SOCIAL WORK IN HEALTH AND MENTAL HEALTH: Issues, Developments, and Actions

Tuula Heinonen
Anna Metteri
Editors

Canadian Scholars' Press Inc.

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PREFACE

This textbook is aimed at undergraduate and master's level social work students who are interested in the health and mental health care fields. It is primarily a book on social work practice, or how one might approach a particular kind of human issue or problem related to health and well-being. An international group of contributors is represented among the 23 chapters. The book fills a need for social work textbooks that incorporate theory and practice from different parts of the world (Australia, Finland, China, South Africa, Wales, Canada, and the United States). As such, it is attractive not only to a North American audience, but also to readers in Europe and other parts of the world. The authors have included in each chapter a discussion of relevant literature related to their topic area, a case situation that applies concepts and ideas for practice, and a set of reflection questions that help students to critically examine their own ideas and reflect on key issues and challenges facing social workers. Finally, each chapter gives a list of references used in the work. We have tried to retain some variety in the presentation of material in the book and have strived to make it reader-friendly, stimulating, and unique.

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CHAPTER 1

INTRODUCTION

Tuula Heinonen and
Anna Metteri

Genesis of the Book

The idea for this book came from a review of abstracts sent for the 3rd International Conference on Social Work, Health, and Mental Health held in Tampere, Finland, in 2001. It seemed to us that social work textbooks focusing on practice in the fields of health and mental health were difficult to find and that this gap needed to be filled. We hope that the chapters in this book, through their discussion of theoretical content and practice applications, will serve the needs of undergraduate students, especially those in health or mental health practica or with related experience and interests. We also hope that all undergraduate and graduate students, classroom and field instructors, and social work practitioners will find the book engaging, interesting, and stimulating.

The book is aimed at international social work audiences and offers to social work students a closer view of topical areas and their significance in health and mental health. It also enables social work students to reflect on and weigh issues in health and mental health, and to apply concepts learned and their own ideas to practice situations.

Health and mental health are conceptualized broadly. We hold that the health and well-being of body and mind are integrally connected, shaped by biological, physical, psychological, material, social, and structural features and determinants, and that they are dynamic and embedded in one's everyday life patterns. Further, people are viewed as active, engaged agents with strengths and resources from which to draw in meeting both ongoing challenges to health and major life crises.

A social worker in the fields of health or mental health strives to understand and work with people in their situations, applying values that foster well-being, healing, growth, and change in individuals, families, groups, and communities. The effects of specific forms of illness and injury on people affected are examined as are health-promoting strategies useful in many situations. Social work intervention and its methods will be discussed through existing literature and case situations, examples, and illustrations. This will allow readers to make connections between theory and practice in health and mental health care practice settings.

Each chapter is structured according to a broadly similar format; however, there is some differentiation for variety in presentation. The chapters in the book cover a range of areas germane to social work in both health and mental health, including newer topics and those that have been important issues in social work for decades. In addition to the introductory and concluding chapters, the book contains 21 chapters written by experienced practitioners and scholars from around the world.

Instructors may wish to make use of the reflection questions and other material in the chapters for group discussions or assignments. These questions have been formulated to help readers reflect on and respond to the ideas, practice methods, and case situations described in the book.

In most Western countries, the roots of social work in health care and in mental health in the late 19th century were entwined with medical or psychiatric practice, often seen as offering practical help or counsel to indigent hospital patients. Social workers provided a service that was much needed at the time. Much changed as the profession grew and developed, incorporating ecological, bio-psychosocial, cognitive, family-centred, and various other approaches as indicated by the workplace setting, particular theories of practice, or by client or patient needs. Social work in health and mental health fields has seen shifts in scope and methods as social policies and service delivery change. In this book, we focus on current practice in hospitals, mental health clinics, counselling centres, and other places where social workers practise.

Part Overviews

There are four parts in the book, each containing chapters related to the section theme: (1) practice approaches, frameworks, and methods; (2) social issues and health effects; (3) structural and institutional challenges affecting health and mental health care; and (4) responses to serious threats to health and experiences of loss.

In Part A: Practice Approaches, Frameworks, and Methods, the focus is on approaches, methods, or models, and their applications to social work intervention in health and mental health. These are important topics for social work students as they orient themselves to social work and learn to select from and apply suitable practice methods in their own work. The first chapter provides a brief introduction of the book and an overview of the whole book and its chapters.

The second chapter—by Toba Schwaber Kerson, Judith McCoyd, and Joanne Chimchirian—describes an enhanced ecological perspective to enrich social work practice. The ecological perspective is well known in social work and this chapter adds further depth to the topic. In Eileen Ain's chapter, ethics and ethical dilemmas that social workers face while working in health settings are discussed. Len Spearman, in Chapter 4, highlights the use of a strengths perspective in mental health. In Chapter 5, Julian Buchanan describes a method of working with dependent drug users who experience many obstacles in regaining health. In the final chapter of the section, Alex Keen discusses the application of music to helping people with mental health problems.

Part B: Social Issues and Health Effects highlights the ways in which current social problems that affect individuals and groups of people are related to or bring about ill health. Poverty, social discrimination, and family violence all have impacts that resonate at family and individual levels. Chapter 7, by Bruce Bidgood, Stephen Krzyzanowski, Laura Taylor, and Shelley Smilek, is about the situation of people who are forced to use food banks (charitable donations of food hampers) because they cannot afford to purchase enough for their survival needs. The eighth chapter, written by J. Elaine Walters and Jeff Todahl, examines the impact of domestic violence on children's mental health and how sensitive and appropriate intervention can occur. Chapter 9, by Deborah Walsh and Wendy Weeks, discusses the health effects of domestic violence against women during pregnancy. The final chapter in the section is written by Grace Elliott, Ron Levin, Jean Lafrance, and Margot Herbert. It addresses the barriers experienced by western Canadian

Aboriginal peoples in seeking and receiving culturally sensitive urban health care services.

Part C: Structural and Institutional Challenges Affecting Health and Mental Health Care addresses organizational or system-wide contexts that affect people with needs for health or mental health services. Although these chapters draw from particular national or regional experiences, they are relevant for social work in many parts of the world. Chapter 11 is written by Glen Schmidt, who describes limitations in rural mental health services and how cultural barriers and misunderstandings affect care seeking and its acquisition. Domestic violence intervention in health care is the topic of Chapter 12, written by Kathleen Mackay and Stan de Mello. Screening and social work intervention in hospital emergency areas are the primary focus of this chapter. In the next chapter, Anna Metteri and Marja Nieminen describe how social workers act as conflict negotiators on behalf of clients in Finnish health care settings. Joanne Sulman, Diane Savage, Paul Vrooman, and Maureen McGillivray, in Chapter 14, discuss the use of peer social work management in a large hospital setting. The final chapter in this section, written by Pirjo Nikander, describes multidisciplinary work with teams in elderly care. Institutional practices, financial constraints, and professional influence that give shape to decisions affecting patients' long-term care are examined.

Part D: Responses to Serious Threats to Health and Experiences of Loss shows how clients' responses to challenging individual and family health events and various forms of loss often involve significant strength and resilience. Chapter 16, written by June Allan, describes how people make meaning from serious, often life-threatening conditions. Cecilia Lai-Wan Chan, Amy Yin-Man Chow, and Rainbow Tin-Hung Ho, in the next chapter, discuss how Chinese ethnic populations face losses due to cancer and other factors and how Eastern methods of healing can help. Chapter 18 is written by Pirkko Ollikainen and provides, through client narratives, a micro view of what living with cancer entails. In Chapter 19, Eileen Widerman and Lois Millner shed light on the experiences of adults who have been given a diagnosis of cystic fibrosis. Only a few decades ago, this was seen as a childhood illness, and health and social services continue to be designed for young populations rather than adults. The next chapter in this section, by Nancy Williams and Maureen Davey, discuss the lives of burn survivors and how they cope with the physical, psychological, and emotional effects of their injuries. What is most striking in this powerful chapter is the human spirit that strives to heal and grow, despite serious bodily injury. Chapter 21, about the use of grandparent bereavement support groups in response to death of a child, is written by Deanna Angelico and Jane Sullivan. The section's final chapter, by Maureen McInerney and Lynette Joubert, is also about providing support, in this case to children whose mothers are living with terminal cancer. The importance of social work involvement in helping people deal with serious illness and loss situations is highlighted.

