the just discussed nurse practitioners and certified midwives as well as physician assistants.
4. ***Allied Health Care Professionals***: Allied health describes a large group of health-related professions that fulfill necessary roles in the health care delivery system. These allied health care professionals assist, facilitate, and complement the work of physicians, dentists, and other health care specialists. These health care workers provide a variety of services that are essential to patient care. Oftentimes they are responsible for highly technical services and procedures. Allied health care professionals can be categorized into several groups. These include (1) laboratory technologists and technicians, (2) therapeutic science practitioners (e.g., occupational, and respiratory therapists and speech pathologists); (3) behavioral scientists (e.g., health educators, social workers, and rehabilitation counselors); (4) support services (e.g., medical record keepers and medical secretaries). The educational backgrounds of allied health Workers range from vocational training to master's degrees. Most of these professionals also must pass a state or national licensing examination before they can practice. The demand for allied health care workers in all of the areas previously noted is expected to continue well into the twenty-first century. The primary reasons for this are the growth of the entire health care industry and the impending arrival of the baby boomers as senior citizens.
5. ***Public Health Professionals:*** A discussion about health care providers would be incomplete without the mention of a group of health workers who provide unique health care services to the community public health professionals. Public health professionals support the delivery of health care by such hands-on providers as public health physicians, dentists, nurses, and dieticians who work in public health clinics sponsored by federal, state, local, and voluntary health agencies.

Health Care Facilities

Health care facilities are the physical settings in which health care is actually provided. They include practitioners' private offices, public and private clinics, hospitals, ambulatory care facilities, rehabilitation centers, and continuing care facilities. One other place that many people do not think of as a health care facility is a patient's home. Yet, for a variety of reasons, more and more health care is being provided in this setting.

1. ***Practitioner Offices:*** The setting for much of the preventive and primary care provided in America is the offices of health care practitioners. These practices are often referred to as *group practices* to distinguish them from *solo (single practitioner) practices.*
2. ***Clinics:*** When two or more physicians practice as a group, the facility in which they provide medical services is called a *clinic.*
3. ***Hospitals:*** Like clinics, hospitals vary in size, mission, and organizational structure. The major purpose of hospitals is to provide secondary and tertiary care.
4. ***Ambulatory Care Facilities:*** Ambulatory care facilities**,** are free-standing/outpatient tentative facilities that provide a wide and rapidly expanding array of services. These facilities are designed for ambulatory patients without the hotel-like services traditionally available in hospitals. These alternative sites for care have developed because of technological advances that make their purchase, maintenance, and operation feasible and cost-effective; consumer demand for convenient, user friendly environments; and profitability. It is another way to offer primary care in addition to the more traditional physician office mode.
5. ***Rehabilitation Centers:*** Rehabilitation centers are health care facilities in which patients work with health care providers to restore functions lost because of injury, disease, or surgery. These centers are sometimes part of a clinic or hospital but may also be stand-alone facilities. Rehabilitation centers may operate on both an ambulatory and an inpatient basis.
6. ***Long-Term Care Options:*** Not too many years ago, when the topic of long-term care was mentioned, most people thought of nursing homes and state hospitals for the mentally ill and emotionally disabled. Today, however, the term *long-term care* includes not only the traditional institutional residential care, but also special units within these residential facilities (such as for Alzheimer patients), halfway houses, group homes, assisted living facilities, transitional (step-down) care in a hospital, day care facilities for patients of all ages with health problems that require special care, and personal home health care. One area of long-term care that has received special attention in recent years is home health care. The demand for home health care has been driven by the restructuring of the health care delivery system, technological advances that enable people to

> be treated outside a hospital and to recover more quickly, and the cost containment pressures that have shortened hospital stays.

Home health care should not be confused with home care. Home care is a more inclusive term and denotes a range of services provided in the home, including skilled nursing and therapies, personal care, and even social services, such as meals, and home modifications. *Home health care* involves providing health care via health personnel and medical equipment to individuals and families in their places of residence, for the purpose of promoting, maintaining, or restoring health or to maximize the level of independence while minimizing the effects of disability and illness, including terminal disease. Home health care can be either long-term, to help a chronically ill patient avoid institutionalization, or it can be short-term to assist a patient following an acute illness and hospitalization until the patient is able to return to independent functioning. Home health care can be provided either through a formal system of paid professional health caregivers (e.g., home health care agency), or through an informal system where the care is provided by family, friends, and neighbors. Though the need for professional health caregivers has increased and will continue to increase because of the aging population.

Chapter Two: Social Work Roles and Health Care Settings

Social Work's Bio-psychosocial Approach to Health 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 is so by treating the whole person by taking a bio-psychosocial approach to intervention and care. The term *bio-psychosocial* 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.

Increasingly, the recommended approach for health-care service delivery today is *bio-psychosocial.* Proposed by Engel in 1977, professor of psychiatry and medicine at the University of Rochester. The bio-psychosocial 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 bio-psychosocial model considers the *nonmedical* determinants of disease in collaboration with the purely biological components. Interactive bio-psychosocial model includes general health status rather than illness alone and consideration of the important role of social networks and cultural contexts in health. Intervention that considers bio-psychosocial 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 etc.