Chapter 23, the final chapter, written by the book's editors, summarizes some key ideas in the chapters and offers ways to think about social work practice in health and mental health.

PART A

PRACTICE APPROACHES, FRAMEWORKS, AND METHODS

Social work requires new approaches and frameworks and fresh insights into existing theories and practices to respond flexibly to changing client situations. Social work concepts and theories are applied, adapted, and refashioned so that they address better the problems and issues that our clients and workplaces present. In this section are five chapters that describe ways to frame and understand practice issues and use various methods to respond to complex problems and to generate solutions with diverse clients.

CHAPTER 2

SPANNING BOUNDARIES:
An Enriched Ecological Perspective for Social Workers Practising in Health and Mental Health Care

Toba Schwaber Kerson, Judith L.M. McCoyd, and Joanne M. Chimchirian

Introduction

Although not named as such, an ecological perspective has been familiar to social workers since Mary Richmond and Jane Addams first insisted that people's social context (their families, work environments, ethnic and spiritual communities, neighbourhoods, etc.) was an important part of their life circumstance and critical to understanding how to help them improve their situation. While Bronfenbrenner (1979) developed the idea of an "ecology of human behavior," social workers tend to look to the work of Carel Germain (1984) and Germain and Gitterman (1995) as the best explication of the ecological perspective. The term "ecological" comes from the biological study of ecology, a scientific approach that recognizes relationships between and among organisms and all parts of their environments. Ecology views organisms (including humans) and their environments as interdependent.

The ecological perspective also draws on systems theory, which is guided by two central principles. First, "structure influences behaviour." This refers to the idea that the ability to influence reality comes from recognizing various structures that are controlling behaviour and events (in social work, these would include laws, family roles, economic circumstances, organizational policies, etc.). The second principle, "policy resistance," refers to the tendency of complex systems to resist efforts to change their behaviour. Therefore, efforts to manipulate behaviour will generally improve matters only in the short run and often lead to more problems in the long run (Senge 1990, pp. 373–374). For example, a mastery of systems thinking leads one to understand family problems or organization problems as resulting from underlying structures rather than from individual mistakes or negative intentions. Systems thinking leads to seeing "wholes" instead of "parts" and experiencing the interconnectedness of life.

Boundary-spanning social work enriches the above ecological and systems perspective by suggesting a broader focus for assessment, intervention, and evaluation. This approach challenges the social worker to locate boundaries that limit client functioning, to assess the ability to span those boundaries in effective ways, and to intervene to modify the functioning of the structures surrounding the client as well as to intervene with the client directly. This approach allows social workers to link health and mental health, intervene with clients by promoting more functional behaviour patterns as well as more functional policies, and evaluate their own work in terms of how they have improved circumstances not only for a particular client, but for client populations.

A Word about Mapping Devices

Mapping devices, such as ecomaps, genograms, and organigraphs, help social workers to make use of this approach in several ways. First, visualizing complex sets of relationships and activities broadens social workers' scope and deepens their understanding of a client's situation, allowing choice regarding points and methods of intervention. Second, mapping devices allow viewers to see elements clearly enough to give them some sense of control and free them from the tyranny of measurement and numbers. In this regard, mapping devices can help social workers to concentrate on conceptual work, and then to collect data necessary to the analysis (Christensen 1997). A third benefit is that mapping devices require that assumptions be made explicit, thus enabling those who work together to achieve consensus more easily. They facilitate reaching agreement or contracting about how to view systems in context and determining the most appropriate targets for intervention. Additionally, they provide ways to intensify moments in helping relationships by creating a concrete focus of attention. In sum, such devices help social workers to assess, plan, make concrete, monitor, and compare.

Boundary Spanning: An Enriched Ecological Perspective

An ecological perspective is comfortable for many social workers, especially social work scholars, because it best accounts for the overarching values of the profession. It is, in fact, the value system of social work that unites all domains, methods, and specializations. The ecological perspective informs this work in two major ways: as a meta-construct (or construct about a construct) and as a metaphor. First, as a meta-construct, it offers an all-inclusive framework for social work. As theorist Max Siporin noted:

> … ecological systems theory is such a general meta-theory, one that provides for the many, and at times contradictory, purposes and activities of social workers. It constitutes an essential element of the generic core of social work knowledge, of its common person-in-situation and dialectical perspective, and of its basic helping approach. It supports the social work assessment and interventive focus. (Siporin 1980, p. 525)

For practitioners, the perspective works best as a metaphor for thinking about all the elements as well as the whole of social work practice. It functions as a lens that brings parts of the social environment or client into sharp focus for assessment and intervention, and then allows "panning" to view the entire client/environment/organizational context.

One problem with an ecological perspective is that while it maintains the focus on the individual, it does not easily support a shift in focus to other dimensions of the environment or to client populations other than individuals. This ability to shift focus from individual client units (individuals, families, or small groups) to organizations, communities, or populations is difficult using any perspective or theory thus far developed for social work practice (Tolson, Reid, and Garvin 1994, p. 6). Viewing social work as a boundary-spanning endeavour addresses that problem. For example, a study of adolescent mental health and urban families argues that prevention and intervention strategies must be more responsive to families' contextual realities rather than being based solely on traditional clinical theories (Stern, Smith, and Jang 1999). "Viewing disturbed mood as a response to social context rather than as parent psychopathology points to interventions that help families cope with adversity" (Stern, Smith, and Jang 1999, pp. 22–23). At those times, the focus of the work becomes the organization or delivery system, that is, the social context. That vantage point does not seem to be a good fit with an ecological perspective as it has been drawn for social work because the focus is again limited to one arena—the environmental social context. However, it fits well with the systems perspective drawn by the business management scholars such as Drucker, Argyris, Senge, and Mintzberg, whose work is incorporated in our understanding of systems theory. It also supports emphasizing the legal and ethical dimensions and organizational understanding as critical for contemporary practice in health and mental health. Further, it supports our contention that boundary-spanning assessment and intervention act as a link between systems and ecological perspectives. This is an example of an ecological reinterpretation.

Certain questions remain. For example, what dimensions must be studied and understood in order to have social workers intervene most effectively and efficiently? Also, even when social workers are sure they have included all the salient dimensions, how do they choose which dimensions to concentrate on for maximum effectiveness? It is most helpful to keep goals and objectives clear and agreed upon and to maintain a partnership with the individuals, groups, and committees with whom, and on whose behalf, one is working. "Ecological thinking suggests that we should be less concerned with causes than with consequences, and that we should concentrate on helping change maladaptive relationships between people and their environments. We should ask the questions: 'What is going on?' rather than 'Why is it going on?' and 'How can the What be changed?' rather than the 'Who'?" (Germain and Gitterman 1996, pp. 7–8).

■ An Application to Practice in Social Work: An Example of Boundary Spanning

The following example illustrates a patient's relationships to the mental health system in the United States. Mental health law varies from country to country, even from state to state within countries, so it is important for social workers to understand how their country's laws affect the lives of their clients.

In January 2000, the United States' Secretary of Health and Human Services sent a letter to all state governors regarding the strides that were made in enabling individuals with disabilities to receive necessary services in their communities rather than in institutions. The letter reminds the governors of the recent Supreme Court decision in *Olmstead* *v. L.C.* (1999), which affirms the belief that no person should have to live in a nursing home or other institution if he or she can live in his or her own community, and that unnecessary institutionalization of individuals with disabilities is discrimination under the Americans with Disabilities Act (ADA) of 1990. The court's decision says that a state may be able to meet its obligation under the ADA by providing comprehensive, effectively working plans to ensure that individuals with disabilities receive services in the most integrated setting appropriate to their needs. The letter reminds the states that they must provide effective, fiscally responsible policies designed to increase access to community-based services.

The Olmstead case was brought by two women in the state of Georgia whose disabilities include mental illness and mental retardation and whose treatment professionals thought they could live in a community setting. Their lawyers argued that their continued institutionalization was a violation of their right under the ADA to live "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (28 CFR 35.130[d]). Under the court's decision, states must provide community-based services when treatment professionals determine that such placement is appropriate, when the patients do not oppose the treatment, and when the placement can be reasonably accommodated. The court cautioned, however, that nothing in the ADA condones termination of institutional settings for people unable to handle or benefit from community settings. The following is the story of an individual who may not be able to live outside the state hospital.

Case Situation: Donna

Donna Hauck, age 50, has an extensive history of in-patient hospitalization for the treatment of severe mental illness. Schizoaffective disorder (bipolar type) and personality disorder (not otherwise specified) have been diagnosed. Figure 2.1 illustrates a lifeline for Donna Hauck that shows the pattern of her illness over time.

Ms. Hauck regularly cycles in and out of the state mental hospital. She does not believe that medication is responsible for her dramatic improvement. Each time she is discharged, she initially attends a partial hospitalization program and takes her medication as prescribed. However, as life stresses mount, Ms. Hauck gradually stops all treatment because she believes that the medication is causing her depression and her inability to think clearly and concentrate. As she further decompensates (becomes more ill), she has delusions and becomes agitated. Eventually her bizarre and threatening behaviours bring her to the county mental health court, resulting in commitment to the community psychiatric hospital. Ms. Hauck's latest admission was precipitated by an event in which she started a fire. The fire department was called, and the accompanying police took her to the community hospital, where she was committed for treatment of her psychosis. Ms. Hauck's Medical Assistance Health Maintenance Organization, the organization that pays for her health care services, will cover a maximum hospitalization of 60 days, but stabilization usually takes about 90 days, with additional time needed for discharge planning. Eventually the staff from the County Office of Mental Health utilized one of their apportioned beds at the state hospital for further stabilization and discharge planning. Over the years, Donna's need for hospitalization and the length of her hospital stays have increased. Her last hospitalization is one of eight state hospital admissions.

The state Office of Mental Health and Substance Abuse Services establishes requirements for admission to a state hospital, with regulations that follow the directives of the state Department of Public Welfare, which receives funding from the state and federal government and must satisfy the regulations of the federal Department of Health and Human Services. The impact of the law on treatment and service options can be seen in the current effects of the Americans with

Disabilities Act on discharge initiatives. Also, the Supreme Court's decision in the Olmstead case reinforces the need for community placement for those who do not require in-patient care and has intensified the expansion of community-based services.

Patients who meet the criteria for an involuntary commitment are admitted to the state hospital. The mental health review officer who hears the case determines whether the petitioner presents enough valid evidence of a person being a danger either to himself or to others. In addition, the state hospital is not available for acute care; therefore, all patients must have received treatment at a community hospital prior to admission. The state hospital administration then facilitates admissions from the individual community hospitals.

Every patient in the state hospital is assigned a treatment team composed of a psychiatrist, a social worker, and a nurse. The social worker's tasks include providing an accurate psychosocial assessment, participating in therapeutic interventions, maintaining communication with family members and significant others, and collaborating with the patient and community providers to formulate and implement an appropriate discharge plan.

Social worker Sophia Regal finds that working with Ms. Hauck can be both pleasant and very frustrating. Ms. Hauck seems co-operative and is superficially co-operative, never disagreeing with what is being suggested; however, whether or not she will follow through with developed plans always remains a question. Also, she can find the silver lining in any situation, but uses considerable denial in her judgments. She is very forgiving of any wrongs that may have been done to her, a quality that consistently places her at risk for future abusive relationships. Impaired judgment and minimal insight significantly affect her problem-solving and decision-making capabilities. For example, she sincerely wants to live life fully and is quite willing to try new possibilities; however, her denial of her illness severely affects her ability to accept necessary medication and therapy. Because she has had long periods of moderate stabilization in the past with a minimal amount of medication, she cannot accept that at present her illness requires different medications to achieve the same quality of thinking. The social work value of self-determination is tested when Ms. Regal considers the need to protect this vulnerable woman. Advocating on her behalf requires a delicate balance among practice wisdom, ethical commitment to and knowledge of client's rights, and awareness of the available organizational mental health resources and laws. Boundary spanning is imperative.

Each time Ms. Hauck's condition stabilizes, the treatment team recommends initiation of discharge planning. For her, stabilization requires a daily combination of four different medications (one for disordered thinking, one for depression, one for mood stabilization, and one for anxiety). On these medications she is fully alert, able to function during the day in the community, and able to sleep peacefully at night. Without depression, delusions, or mood fluctuations, she can relate to others quite effectively and can meet her needs with minimal assistance.

Ms. Hauck's family has cared for her for most of her life; however, with advancing age, they are no longer willing to provide her with a residence. She is eager to be discharged and has engaged a patient advocate to pressure the hospital for immediate release back to the community. She was able to contact the patient advocate by calling a toll-free number, and she requested that the advocate attend her treatment team meeting. With Ms. Hauck's permission, Ms. Regal begins to formulate a plan that will accommodate her needs for housing, financial benefits, and aftercare. The County Office of Mental Health is notified of the plan to discharge Ms. Hauck, with an accounting of her resources. Applications are initiated for placement in a county residential facility with intensive case-management services provided by the County Case Management Office. State hospitalization automatically establishes eligibility for these scarce and high-cost services, which are funded by the patient's county of residence. Financial benefits can be obtained through the Social Security Office, with eligibility established prior to discharge, or through the Department of Public Assistance on the day of discharge. Medical insurance and prescription coverage are also obtained through these offices. Once these services and benefits are in place, a firm discharge date is set, and aftercare plans can be established through the county mental health clinic.

Because Ms. Hauck has a long history of stopping her treatment and medications after discharge, the state hospital petitions the Mental Health Court for an out-patient commitment to the partial hospitalization program she will attend after discharge. This commitment can be converted back to an in-patient commitment if Ms. Hauck misses scheduled treatment appointments or begins to decompensate regardless of the treatment, thus avoiding serious decompensation before intensive treatment in a hospital setting can begin again. For Ms. Hauck, decompensation begins with difficulty sleeping, agitation subsequent to auditory hallucinations, and argumentative behaviour. At this point, placing her back on her medication can fairly easily stabilize her. If treatment does not occur at this point, she will become increasingly delusional, agitated, and, eventually, assaultive. Contact with the police will then precipitate hospitalization. The likelihood of criminal charges increases, and Ms. Hauck will require a longer period of time for stabilization to occur.

While Ms. Hauck is in the community, the county mental health system will provide housing, usually in the form of a community rehabilitative residence or supported living arrangement. Intensive case-management services, also provided by the county, will help Ms. Hauck access needed services and solve whatever problems she faces. Although Ms. Hauck is quite capable of budgeting her own money, individuals who are not financially aware can receive money management services through Lifetime Support, a non-profit organization that serves this population. Psychiatrists, therapists, and milieu settings (which offer socialization and job opportunities) will provide treatment. Income is provided through agencies outside the mental health system, but the process of obtaining those benefits can be too daunting for those with mental illness, so successfully securing these benefits is part of the discharge process.

Ms. Hauck's ecomap indicates how her life changes when the symptoms of her mental illness influence her life (Figure 2.2). In the ecomap, an unbroken line indicates a strong positive relationship, the arrows at the ends of lines indicate the direction(s) in which the relationship is going, a dotted line indicates a troubled relationship, and a line of dashes indicates a very difficult relationship.

Ms. Hauck's prognosis is guarded at best. Her history includes repeated non-compliance with her medication regimen and out-patient therapy. If coerced into continuing treatment, she will relocate and disappear from the mental health system. She will not resurface until she has totally decompensated and her psychotic behaviours bring her into contact with the police again. Her only hope for long-term stabilization is to accept the need for medication. One of the most frequent deterrents to medication compliance in women is weight gain, but the newer medications are showing promise in reducing this side effect.

Ms. Regal's job is to balance Ms. Hauck's needs and the community's needs within the financially constrained system of service delivery. Ms. Hauck has a right and a desire to live in the community. She has one personal financial resource, social security disability benefits. All other needs must be met by publicly funded programs. Ms. Regal's ability to engage Ms. Hauck in the planning process and her knowledge of the available programs and how to access them, while also enhancing Ms. Hauck's motivation to maintain the treatment plan, are critical for implementing a discharge plan that will give Ms. Hauck the best chance to remain stabilized in the community.

Discussion of Key Points

Understanding Ethics and Laws

This case illustrates several of the ethical dilemmas in which social workers might be involved, including issues regarding allocating limited health care resources; beginning or ending aggressive treatment; returning patients to a home or a residential facility; and clashes between patient, family, and institutional interests. Also illustrated are the actions related to overarching social work values such as self-determination, social justice, personal values, the dignity and worth of all people, competence, and social workers' responsibility for their own ethical conduct and the quality of their practice. It is critical that social workers understand the law in relation to their particular clientele, including laws that "entitle" and laws that "restrict" (Dickson 1995). Legal issues in the United States that affect many client populations include guardianship, advance directives, durable power of attorney, confidentiality/privacy, authority to practise, licensure, and informed consent.