The Limitations of the Medical Approach: *Psychosocial Issues Related to Health*

The biomedical model, still the dominant framework guiding medical research, education, and clinical care today, focuses on the root cause of disease, where disease is "fully accounted for by abnormalities from the norm of measurable biological variables." Engel offered, instead, a model designed to provide a basis for understanding determinants of disease and arriving at rational or balanced treatment patterns of health care. Engel believed that to understand and respond adequately to patients' suffering-and to give them a sense of being understood-clinicians must attend simultaneously to the biological, psychological, and social dimensions of illness.

Prior to the introduction of Engel's bio-psychosocial model, it is 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. 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.

Emotional problems can be caused by and result from health problems. Patients' social support networks can influence their health status significantly. Families can provide important support and assistance during times of health crisis, or they can also represent barriers to optimal care. Family structure and the availability of social support impacts the health of patients across their life course. Conversely, illness may exacerbate existing psychosocial problems, Psychosocial issues which occur outside hospitals and doctors' offices, greatly influence individuals' abilities to maintain their health. Many individuals who seek medical care also have "social illnesses and problems." These illnesses and problems are psychosocial rather than biological in nature. All are factors that require social work attention and intervention to improve bio-psychosocial status and, consequentially, health status.

Health Settings and the Social Worker's Place

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. Health is considered across the life course in micro- and macro level 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 macro level, and social workers play an important role in each of these care settings. 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.

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. 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 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. 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". 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. Health social workers use their clinical skills to help patients and their families cope with illness and treatment recommendations. 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. For older individuals, social workers in health care are able to provide couples and family counseling. 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.

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. 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. Social workers in health care serve as mediators between the health-care system and consumers. This also involves advocating at the systems level for improvements in the delivery of care.

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 bio-psychosocial approach to health care. 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. 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.

1. ***Conducting Assessment*:** One important role of social workers in health care setting is to conduct an assessment on patients. Social workers carry out an assessment on the strength and necessities of patients and people within their social networks in order to recognize advantages and obstacles to the process of medical care. The assessment depends on the rules and regulations of the organization and the types of services provided by the organization. Social work assessment can be done with an assessment tool. Assessment tool can be disease specific or general.

   In the *general social work assessment tools* issues like; age, educational level, economic status, biological, psychological, social and spiritual aspects are included. 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 socioeconomic barriers to the attainment of quality health care. *Disease specific social work assessment tool* ESRD (end stage renal disease). For instance, in a kidney disease which requires a replacement of a kidney the assessment tool contains; age, education, employment, bio-psychosocial and spiritual, economic status. Hence, specific assessment tools are limited to the disease and help health care professionals to understand the psychological and social issues related to the disease.

2. ***Counseling***: Involves contact with clients to help them make right decisions regarding different life issues. During counseling, the social worker should actively listen to the client when speaking about his or her problems. Moreover, it involves calming them and helps them think clearly on how to solve their problem. Counselors work hard on the empowerment of their clients to help themselves. Social workers in hospitals provide medical crisis counseling and emotional support to patients and families as well as counseling around end-of-life, grief and bereavement issues. 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. For instance, social workers in health care setting provide counseling for patients who are about to go through a surgery and their families as well. They give them hope that everything is going to be okay and that they should never give up on things. Moreover, social workers also give counseling (grief counseling) to clients who went through a loss of family members
3. ***Advocacy***: The main aim of social workers in health care setting is to advocate for human rights and social justice by avoiding health inequalities. Social workers are expected to advocate for the economically deprived and marginalized segments of the society. In this role, social workers speak on behalf of these people or motivate them to speak for themselves. Social workers advocate for equal access to services and equal treatment before the law. For instance social workers in hospitals may advocate for patients in order not to be discharged from the hospital quickly unless the finish their treatment properly. Moreover, social workers who have medical background also check patients' medical records whether they are given the right medication or not. Social workers protect patients from misdiagnosis and negligence.
4. ***Discharge Planning*:** In some places discharge planning is considered as the major responsibility of social workers. In this role, social workers identify and address barriers to discharge; locate resources; identify options and supports; facilitate referrals and applications to government/community agencies, assist patient and family to emotionally prepare for transitions. Therefore, it can conclude that social workers in health care setting have a fundamental role in the secured and well-timed discharge of

patients. Community consultation and collaboration are the roles social workers play in the process of discharge planning (on how to welcome patients after being discharged from hospitals).

5. ***Education/Information*****:** Social workers act as educators for clients, families, the community, and other professionals regarding disease prevention, impact of illness and disease progression, advocacy for benefits, health maintenance, and adherence to treatment and medications. Social workers in health care setting initiate and participate in teaching activities by presenting at workshops, rounds or conferences; provide training to health care colleagues, students and staff in community agencies; and offer education to patients and families.

   Social workers in health care setting provide education for patients and families to improve their knowledge regarding the hospital process as well as their illness and help them acquire a healthy status through a change of lifestyle. Most of the time, at the different stages of illness, patients and families face some difficulties to understand and be familiar with the whole situation happening physically to the patient. Mostly, patients and families mystified with medical term and exposed to anxiety and fear. These situations social workers swoop in and clarify the treatment plan to patients and their caregivers.
6. ***Take Care of Patients Who Does not Have Attendants***: Social workers take care of patients who don't have attendants and provide them with their basic needs such as food and cloths. Social workers take care of patients who don't have any one to help them, those who don't have anywhere to go, children who don't have parents after reporting to the police.
7. ***Create Linkage to Services***: In this case, social workers in health care settings take those patients who have nowhere to go after discharge to organizations that can provide them with their basic need such as food, clothing and shelter. For example, street children who had an accident, social workers make sure that those children will not go back to the streets after discharge from the hospital. Social workers look for different governmental of non-governmental organizations who can accept those patients and provide them with basic needs. Social workers provide these services mainly to vulnerable groups of the society such as children who are abandoned by their families, mothers and elderly people.
8. ***Facilitating Free Medical Services***: Social workers facilitate free medical services and free medicines for patients who have financial problem. Social workers facilitate free medical investigations that are not found in the hospital such as MRI and CT scan and other laboratory tests.
9. ***Facilitate Ambulatory Services*****:** When patients referred to another hospital for more medical investigation, social workers help patients to be provided with ambulance service from the hospital. Moreover, social workers also help patients to get ambulance services after discharge to get home.
10. ***Family Reunification***: Social workers in some cases provide a service of reuniting separated family members.

11. ***Co-ordination of Volunteer Activities and Social Events*:** Social workers in health care settings involve in volunteer activities such as establishing volunteer club in the hospitals, co-ordinate blood donation from volunteers, collect money from volunteer hospital staffs to help patients with financial problems with their basic needs such as food and clothing as well as transportation, collect clothes and shoes from volunteer hospital staffs and gather wheel chair and other devices for handicapped patients who cannot afford to buy those instruments. Aside from all the involvement in volunteer activities in the hospitals, social workers also organize different social events in the hospitals such as HIV/AIDS day, mothers' day and so on.
12. ***Assisting Weak Patients***: In many cases, social workers in health care settings help very weak patients in feeding, dressing and cleaning.

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. A wide variety of health social work tasks exist in non-direct 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 macro level 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. 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. 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 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.

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 macro level 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.

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 interceptive preferences), or *trans-disciplinary* (close collaboration among the professionals, including sharing a common language and approach to programming and intervention planning).

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.

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. As discharge planners, nurse case managers to be paid more than social work case managers. In the case of USA, it is reported 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.

Social workers are both trained and ethically obligated to advocate for their patients. This may lead to inter professional 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.

Health social work recommendations for effective team collaborations:

- 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

Chapter Three: Theoretical Perspectives/Models in Health Social Work Practice

3.1. The Use of Theory in Social Work Practice

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. He defines constructs as concepts that have been deliberately and consciously invented for a special scientific purpose. 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 and directly measurable subjects of inquiry of the natural sciences (e.g., molecular weight or temperature).

Theory helps to order the panoply or display 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 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, the hopelessness that results from multiple treatment failures can be avoided.

Theories 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.

Social workers in health care make ample or plenty use of theory if our definition of practice theory were limited exclusively to orienting theories, such as cognitive, behavioral, group, or family systems. Orienting theories describe and explain behavior and how and why certain problems develop. They provide important background knowledge and are usually borrowed from other disciplines such as biology, psychology, sociology, economics, cultural anthropology, and the like. Examples include the various theories related to human development, personality, family systems, socialization, organizational functioning, and political power, as well as theories related to specific types of problems such as poverty, family violence, mental illness, teen pregnancy, crime and racial discrimination. Social work interventions are based on orienting theories, most of which come from the field of psychology. Social workers in health care have used orienting theories amply and creatively, such as the adaptation of cognitive and behavioral theories to produce stress immunization, a technique for preparing patients for difficult medical procedures.

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 relevant 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.

3.2. Theories of Health Behavior

1. 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 is an extension of the theory of reasoned action and not a theory in itself.

I. The Health Belief Model

The health belief model 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. 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, obtaining influenza vaccination by individuals at high risk for acquiring life-threatening complications of influenza and lower-socio-economic status mothers' adherence to weight-loss regimens for their obese children.

Empirical evidence supports the Health Belief Model's ability to predict health outcomes. 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 for which significant results were obtained.

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

Self-efficacy is defined as a personal judgment of “how well one can execute courses of action required to deal with prospective situations”. Expectations of self-efficacy determine whether an individual will be able to exhibit coping behavior and how long effort will be sustained in the face of obstacles. Individuals who have high self-efficacy will exert sufficient effort that, if well executed, leads to successful outcomes, whereas those with low self-efficacy are likely to cease effort early and fail. Self-efficacy affects every area of human endeavor including health. By determining the beliefs a person holds regarding his or her power to affect situations, it strongly influences both the power a person actually has to face challenges competently and the choices a person is most likely to make. These effects are particularly apparent, and compelling, with regard to behaviors affecting health.

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.

II. The Theory of Reasoned Action

The theory of reasoned action 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. 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 grow 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, weight loss, and hypertension. 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, abortion, and AIDS risk behavior.