Understanding Organizations and Systems

Also important here is the social worker's understanding of organizations. Understanding linkages and forms of communication between and among organizations is of paramount importance if one is to successfully span boundaries. This knowledge allows social workers to move more freely, to build professional and interdisciplinary networks, to understand patterns of authority and responsibility, and to make organizations more responsive to direct and indirect client systems. Issues and dynamics such as interdisciplinary turf conflicts, access, racial bias and harassment, authority, and ethnic and racial differences are also important. Teamwork and interdisciplinary, intra- and interagency work are also critical (Griffiths 1997; Saltz and Schaefer 1996). To help her understand where in the system she needed to build relationships, Sophia Regal drew an organigraph that indicated the parts of the system that had to be pulled together to address her client's needs (Figure 2.3).

The Continued Importance of Knowledge Building and Relational Abilities

An overarching theme in this chapter is the critical importance of very high levels of knowledge and skill that social work requires, regardless of practice setting. For example, because ill people are now hospitalized for as short a time as possible, work that used to occur in a hospital setting may now have to take place in a rehabilitation centre, a nursing home, a senior centre, or the client's home. Ability to quickly assess the client, the social context, and the availability of resources across organizational and community boundaries is more important than ever before.

Another theme, and in fact a basic premise in this boundary-spanning perspective, is the essential utility of relationship as the primary conduit for effecting change of the client system in direct and indirect practice. Although both the context and strategies of the social worker in health care have become more extensive over the decades, the importance of the relationship between social worker and client system remains constant. No matter how large the unit of attention—whether

Image not available

it is a community, a large organization, a family, or an individual—the accomplishment of goals depends on the social worker's relationship abilities with individuals as clients or with individuals who represent larger client systems or health care organizations.

Communication skills remain critical. Social workers' ability to understand the psychological nuances of relationship and to carry themselves differently in the relationship, depending on the needs of the client system and the goals of the service, are critical to this endeavour. Therefore, traditional social work concepts such as self-awareness, conscious use of self, helping alliance, and the overall capacity to develop and sustain relationships are expected skills for social workers in every practice setting. Certain relationship tasks such as acting as a conduit or catalyst for helping the client to reach goals; carrying hope; lending a vision; and intervening in varied ways depending on the capacities and needs of the client system, the needs of other systems with whom social workers may be working, and the tasks necessary to meet needs and objectives are important.

The notion of boundary spanning is essential to social workers' building and maintaining such relationships. The boundary-spanning perspective guards against tunnel vision and allows creativity in considering multiple options for enhancing client functioning and well-being.

Assessment

Social work practice in both the example and the perspective involves making judgments about capacities, needs, and goals and acting on those judgments. The relationship of assessment to the development of goals, objectives, and outcome measures is critical, underscoring the increasing importance of outcome measures for evaluation and continued support of individual client systems and programs. Every attempt is made for practice to be empirically based, that is, closely linked to the products and processes of research. Clear assessment allows concretely specified goal setting, which in turn allows evaluation of whether these goals were accomplished once the work is finished. Assessment also underscores the importance of differentiating between short- and long-term goals. By specifying which goals are short term and which are ongoing, the social worker and client systems are aware of the relationships between their activity, the goals they are working to reach together, and the goals the client system will continue to address over time. Assessment within a boundary-spanning perspective also requires assessment of the accessibility of the surrounding social environment and its capacity to change. Policy changes, new uses of organizational resources, and program development may all become social work targets for change when a full boundary-spanning assessment is complete.

Planning

The planning process is critical in relation to determination of goals and objectives, uses and types of contracts, the process of strategizing, and the overarching importance of teamwork in all of social work practice (Kettner, Maroney, and Martin 1999). Typically, strategies are an amalgam of professional, family and other social supports, governmental, voluntary, self-help, relational, informational, and in-kind interventions. These may not occur at the same time or be carried out by one social worker, but the social worker is part of a large network of helpers moving in and out of work with the client system over time. Particular attention is paid to the relationship between self-help and professional help, as well as to interdisciplinary teamwork. Assuring that planning is occurring in tandem across boundaries ensures that multiple entities involved with the client system do not work at cross-purposes.

Intervention Skills

Social work practice interventions vary with the needs of the clients. Throughout the history of social work practice in health and mental health systems, social workers consistently work as advocates and case managers. Advocacy is seen as an intervention in its own right, as well as part of all other interventions (Sunley 1997). Advocacy includes case advocacy, in which a social worker helps a client to meet a specific need. It also includes cause or class advocacy, in which similar unmet needs are grouped and organized into advocacy activity by a group of people (an agency, a section of an organization, or a combination of professionals and community people) for the purpose of meeting a larger clientele's needs (Erickson, Moynihan, and Williams 1991). Universal strategy issues include: the place of relationship techniques in all interventions, problem solving, the ability to partialize (to break problems down into their component parts), giving informed advice, the place of insight-interpretation-reflection, the use of questions designed to refocus the work (Are we working? What are we working on?), issues of timing (including sources of time constraints), court orders, funding sources, and varied models of intervention. Succinctly put, advocacy is the act or process of supporting a cause.

With regard to case management, the job of the case manager is to work with clients to identify the type of help needed, to identify and overcome barriers to using that help effectively (a form of advocacy), to provide direct service to overcome those barriers, to connect the client with potential helpers, and to provide indirect coordinating services to maintain these connections until the problems are resolved (Ballew and Mink 1996). Case management has always had an implicit boundary-spanning perspective. By making it explicit, case managers can consider how crossing boundaries into other organizations and service areas requires relationship skills, strategizing, and deliberate knowledge gathering.

Group work skills are also important as tools for work with individuals, families, organizations, communities, in relating to other social workers, to interdisciplinary teams, and even in adversarial situations. Thus, group techniques from psychotherapy, problem solving, and community work are all part of the social work armamentarium. Likewise, skills for developing and implementing policy are vital if social workers are to maintain active involvement in policy debates and policy formation. The usual boundaries must be spanned in order to enhance client well-being, and health and mental health social workers must utilize a full panoply of interventions in accomplishing this goal.

Evaluation

Evaluating the relationship of the original planned goals and objectives to concrete measures of outcome after the work has finished is also critical. Evaluation typically entails looking back at the assessment, planning, and contracting/goal-setting stages to consider whether goals have been met and whether all targets of intervention have received service. Most frequently, social work departments gather this information systematically to enhance individual social workers' accountability to the departmental standards and to ensure the department's accountability to the entire organization (e.g., hospital, mental health clinic, etc.) within which they function.

Most often, departments and supervisors set target goals for accomplishment of the set worker/client goals. For instance, within a hospital, the social workers set individual goals with each patient as they plan for a successful discharge. The supervisor or department may set the goals for each social worker of having only one failed discharge (possibly defined as the patient not being ready for discharge as planned or being readmitted to the hospital in a short period of time) per month. Setting positive goals, such as "95 percent of the discharges per month will be successful," is encouraged.

Quality assurance requires evaluation of the particular work with the client system, evaluation of the individual social worker's effectiveness, and evaluation of departments as a whole. In differential discussion, at the end of work with each client system, social workers review all the decisions they made to structure work with the client system, and then they predict what they might alter the next time they work with a similar client system.

Conclusions

An ecological perspective serves the following purposes: (1) helping social workers to avoid linear, unidimensional, and single-motive thinking; (2) speaking to the social work value system; and (3) including multiple social work endeavours and all possible levels and kinds of information the social worker needs for understanding. Still, it does not help the practitioner to define levels and kinds of action. Even so, boundary spanning provides an ecological reinterpretation and enrichment of social work practice in health and mental health systems. It helps social workers to proceed responsively, flexibly, professionally, and efficiently to help client systems to enhance their well-being. The boundary-spanning perspective expects social workers to have a fine knowledge of history; legal and ethical issues; organizational and systems concerns; excellent relationship skills; and a wide range of assessment, intervention, and evaluation techniques, all of which are used to help a range of clients to reach their goals. Thus, a boundary-spanning approach to health-related social work extends over previously drawn barriers in order to afford social workers a greater scope of understanding, greater latitude in interventions, and greater access to organizations and systems. Boundary spanning in all these areas is critical to social workers' abilities to help their clients to reach their goals.

Reflection Questions

1. How does the concept of boundary spanning allow you to make a more comprehensive and complete assessment of clients' goals and capacities?
2. Think of a new way to use a mapping device (ecomap, genogram, organigraph, or systematic planned practice diagram) that will aid your work. Draw that mapping device.
3. In reviewing the practice example, how would you evaluate social worker Sophia Regal's work with her client, Donna Hauck? What would you do similarly or differently and why?
4. Are there laws that have recently been enacted in your country that affect the kinds of services that are available for certain groups of clients? Describe one such law and its effects on practice.
5. Give an example where your understanding of the organization or system in which you work expedited your work with clients.

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CHAPTER 3

SOCIAL WORKERS' RESOLUTION OF ETHICAL DILEMMAS IN HEALTH AND MENTAL HEALTH PRACTICE

Eileen J. Ain

Introduction

Inevitably all health and mental health practitioners face ethical dilemmas in their respective practices when there are two competing right ways to resolve a situation. Although both choices may appear good, one course of action is better so that no harm threatens the client's welfare (Linzer 1999). Yet, faced with many choices to take action in resolving an ethical dilemma in the health and mental health fields, how does the social worker proceed? Which guidelines, rules, laws, and theoretical foundations best support decision-making processes?

This chapter seeks to mark a beginning pathway on how to identify an ethical dilemma and processes needed for its resolution. The chapter's format begins with a case vignette of a dilemma faced by a social worker in a mental health setting in an urban hospital clinic. Then, the United States' National Association of Social Workers (NASW) Code of Ethics (1993, 1996, 1999) is briefly explicated. Next is a review of ethics theories related to social work and methods used to resolve the dilemma. This section also contains hypothetical actions of the clinical social worker described in the vignette. The conclusion of the chapter summarizes pertinent topics and focuses on the outcome ensuing from the resolution of the ethical dilemma.

As you read the chapter, please note an ethical dilemma or issue that personally carries apprehension, an ethical situation you might face, or a dilemma you are aware of in your health and mental health practice. Also consider how the case vignette, which is revisited in the text, provides perspective for resolutions of ethical dilemmas.

Health and Mental Health Perspective of Ethical Dilemmas

Organizational ethical cultures provide ground rules from which social workers begin to identify ethical dilemmas. In private practice too the ethics of the clinical relationship are based on the Hippocratic premise to do no harm and to provide the most benefit. Although the U.S. NASW Code of Ethics and other professional codes provide standards of practices, there are discrepancies in how organizations implement ethical standards and interpret processes needed to resolve ethical dilemmas. For example, in some settings, peer case reviews are not conducted to preserve client confidentiality, while in other settings, an informal peer review of cases is the norm, with the understanding that confidentiality is preserved among clinicians. In some areas of health practice, charting is designed to preserve anonymity about clients' HIV/AIDS status, whereas in other instances charts indicate if a client has been diagnosed with HIV/AIDS. Through these examples, we begin to see that there are different value systems in mental health agencies and health care facilities.

Although recent research in New York City and Israel indicates that the main types of ethical dilemmas in mental health and health relate to confidentiality, informed consent, and competency (Ain 2001; Linzer, Conboy, and Ain 2000a), it remains unclear as to what types of dilemmas exist in other settings and locations. Cases in adjudication at professional social work organizations involving, for example, sexual issues, competency of the practitioner, and treatment of impaired colleagues indicate that inappropriate practice ethics need rectification. As greater numbers of higher educational institutions and extended learning programs include ethics training in their programs, future social workers will learn philosophical orientations and guidelines to support their resolution of ethical dilemmas.

To anchor the learning processes that help social workers in resolving a dilemma, an example of an ethical dilemma in a health care organizational setting is given. Specifically, this dilemma occurred in a substance abuse treatment clinic funded through grant monies from a state university teaching hospital. The clinic's stated mission was to provide long-term treatment for substance abuse. In this particular treatment culture, one basic assumption is that substance abuse is a form of self-medication. Other assumptions are that change and transformation in people occur incrementally though in-depth analytical and experientially oriented treatment and that, in conjunction with treatment, the client's chosen behavioural method of maintaining abstinence is his or her responsibility. This innovative clinic also respects client self-determination and autonomy as clients explore psychosocial issues related to their addiction.

Case Situation, Part One: Ms. J. and Ms. B.

The dilemma occurred when Ms. B., an experienced social worker, was assigned to conduct an intake diagnostic session with Ms. J., a woman in her late thirties. As information was gathered, it came to light that Ms. J.'s lover, Mr. S., had previously been married to one of Ms. B.'s former clients. Mr. S. was now divorced. As the interview progressed, Ms. J. told Ms. B. that she wanted to have a baby. Although Ms. J. did not think Mr. S. wanted a child, she was determined to become pregnant and give birth. While listening, Ms. B. remembered that a peer therapist who had been treating Mr. S. revealed that Mr. S. was newly diagnosed with HIV. It seemed to the social worker that Ms. J. did not know about Mr. S.'s HIV condition. Ms. B. felt stunned as she realized she was facing an ethical dilemma in terms of confidentiality and the duty to warn (although she could not articulate this at the time). Ms. B. proceeded to conclude the interview after the assessment information had been acquired.

During the course of the day, Ms. B. became more perplexed about which action would do no harm and would be best for all. She asked to speak with her supervisor, Dr. T., a psychologist whom she had consulted for many years. Dr. T. recommended that Ms. B. seek a transfer of the case. His justification was that Ms. B. knew of Mr. S. through her sessions with his former wife and the peer therapist and was unable now to maintain professional distance in her work with Ms. J. Although Ms. B. accepted this decision regarding treatment for Ms. J., gnawing feelings lingered as she questioned her ethical role, especially with regard to Ms. J.'s wanted child.

As days went on, Ms. B. realized that Ms. J. was either unaware, ignored, or knew of Mr. S.'s HIV status and the potential risks to her own health. Furthermore, she considered it possible that Ms. J. could give birth to a baby infected with HIV/AIDS if there was no intervention. In this case, Ms. B., adhering to the NASW Code of Ethics rules of confidentiality, began to question her role in the case. She knew the case facts and about the relationship between the two clients and wondered if she had the responsibility to warn Ms. J. about the risk of HIV infection to herself and the baby she wanted to have with Mr. S. Was it Ms. B's duty, then, to warn Ms. J. with the intention of preventing the conception of a child possibility infected with HIV/AIDS?

Although this vignette alerts us to only one type of dilemma in mental health and health, other ethical dilemmas relate to truth telling, informed consent, managed care practices, whistle blowing, end-of-life decisions, living wills, competency, and genetic testing, among others. Subsequent professional behaviour may be affected by a social worker's choice between action or inaction in resolving an ethical dilemma. This will be discussed further as Ms. B.'s ethical dilemma is taken up later in the chapter.

Codes of Ethics

Social workers' ethical decisions will become increasingly difficult and complex as limited availability of funding and other resources lead to increased scarcity in services, technology continues to advance, managed care affects treatment protocols, and new, emerging social issues become a crucial concern for all. Ethical decisions function as a validation and reflection of social institutions and their laws, social policies, organizational rules, and indigenous cultural beliefs. These are all in a continuing state of change.

Five years after the formation of the National Association of Social Workers, a Code of Ethics was established. Since then, social work's Codes of Ethics has undergone periodic modifications and restructuring. At the 1996 Delegates' Assembly in Washington, D.C., the code's most recent draft was accepted (NASW 1996). This code, now in effect, contains 155 standards for sound ethical practice to guide professional conduct. The prescriptive rules of the code are sanctioned or authorized by long-standing custom or usage. For example, social workers can ask the courts to withdraw a subpoena or hold a hearing in its chambers to protect information about a vulnerable client. The code's proscriptive rules prohibit social workers from certain behaviour, such as engaging in sexual relationships with clients. With many social work Code of Ethics available on-line and in booklet form, it is possible and expected that social workers will read the code to guide and inform their practice (Ain 1997, 2001).