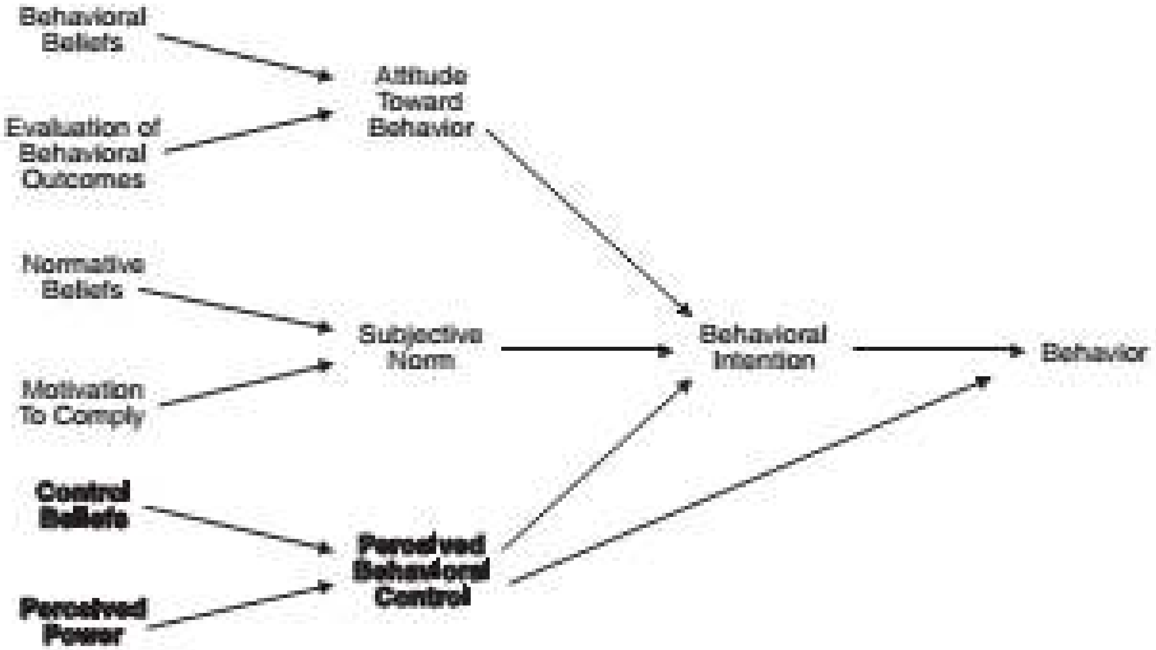

Figure 7.1 Combined Theory of Reasoned Action (TRA) and Theory of Planned Behavior (TPB). Components shared by the TRA and TBP are shown in regular type. Those unique to the TPB are shown in bold type.

III. The Theory of Planned Behavior

Ajzen and Madden (1986) extended the theory of reasoned action to include perceived control over behavior. Their idea was that intentional one could not predict behavior if the behavior was one over which the individual did not have complete control. 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, cervical cancer screening, and fighting by adolescents. 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.

2. 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 models 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. 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. The middle layer is comprised of social networks and 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 and the behavioral model of health services use.

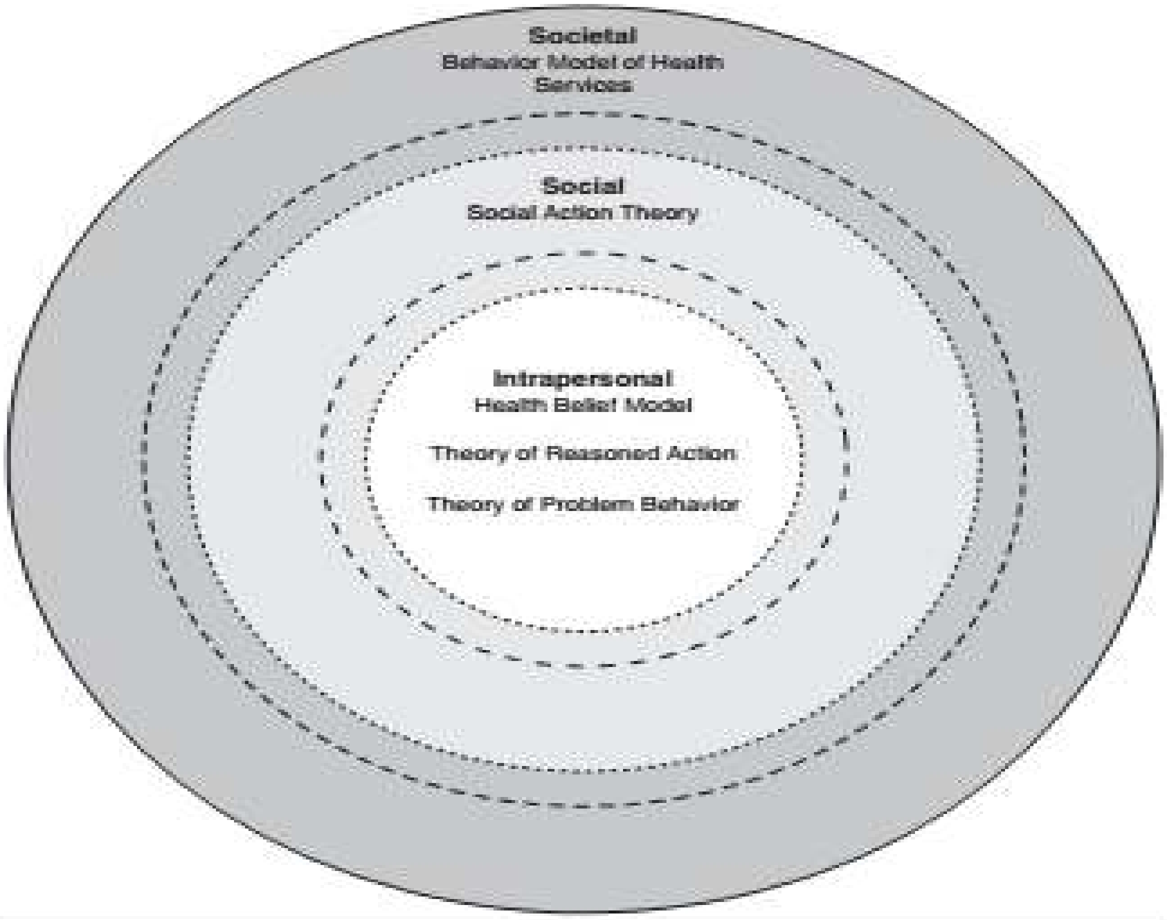

Figure 7.2 Concentric circles representing the three layers of influence on health behavior, with theories and models superimposed. The Behavioral Model of Health Services Use is on a stippled background. Social Action Theory is on a background that is dotted. The Health Belief Model, Theory of Reasoned Action, and Theory of Planned Behavior are on a clear background.

Social Action Theory

Social Action Theory 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. Individuals' desired states are influenced by what is necessary to achieve goals such as social influence, personal safety, material resources, and intimacy.

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. 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.

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.

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 and fairly recently underwent another major revision, the behavioral model for vulnerable populations. 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 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 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. Use of 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.

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.

The behavioral model for vulnerable populations 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.

Chapter Four: Socio-economic Issues in Health

Number of social, economic, cultural factors affect the health of an individual or the community at large. Some of these include socio-economic status [SES]; sex and gender; ethnicity and race; social support; life style and religion and spirituality. In this chapter, we will look these socio-economic factors one by one.

Socio Economic status

A number of studies shows that socio-economic status has a greater impact of on people's health. Most of the studies indicated that people who live in lower the socio-economic statists have a higher level of vulnerability to the diseases and death rates. These group of people are highly susceptibility to infectious diseases. Reports also confirmed that people who live in the lower socio-economic status are facing with higher level of maternal mortality rate; infant mortality rate and low birth weight babies. Poorer quality of Medical care is accessed for low socio-economic status groups more likely to be issues of affordability, etc.

Social Support

Social support mediates / moderates impact of stressful life events on negative health outcomes. Studies in USA show that African Americans have a suicide rate half that of white Americans. Different forms of social support system such as families, peers, social networks, social programs have a greater impact on human health positively or negatively. In history, the 'Social security' program of USA excluded the African Americans and influenced their health negatively than the White American counter parts. Social support adds on to our own resources and makes us feel stronger.

Life Style

Nearly 70-80 % human cancers are caused by poor environmental conditions like polluted air, soil, water etc. Use and abuse of alcohol, tobacco, drugs and other substances are also significantly affected human health. Unemployment and occupational stress are linked to hypertension and heart disease. Change over to more comfortable life style is also become detrimental factor to good health in more recent times. Can you think of some examples? For example, we walk less, use elevators, household gadgets (tools), aerated drinks, carcinogenic, harmful fertilizers in fruits, vegetables, dairy, sea food and meat products. Use of junk food which provides only ‘empty calories’ and no nutrition can be also another life style that really affect our health.

Sex and Gender

Women are biologically stronger than men; males have higher death rates than females at every stage of life including unborn fetuses. Because traditionally men have less healthy habits, like smoking, drinking, ‘chewing chat’. How does the above apply to Ethiopia?

However, from the gender perspectives, girls and women are more vulnerable to various health challenges across different life stages than their boys and men counterparts because of socially constructed factors. For instance, in the pre-birth and early childhood, ultrasound technology puts female embryos at abortion risk. The practice of infanticide in some regions within countries may also put their life at risk. Harmful traditional practices such as female genital mutilation adversely affect physical and mental health of many girls and women. In many cultures, girls have been received lesser food and medical attention than boys. Still, in many counties and cultures, the birth of boys celebrated and for girls’ impacts mother’s social status and mental health.

In the adolescence stages, cultural belies and number of social factors can be influenced the health of the people. Boys under social pressure and their own hormones engage into unsafe sexual practices at risk of sexual transmitted infectious diseases and HIV (e.g. in Wollo male try sex before marriage, south sex before marriage, otherwise be considered as unwanted). Early marriage for girls, early child bearing may also cause for fistula, anemia, sexually transmitted infectious diseases and HIV. In Ethiopia, social pressure forces girls to accept marriages with partners they don't like, may be also older men.