Review of Literature

Three topics are important to examine: the study of values (axiology), ethics theories influencing social work, and models for the resolution of ethical dilemmas. Social workers in health and mental health focus on human needs and help clients in defining relevant life choices. Conflicting value systems need to be openly and thoroughly discussed in relation to each situation so that decisions are made with care and attention. In fact, the more collaboration and deliberation that is possible for resolving the dilemma with knowledgeable others, the better. This is especially apparent when social workers must decide on behalf of clients which of two competing roles and actions within the broad context of the betterment of society is most appropriate for resolving ethical dilemmas (NASW 1999).

Values (Axiology)

Our values are powerful beliefs and judgments expressed cognitively, emotionally, or behaviourally. Values and the evaluations we make regarding the worth of any person, construct, action, or situation remain part of daily life situations and affect our behaviour (Reamer 1995). When we reflect on our actions, we begin to understand how deeply our behaviours are driven by value components (Levy 1993). The social work profession, with its professional value base, urges practitioners to also explore their personal value systems to become and to remain conscious of what drives their practice decisions (Lewis 1984). By considering individual and professional values and applying them to practice, social workers fulfill their unique duty to improve the welfare of society (NASW 1993).

Facts provide the necessary information to determine the outcomes of dilemmas. In Gordon's (1965) classic article about the relationship between facts and values, he states that facts are bits of information and values are powerful belief systems necessary for any action. Confusing facts for values, and values for facts, however, creates unnecessary hardship when deciding how to resolve a dilemma. Linzer's (1999) and Levy's (1993) assertion that ethics are values in action provides yet another means for understanding the place of values in ethical decision making.

All social workers, regardless of workplace or role, operate within the profession's values. These include honouring client autonomy; respecting human relationships; maintaining the dignity and worth of a client; challenging social injustice; providing service to vulnerable, oppressed, and impoverished individuals and groups; and ensuring that their duties are competently planned and administered (NASW 1999). While values guide the profession, the social worker's personal value system may sometimes conflict with professional and/or client values (Levy 1976a, 1976b).

For Levy (1972, 1973, and 1993), the social worker's value patterns have two functions: defining a direction of choice and constituting a commitment to action. In their view, social workers have a duty to understand their own and others' value systems as they engage in compassionate exchanges with clients in health and mental health practices (Palumbo 1976). Countertransference (an expression of social workers' unconscious responses to clients), when not brought into consciousness, is likely to be projected onto the client (Boesky 1995). Such projections, often involving values, can enrich social work practice, but projections can also cause harm when inappropriately acted out (Kelly and Strupp 1992; Levy 1976b).

As we reflect on the value systems shaping the behaviours of the actors in Ms. B.'s dilemma of confidentiality versus the duty to warn (described earlier), we realize that value conflicts lead to the ethical dilemma and drive its resolution. The following examples of varying psychological perspectives illustrate this point. A feminist practitioner might interpret Ms. J.'s desire for a child as an aspect of cultural manipulation of the female psyche, whereas another feminist practitioner might support the generic value of motherhood as a sacred profession (New York State Task Force on Life and the Law 1998). Still other social workers might see the unborn child as a fantasy of a healthy extension of Ms. J.'s need for affiliation. Those subscribing to a radical family therapy model might wonder why all of the players, including Mr. S., are not invited into a session to resolve the dilemma. Thus, value orientations need to be defined in relation to the resolution of the ethical dilemma.

In Ms. B.'s belief system, dignity and quality of life are assured to all, truth in relationships is upheld, and confidentiality is maintained. These values, in tandem with the social work profession's value system, also provide the basis for professional planning and expertise. Dr. T., an authority figure to Ms. B., implements his standards of practice and values of quality of care and maintenance of clear boundaries for Ms. J.'s treatment by removing Ms. B. from the case. Although she might be relieved not to have to address countertransferential issues arising in treatment sessions with Ms. J., Ms. B. is still left with a moral decision about whether or not to fulfill the duty to warn. The social worker needs to understand the role of beliefs and assumptions so that she or he can identify the different value orientations that drive the actors in the situation. With such information, resolving the ethical dilemma can be approached.

Theories about Ethics

Social work practice is influenced by ethical theory. When an ethical dilemma occurs, a choice must be made between two actions that are based on conflicting values (Linzer 1996). Four different theories of ethics are used in this article to justify decisions made about a perceived ethical dilemma: deontological theory, utilitarian theory, the theory of distributive justice, and the ethic of care.

Deontological theory refers to behaviours that are determined by the duty and ethical principles that force an action. Deontological theorists say that the action taken derives from the obligation and duty inherent in the relationship with the other. Implicit in deontological theory is the ethical imperative for action (Beauchamp and Childress 1989).

Referring again to Ms. B., and considering the ethical dilemma from a deontological theoretical framework, we would view her duty to warn as overriding the client's right to confidentiality. Ms. B. might be most concerned about maintaining confidentiality if, like some professionals, she viewed HIV/AIDS as a chronic illness maintained by a strict drug regime. She might possibly decide not to breach Mr. S.'s right to confidentiality by telling Ms. J. about his health status. Others, however, view HIV/AIDS as a deadly transmittable disease. Yet it is possible that a baby born to an infected parent could be virus-free. Some social workers, in accordance with deontological theory, might believe that the desired child should be born despite possible illness and under no circumstances should a fetus be aborted. Thus, the actions are driven by values and the social worker's perceived duty in the situation. As well, social work ethics guides and specific laws bind practitioners to act in a prescribed manner, even when their personal values might conflict with such action.

In utilitarian theory, principles that lead to the greater good for most of the people guide our judgments (Joseph 1989). Utilitarianism considers the moral judgments of the consequences of an act if it were to be performed (Lewis 1982). In utilitarian theory one continues to assess the problem as the variables change (Loewenberg and Dolgoff 1992). There are two aspects of utilitarian theory. In "act" utilitarian theory, our moral act is based on the usefulness of the outcome, whereas "rule" utilitarian theory follows moral rules (Beauchamp and Childress 1989).

Social work practice policy considerations are often based on utilitarian thinking, in which acting to achieve the greatest good for the greatest number is a guiding principle. Individual case examples might also be served by this theory. In applying utilitarian theory to our case situation, the "act" of breaching confidentiality applies to protection of the unborn fetus. The action taken would be aimed at maximizing the greater good.

Thus, Ms. B. would attempt to talk to Ms. J. about HIV-related illnesses and the need for Ms. J. to have a blood test to learn whether she has been infected. Ms. B. would discuss with her client the severity of the situation, explicitly breaching the confidentiality of Mr. S., another practitioner's client. The rule to do no harm and to warn the prospective mother follows the moral rule that both the mother and the child must be protected and society's standards of social welfare in the community upheld. Yet, before taking any action, the case must be reassessed in terms of the prospective mother's emotional responses. One is not sure if Ms. J. would bring harm to herself, or whether or not she would accept changing the rules for confidentiality, or accept the reality of mandatory testing for HIV/AIDS. The steps involved in resolving a dilemma require that all the factors be carefully weighed. That which is better for all or most, however, is not necessarily applicable to a specific case.

Rawls's (1981) theory of distributive justice, which encompasses social work's core values of social justice, integrity, dignity, and worth of the person (NASW 1996), is the third theoretical orientation. In his theory, Rawls has "directly (and indirectly) influenced every facet of professional social work and his work has become the profession's 'organizing principle'" (Wakefield 1988, p. 193). While there have been many interpretations of his theory, the focus here is on how a hypothetical contract provides a "moral foundation for a liberal welfare concept of justice" (Sterba 1995, p. 1310).

Rawls sets out two basic assumptions. First, in a just society, the greater good guiding judgment cannot deny that the liberties of equal citizenship are taken for granted. Second, the rights secured by justice are "not subject to political bargaining nor to the calculus of social interests" (Rawls 1967, p. 253). These assumptions follow from the premise that all who enter into a contract about a just society are rational, free, and independent people who have agreed on their original position of equality (Wakefield 1988). That is, the contractees choose together in one joint act, without knowing the other, which will count among them as just and unjust (Rawls 1981).

In this orientation to resolving ethical dilemmas, the standards of society and the dignity and worth of each person are upheld. The actors in an ethical dilemma enjoy equality with one another based on their actions within a societal contract arrangement. For example, Ms. B. might envision a just society where there is access to health care, no moral and prejudicial aspects of HIV/AIDS, and equality of all people, and these are considered just by a rational people who have agreed that these features are a means to eradicate HIV/AIDS. Thus, the dilemma would be differently weighted and considerable discussion of social policy would be included in the decision.