After marriage, women's low status in the family limits that their life and reproductive health choices. Mainly the don't have the say in regulating fertility including numbers of children, spacing, limiting family and other family issues. Women cannot also negotiate contraception methods such as condom use because cultural factors which may have an impact on their health to prevent sexually transmitted infectious diseases and HIV. In many cultures, married men can have multiple sex partners and bring diseases. Women can also entertain other men standing stick which can be considered as health predictors. Women also have low access to health care and only reproductive roles of women cared for the family.

Violence against women is another culturally promoted health issue that affect women's health. Domestic abuse is social sanctioned in some places and women suffered a lot because it. The abuse also leads women to faced various sort of physical, mental, sexual health consequences. In many instance, coerced sex leads to unwanted pregnancies, gynecological problems and other resultant health problems. Violence in pregnancy also can cause abortion, still birth, low birth weight babies and produced bad health for women too. The practice of 'honor killings' is also affect the health and life of females.

Gender sensitive reproductive health and other health services are important for services provider including social workers. Professionals should recognize that (a) social practices such as domestic abuse, female genital mutilation, harmful traditional practices harm a client's health (b) many women have little control over their bodies, contraceptive decisions and choices (c) women have a right to safe and satisfying sexual life (d) women's health needs go beyond fertility issues. Characteristics of gender sensitive health providers may include (1) Consistently treat women with respect; (2) Collect information about a client's sexual problems; (3) Help clients assess their sexual risk; (4) Teach clients negotiation skills in decision making; and (5) Look for signs of sexual transmitted infectious disease, evidence for physical or sexual abuse.

Human Sexuality

Sexuality 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 injures 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.

The natural biological sexual capabilities of humans are 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. At a very young age, children explore their bodies, including their genitals, with pleasure. 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. 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. 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. At each developmental stage, people express their wish to be close to others through displays of physical affection, comforting, and, at times, sexual desire. 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.

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.

Race and Ethnicity

In the past few decades' spectacular advances have occurred in molecular biology techniques. Researchers have been eager to use these new techniques to study ethnic or racial differences in health that are commonly assumed to have genetic causes. Genetic factors do have a large influence on health, but they are just one piece of a much larger picture. We are all continuously developing throughout our lives with a constant interaction between our genes and the environment. Any discussion of genetic tendencies thus makes assumptions about who is normal and what is a normal environment.

The term race has been commonly defined in terms of biological differences between groups that are assumed to be genetic. More recent studies identified that human race into five major racial groups (Africans, Caucasians, Pacific Islanders, Asians, and Native Americans).

However, human races are not and never being pure, and such broad continental groupings explain little in terms of the overall genetic variation of humanity. Skin color, hair form, and nose shape are certainly influenced by genes, but we do not know how many such genes there are, or how they work. On the other hand, about 85 percent of all identified human genetic variation is between any two individuals from the same ethnic group.

This is not to say that there are no genetic differences between races, but very few differences have been found which directly relate to health. Those that have been shown are usually not absolute; rather, they concern differences in the percentage of people that have particular gene types. Furthermore, most known genetic variants that are health related are random mutations in subpopulations or result from regional selection and are not related to continental race.

Ethnicity is a complex construct that includes biology, history, cultural orientation and practice, language, religion, and lifestyle, all of which can affect health. The lack of major systematic genetic differences between ethnic groups, together with the extensive differences in lifestyle (diet, alcohol, housing, smoking, etc), means that ethnic differences in mortality and morbidity to some extent provide evidence against the importance of genetic factors and for the importance of environmental factors. Access to health care is also important for ethnic differences in health.

To sum up, the concepts of genetics, race, and ethnicity are commonly confused. Genetic factors are important for health but are a small part of a large and complex picture. Few systematic genetic differences exist between races, at least with regard to genes that affect health. Ethnic differences in health are due to historical, cultural, and socioeconomic factors, which in turn influence lifestyle and access to health care. Overemphasis on genetic explanations may divert attention and resources from more important influences on health.

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 phenomena. There is no common definition among researchers regarding spirit or spirituality. “Closeness to God,” “satisfaction/efficacy of prayer,” and “satisfaction with religious practice” are constructs that researchers sometimes use to measure spirituality. 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.

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. 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. Because of this, an understanding of some basic themes of religious practice is extremely useful for social workers in helping clients navigate health-care systems. 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 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.

How does religion impact health? Some religious groups prescribe and encourage what Oman and Thoreson (2005) refer to generally as lifestyle health behaviors. Some others religions also prohibited alcohol and illegal drugs use; cigarette smoking; and sexual behavior which could be affect human health negatively. Religions also encourages healthier diets sabbath keeping. Many religious groups promote gratitude for the gift of life, and encourage respect and care for the human body as the temple of God. Religion is associated with increased use of preventative health care and adherence to medical regimens. Religious beliefs may motivate healthier living and use of preventative care. Religious settings may directly provide information, instrumental support (e.g., transportation), or on-site preventative or screening services.

Most religious groups provide significant social support for their members, especially when members need it most. In research on religion and health, a commonplace finding is that people's religious involvement is related to both the amount and the quality of social support they experience. Religious traditions promote altruism and service to others by offering both reasons and opportunities for involvement (volunteering, philanthropy, altruism, etc). These activities are associated with both mental and physical health. These positive emotional states, in turn, may affect health by reducing allosteric load (AL). AL represents the cumulative wear and tear on one's body from adapting to the demands of everyday living. These demands require ongoing adjustments to maintain physiological systems within normal operating ranges. Faith-based efforts to improve community health are becoming more popular. It is also very important to improve community health HIV/AIDS; breast cancer; and colon cancer.

CHAPTER SEVEN: FAMILIES, HEALTH AND ILLNESS

Illness, disability, and death are universal experiences in families. 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 and coping with a greater number of conditions, often simultaneously. This chapter provides a normative, preventive model for assessment, psychoeducation, and intervention with families facing chronic and life-threatening conditions.

Overview of the Family Systems-Illness Model

Over the past 30 years, family-centered, collaborative, biopsychosocial models of health care have grown and evolved. There is substantial evidence for the mutual influence of family functioning, health, and physical illness and the usefulness of family-centered interventions with chronic health conditions. Reports also show the increasing body of research regarding the impact of serious illness on families across the life span and the relationship of family dynamics to illness behavior, adherence, and disease course.

Family can be defined broadly as group of intimates with strong emotional bonds . . . and with a history and a future as a group. 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. However, families enter the world of illness and disability without a psychosocial map. 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 disciplines.

The Family Systems-Illness Model that was developed by Rolland 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. 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. 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, 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. It attends to the 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). The model emphasizes the match b/n the psychosocial demands of the disorder over time and the strengths and vulnerabilities of a family.

1. 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. 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.

1. *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.
2. *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 semi-permanent 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 non-crisis 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.
3. *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.

4. *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). 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. 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.

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 can generate a typology that clusters illnesses according to similarities and differences in patterns that pose differing psychosocial demands.

2. 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.

A. 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 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. 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.

B. 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.

C. *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. 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. 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 following table gives you a summer about the phases of illness and development tasks.

Table 7.1 (Phases of Illness Developmental Tasks)

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 remaining4. Begin the family reorganization process

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. This significantly increases the amount of time and energy families spend considering an illness and lengthens the illness timeline to include non-symptomatic phases. The non-symptomatic phases are awareness, crisis I pretesting, crisis II test/post-testing, and long-term adaptation. These non-symptomatic 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, and living with the psychosocial impact of those choices.

For some, the non-symptomatic crisis phase begins when predictive testing becomes available, continuing through the decision to pursue testing and initial post-testing 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 post-testing 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.

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.

Psychoeducational Family Groups

Preventively oriented family psychoeducational or support groups for patients and their families 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”. 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. 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. Social workers can use historical questioning and construct genograms, or detailed family trees and timelines to track nodal events and transitions. 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. 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 sensitizations 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.

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.

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.

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* 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.

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.

Generally, illness and disability tend to push individual and family developmental processes toward transition and increased cohesion. Analogous to the addition 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.

Chapter Eight: Intensive Loss, Grief and Grief Counseling

Loss

Loss is related to the death of a significant loved or valued person. This can include spouse or partner, siblings, children (including abortion, miscarriage, or stillbirth), and other relatives. However, loss can also occur through separation or divorce; temporary or permanent placement in a nursing home, hospital, hospice facility, adoptive or foster home, or prison; geographic moves due to job relocation or assignment in the military; death of a pet; death of a close friend, coworker, business associate, colleague; and deaths of well-known personalities or celebrities.

Death is not a single event at one single point in time; it is actually a process in which organs stop functioning in a sequence that varies from person to person. Decades ago a loss of heartbeat and respiration signified death. This is no longer sufficient because resuscitation can permit vital signs to be restored. Brain death, irreversible cessation of all brain activity and the brain system, is used in many but no all nations as the sign of death. Determination of death is culturally influenced. In many cases, brain death is not the standard for which to determine whether to stop Rx – **persistent vegetative state**: the cerebral cortex no longer registers cerebral activity but the brain stem remains active. The conditions of illness often do not permit a graceful, serene death but dignity can be offered through affection, care, companionship, truthful diagnosis, and maximum control over one's final phase of life – a "good death". Death may consist of phases such as:

1) ***Agonal phase***: gasps and muscle spasms during the first moments in which the body can no longer sustain life.
2) ***Clinical death***: a short interval follows in which heartbeat, circulation, breathing, and brain functioning stop but resuscitation is still possible.

3) ***Mortality***: the individual passes into permanent death. Within a few hours, the person's body appears shrunken.

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 (e.g., amputations) and loss of functioning (e.g., lack of mobility, impaired bladder or bowel control, reduced sexual functioning). Psychological loss is also relevant for patients at the end of life and can include the loss of independence, dignity, self-esteem or self-concept, memory loss, and 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).

Grief

Grief is a natural response to loss. The process of grief can be conceptualized within three broad categories: *avoidance*, *confrontation*, and *reestablishment*.

A. ***Avoidance:*** includes "shock, denial, disbelief, emotional anesthesia, confusion, numbness, disorganization". It is a survivor experiences shock followed by disbelief; can last from hours to weeks.