The fourth theory is the ethic of care, also known as relational ethics. Relational ethics gained prominence in social work practice and philosophy, especially as the women's movement evolved in the last few decades (Freedberg 1993). This theory is often contrasted with Rawls's contract theory of distributive justice. The ethic of care assumes that the psychological logic of relationship is paramount in all acts and differs from other theoretical approaches to justice (Gilligan 1982). Using the ethic of care model for decision making about ethical conduct fits well with feminist social work principles, stressing the end of patriarchy, empowerment, attention to process, viewing the personal from a political perspective, respect for both uniqueness and diversity, validation of intuitive understanding and use of consciousness raising and praxis (Bricker-Jenkins and Lockett 1995).

Carol Gilligan's work (1982) exemplifies the basis of this theoretical framework. The data from her seminal studies show that women construct moral problems based on care and responsibility for relationships. In the case situation, Ms. B. would be guided by the relationship she has with the other actors in the case. This differs from moral justice, which is based on the logic of equality and reciprocity, with its moral problems of rights and rules. For social workers and others, the ethic of care "reflects a cumulative knowledge of human relationships and that self and other are interdependent and activity of care enhances both others and self" (Gilligan 1982, p. 74). Thus, relational ethics provides a theoretical construct to view ethical dilemmas within social work's powerful value of respect for relationship (NASW 1996).

In our case scenario, Ms. B. would attempt to find a means that Ms. J. could feel empowered through the therapeutic alliance. Through this relationship, Ms. B. can support Ms. J.'s ideas about developing a relationship, whether with the social worker, Mr. S., and/or the wanted child. Depending upon the practitioner's values and orientation, the goal of relationship development may be fostered, yet in this theoretical framework, they become the prime focus in the process of resolving ethical dilemmas.

Models for Decision Making and Resolution of Ethical Dilemmas

Ethical dilemmas emerge from values in conflict and can be resolved through deliberate process of decision making (Linzer 1996). Loewenberg and Dolgoff (1992) note that choices are influenced by preceding ethical decisions and lead to new bearings. Ethical dilemmas demand decisions; they cannot be ignored and not making a choice can sometimes be just as harmful as making the wrong choice. A no comment/no opinion approach does not mean value-neutral objectivity, and can be a passive means to avoid the dilemma. Principles of ethical decision making, thus, direct all parties concerned to seek a well-considered, determined resolution of the conflict (Yelaja 1982).

When social workers resolve ethical dilemmas, many variables affect the decision-making process. Reliance on prescriptive and proscriptive provisions of codes of ethics, ethics education, moral reasoning, awareness of conflicts in personal and profession values, agency policies, the culture of the agency, public policies, and adherence to the laws of the land are among the many factors that influence the social worker. In the end, when the social worker does make the decision after rank ordering ethical principles to resolve the dilemma, moral questions invariably remain (Nozick 1968).

This author concurs with Levy's (1993) premise that each ethical circumstance in social work requires the art of professional discretion. Subsequently, sole reliance on the NASW Code of Ethics (or other codes) is rarely the final word on content or formulation of decisions during resolution of a particular ethical dilemma. Levy (1993) states that "neither the imperatives of science and scientific method, nor the realities of law—which must of course be taken into account and related to—exempt the social worker from the art, which constitutes a critical component of professional practice" (p. 130).

To move through the maze of variables in decision making, six models that guide social workers' resolution of ethical dilemmas are discussed. Although there is repetition and overlap, each model presents a viable approach that can be used to resolve ethical dilemmas.

The first is Beauchamp and Childress's (1989) model based on a medical bioethical framework. Practitioners applying this model must retain an element of skepticism about advocating any order of hierarchical principles when resolving an ethical dilemma. Further, while moral reasoning might prevent the use of intuition as a means of resolving a dilemma, intuition is never eliminated as a factor in assessing an ethical dilemma. Two basic assumptions underlie Beauchamp and Childress's guidelines: The social worker is knowledgeable about utilitarian and deontological theory, and the actors involved in the ethical dilemma can be readily identified by the social worker.

Beauchamp and Childress's (1989, pp. 26–41) four-part sequence for the resolution of an ethical dilemma relies on deontological and utilitarian ethical theories, use of a moral code, a system of rules understood as principles, a statement of moral rules that extend beyond the individual, and the particular judgments and actions that the individual chooses to place belief systems into effect. Therefore, actions are justified by rules, which are justified by principles and supported by theories that legitimate the decision as rational and ethical.

Following this model, Ms. B. would first examine the value conflicts inherent in the decision to breach confidentiality and the duty to warn. Each action she takes would be justified by the rule to do no harm, further justified by the principle of duty to warn, and supported by deontological theory, which stresses that the action's consequence is less important than the duty to act. Ms. B. also needs to consider that Ms. J. and other parties might potentially be harmed through breaching confidentiality, thereby having a destructive effect on others. This would result in the reverse of utilitarian theoretical treatment. This brief overview of Beauchamp and Childress's model always considers, as do all other models, that which is best for the client in the context of the general welfare of society.

The collaborative model is based on the International Federation of Social Workers' (IFSW) and Fall's (1994) training for resolutions of ethical issues and problems. It asks that individual social workers bring ethical dilemmas into a collective organizational setting with peers, experts, and actors affected by the ethical decision, where they discuss, analyze, and consider the issues (Fall 1994; IFSW 1994b, Provision 2.4). The social worker then receives advice and options for resolution. For example, if the ethical principles of social work conflict with a country's legal system or local policy, the IFSW Code of Ethics recommends that the social worker adopt particular ethical standards for the specific field in which the dilemma exists (Fall 1994; IFSW 1994b, Provision 2.2). The adopted standards could then provide a basis for ethical decision making. In the collaborative model, five guidelines inform decisions: the basic provisions of the Code of Ethics; the context of the action, including ethical, moral, and political analysis of the values and forces that frame the conditions for the action; the motives of the action, including the aims and intentions of the social worker regarding a course of action viewed from an abstract level and analysis of the nature of the action based on its moral content (i.e., use of compulsion, cooperation, guardianship, paternalism, participation, or autonomy); and, lastly, analysis of the long- and short-term consequences and effects of differing actions on all parties (Fall 1994; IFSW 1994, Provision 2.2).

In this case, Ms. B. needs to bring her concerns for the resolution of the dilemma to an ethics committee and/or to her peers for discussion rather than trying to resolve the ethical dilemma on her own. Ms. B. first prepares a comprehensive history of Ms. J. and gathers information on the facts about transmission of HIV/AIDS in newborns and programs that support partner notification of HIV/AIDS status. Ms. B. also works through her own feelings about the case and considers what might be best for the client. With all of this information, Ms. B. begins to deliberate and take action.

The third model supports the resolution of ethical dilemmas is a six-step paradigm developed by Levy (1993). The first step in the process is to identify the principles of ethics applicable in the practice situation and to whom (or to what) they are applicable. The next step entails justifying the order of priorities when ranking principles of ethics to the people and interests involved in the situation. In the third step, the social worker anticipates the risks in and possible consequences of making ethical judgments. Exploring compelling factors and values that might override the principles of ethics in the practice situation comprises the fourth step. In the fifth step, the social worker tries to anticipate and prepare for the consequences of ethical judgments and actions. The sixth and final step is evaluating ethical decisions and actions. Through the steps in this model, social workers explore past, present, and future ethical issues and their effects on persons and institutions.

In Levy's paradigm, Ms. B. must first identify whether or not prioritizing the maintenance of confidentiality over the duty to warn will do no harm, the first principle of ethical decision making. Ms. B. needs to articulate potential harm and the consequences of taking action for all those who are involved. These actions, based on anticipated physical harm to the fetus and mother, also include the possibilities of psychological harm to the Ms. J.'s psyche and to the welfare of society. Levy differs from other ethics theorists in his assertion that the practitioner must explore the dilemma in relation to the laws of the land and other structures that may decide its outcome. For example, confidentiality laws explicitly state that treatment data is privileged information. So, if Ms. B decides to breach confidentiality and override this law, she needs to justify her actions. She prepares herself for whatever consequences ensue by prioritizing her principles and demonstrating that her actions prevent a threat to life.