B. ***Confrontation:*** is a "highly emotional state where in the grief is most intense and the psychological reactions to loss are felt most acutely." Grief is experienced most intensely, often a myriad of emotions including anxiety, sadness, protest, anger, helplessness, frustration, abandonment, and yearning for the loved one. Questions how the death could have been prevented and searching for meaning in the loss. The person may be absent-minded, unable to concentrate, preoccupied with thoughts of their loved one, loss of sleep and appetite. Unmet desire to be reunited with their loved one and a realization that the person is gone and the relationship has to be transformed from a physical presence to an inner representation.

C. ***Reestablishment:*** is the "gradual decline of the grief and marks the beginning of an emotional and social reentry back into the everyday world". Restoration must deal with other stressors that are secondary outcomes of death, i.e. finances, reaching out to others, reorganizing one's life without the person. ***Dual-process model of coping*** with loss is an effective coping process that requires people to oscillate between dealing with the *emotional consequences* of loss and *attending to life changes.* When handled correctly, it can be restorative or healing. Confronting grief without relief can have severe consequences for physical and mental health.

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; and reinvest in a new way of life. Factors that influence how individuals cope with loss include childhood, adolescence, and adult experiences of loss and how recently those losses occurred; previous mental health problems (i.e., depression), life crises (financial crisis…divorce with a spouse, trouble with other family members), or life changes prior to the current loss (losing someone who was the source of an income for the family), The relationship with the deceased person also plays a role in coping with the loss: the relationship (partner/spouse, child, parent), length of the relationship, role the deceased person occupied, strength of the attachment, and degree of dependency.

Grief Counseling

Grief counseling involves normalizing the grieving person's feelings and behavior and helping the griever to identify and express feelings, actualize the loss, facilitate the ability to live without the deceased person and to reengage with life, and provide continuing support throughout the process. Social workers should be alert to symptoms of complicated or uncomplicated grief while providing counseling to help patients and families normalize their often-difficult responses to grief. Complicated grief is a grief reaction that includes difficulty acknowledging the death, disturbing thoughts about the deceased person, and feelings of uselessness and purposelessness about the future. In contrast, 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.

Within their ability, social workers can help families to express their grief appropriately 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 advance directives help people who are at the end of life feel some control and ensure that their wishes are honored.

Similar process of normalize grieving is bereavement interventions. It aims to encourage people to draw on their existing social networks. The emphasis is to protect people from unnecessary re-exposure for those who experienced loss due to violence. Assist the individual’s support system so that they can be supportive -do we have this in Ethiopia?? Assist in finding meaning in one’s relationships o Death education-see from various perspectives.

Chapter Nine: Pain Management and Palliative Care

The 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.

Palliative Care

The Dictionary definition of *palliate* is "to alleviate without cure." The World Health Organization has adapted this basic definition and 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 "the active total care of patients whose disease is not responsive to curative treatment." The goal of palliative care is the achievement of the best possible quality of life for patients and their families. 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, chemotherapy and radiation therapy in an oncology and dialysis for renal disease may be provided as part of the palliative care. Professionals 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.

As a result, palliative care may include both hospice care and pain/symptom management. Hospice care is an interdisciplinary program of care, support, and bereavement services for persons whose life expectancy is believed to be six months or less. The emphasis of 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 many cases is provided in the patient's home or in a center.

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. Palliative care may be provided throughout the course of illness and be complemented and enhanced by referral to a hospice care program.

Pain Management

While pain and symptom management are essential attentions 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. A significant portion of the population suffers from moderate to severe pain at any one time. 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.

Pain can be defined 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. 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 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. 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. 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.

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 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? Are 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. 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.

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 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. 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. 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.

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. 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.

The perceptions, evaluation, and experiences of the patient, family, and healthcare professional are unique. As a result, discrepancies in observations and assessment may occur that should be addressed. Evidence suggests that clinicians underrate pain, especially when it is severe. 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.

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, in 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 represent 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.

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.

A. ***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, advocacy skills can be taught with the goal of increasing self-efficacy. Additionally, there are multiples opportunities for systems change within an institution as well as at a political and policy level.
B. ***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.
C. ***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.

D. ***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.

E. ***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.

F. ***Coping Statements:*** Coping statements are internal or spoken statements designed to distract, enhance coping, or diminish the threatening aspect of a situation or experience. Catastrophic and defeating self-statements about pain can be replaced with internal dialogues that enhance coping and competence.

G. ***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. 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.

H. ***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. 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. Diaries can be useful in understanding the multidimensional aspects of many symptoms including pain, insomnia, anxiety, and depression and thereby guide interventions.

I. ***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. Family conferences are not the same as family therapy. 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. 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.

J. ***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. 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.

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.

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. Social workers have 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.

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 only in few universities across the world. 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. 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, few regulatory agencies 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 experiences 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.

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. 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 non sacred goals either in or outside of a religious context. This phenomenon, also known as extrinsic religiosity, involves using religion to pursue Non sacred 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, thus allowing individuals to reinterpret personal experience in terms of group norms.

The following definitions and characteristics of religion and spirituality that are helpful for clinical research and social work practice.

- *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.

The 12 dimensions of religion that they find present in the work of a number of theological researchers and philosophers.

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

These 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 scared core.
2. Religious affiliation or denomination, or identification with others in a particular group.
3. Organizational religiosity, or participation in the religious institution.
4. Non organizational 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.

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.