Before looking at the next theoretical framework, consider that when social workers encounter conflicting duties, they rank-order rules that apply to the situation with the condition that rules override the duty to not coerce others. For example, because Ms. B. knows that Mr. S. has a life-threatening, sexually transmitted disease and is having unprotected sex with a partner who is likely uninformed of his condition, the social worker must consider overriding the client's autonomy and self-determination. The rules that define a social worker's actions function to prevent serious harm and set guidelines to protect clients and society.

Reamer (1995a) developed six abbreviated guidelines, reflecting Gewirth's philosophical stance, as guidelines for the resolution of ethical dilemmas. The first is that the rules against action that harms a client are of greater importance than other rules against lesser harms. Returning to the case situation, Ms. B. must consider who the client is and which rules are relevant to the client's compromised situation. Next, Ms. B. must consider whether the basic social value of a client's right to self-determination has greater worth than his or her right to basic well-being. This step can be interpreted in many ways depending upon the value system of the actors in the ethical dilemma. Ms. B. might warn Ms. J. so she can determine a course of action that is based on essential information.

Reamer's (1995a) third guideline is that the social worker is obliged to act so that laws obeyed take precedence over other laws that may harm the client. In this case, Ms. B. is obliged to research the prevailing laws related to confidentiality and the duty to warn in order to make an informed decision concerning protection of life. The fourth step is to focus on the client's rights to well-being within laws, rules, regulations, and the service setting. In this step, Ms. B. considers what will bring about well-being to all (or most), applying either an act or rule utilitarian theoretical frame to help her decide on a course of action. Fifth, the obligation to obey laws, rules, and regulations to which one has consented ordinarily overrides one's right to act in a manner that conflicts with these laws, rules, and regulations. Lastly, the obligation to prevent basic harms and to promote the public good has greater weight than the right to complete control over one's property (Reamer 1995a).

Both Reamer and the International Federation of Social Workers' Code of Ethical Practice urge social workers to talk about ethical dilemmas encountered with people who are able to understand the conflict and offer insights and knowledge. Reamer, representing the school of utilitarian ethical theory (M. Joseph, personal communication, April 1996), concurs with Levy that "the very nature of guidelines is such that applications of them to individual cases inevitably require considerable interpretation, speculation, and inference" (Reamer 1995a, p. 60).

Linzer's (1999), Levy's (1993), and Reamer's (1995a) respective uses of the bioethical, paradigmatic, and Gewirth theoretical models offer different guidelines for resolving ethical dilemmas. The last model presented, developed by Congress (1999), relies on the acronym, ETHIC to expeditiously guide the social worker to resolve an ethical dilemma. Congress instructs the reader that the letter *E*, referring to an examination of the values of all relevant actors, begins the process. The next letter, *T*, pertains to thinking about how the ethical standards of the NASW Code of Ethics, relevant laws of the land, and court cases might affect the decision. *H* is for hypothesis, developed to predict the consequences of the actions. The letter *I* denotes the need to identify which parties might be harmed and which might benefit from the decision. The last letter in the acronym, *C*, stands for consult. The social worker "consults with supervisor and colleagues about the most ethical choice" (Congress 1999, p. 33).

Using this model, Ms. B. would begin by examining (*E*) the values of all parties in the dilemma, including the values of the social worker who revealed that Mr. S had been diagnosed with HIV, Dr. T., who recommended transferring the case, and Ms. J., among others. In addition, she would think (*T*) about how the NASW Code of Ethics provides support and sheds light on the right to confidentiality and the duty to warn in relation to this situation. Ms. B. might hypothesize (*H*) that all parties were choosing to avoid the issue, at least to some extent. The social worker identifies (*I*) interventions that stand to benefit, not harm, the most vulnerable people involved in the dilemma.

Conclusion

So that no harm is done and the outcome of actions best serve the needs of clients and the betterment of society, social workers need to examine many aspects of values and ethics to identify and resolve ethical dilemmas. Ms. B.'s hypothetical actions exemplify some approaches to the dilemma of confidentiality versus the duty to warn. This dilemma, along with those based on ethical principles of autonomy, beneficence, social justice, and the tenets of liberty, are commonly found in health and mental health practice, and related public social service areas.

The intent of the chapter was to help readers enhance awareness of their perceptions and hypothetical actions by tracking the case of Ms. B. It would be useful for readers to select and apply an ethical issue that they might have faced, while exploring various ethics theories and models for resolution of ethical dilemmas. This learning method invites ongoing review and hopefully motivates readers to learn more about advanced ethics topics relevant to social work practice.

Each ethical dilemma is a unique situation with its own set of participants within the culture of a social service organization. From this perspective, it is possible to appreciate how the steps taken to resolve an ethical dilemma assume a changing hierarchical order of priorities that require social workers to more clearly understand judgments, rules, principles, and ethical theories that guide the process of resolution. Ms. B. came to understand that confidentiality could be breached, especially with public polices in place concerning newborns infected with HIV, but we might also ask what might be the penalty for this action and who might be harmed? Even though Ms. B. considered the dilemma resolved, priorities in decision making could have shifted with newly gathered information and the passage of time. The social worker may then need to revisit the situation, reflecting, intervening, and seeking further knowledge to make decisions about new actions.

In the processes that social workers use to resolve ethical dilemmas, intuitive feelings and hypothetical questions often lead to similar responses. Simultaneously exploring these two resources often brings to the surface belief systems we may find hard to admit and underlying value conflicts may result. The professional social work Code of Ethics, the laws of the land, court cases, case studies, and on-line resources can also enhance the resolution of a particular ethical dilemma. Lastly, and according to research by Linzer, Conboy, and Ain (2000b) and Ain (2001), all social workers, in intervention at any level of practice, need opportunities to discuss ethical dilemmas in a collaborative or supervisory environment characterized by trust and respect.

In the case vignette, Ms. B. found herself in an untenable position when she realized the difficult issues in the existing relationship between the client and her partner and the potential for harm. As she reflected, Ms. B. realized that discussing safer sexual practices with Ms. J. and the need for HIV testing in all sexual relationships could have promoted client-practitioner collaboration on health protection and prenatal care. Although this approach would not focus solely on Ms. J.' s individual situation, it could have alerted Ms. J. to the ongoing health issues of Mr. S. without implicating any other people. Ms. B., however, did not take this course of action nor address the existing health issues.

Case Situation, Part Two: Ms. B. and Ms. J.

Ms. B.'s sense of moral responsibility lingered. She had to take responsible action, was unsure how to begin, and decided to consult with Dr. T., a psychologist. Dr. T. said that Ms. B. need not focus on acting for the greater good, but this left Ms. B. with distressing feelings about her duty in the case. Ms. B. continued to think about the ethics involved in the case. Her peers were also at a loss as to the best course of action.

To her credit, Ms. B. persevered in her research and discovered a foundation whose mission it was to involve social activist lawyers with HIV ethical issues. Ms. B. took some hours from work and the lawyers mentored her in laws of confidentiality related to HIV and available programs that supported her decision to inform Ms. J. about the possibilities of HIV as a health issue for her. They developed a strategy to urge Mr. S.'s current therapist to locate a partner notification program for Mr. S. to attend. Ms. B. monitored and followed the implementation of the plan to ensure that Mr. S.'s therapist would work with them. Eventually, truthfulness in relationships became a treatment theme for

Mr. S. and he told Ms. J. of his HIV status. Only then could Ms. B. derive satisfaction from the fact that the dilemma had been resolved.

In conclusion, Ms. B. followed her intuition and hypothesized the outcome before taking any action to resolve the dilemma. She explored the laws of the land through consultation with a team of lawyers that specifically addressed these types of ethical issues and learned other options besides breaching confidentiality or directly warning Ms. J. Consulting with this group supported Ms. B., helped her to realize her ethical responsibilities, and take action even when her views were not shared by others.

Reflection Questions

1. Describe a hypothetical or existing ethical dilemma you face or have faced in health or mental health social work. Identify the actors and the conflicting values involved. Propose at least five steps to resolve this dilemma and consider the consequences of each step.
2. What, if any, conflict exists between your personal and professional value systems that can affect you in your field of practice?
3. As you read through the hypothetical resolution of the case situation, what did you think about Ms. B.'s attempts to resolve the dilemma? What would you do differently?
4. What technological and professional resources are available to resolve an ethical dilemma in your practice setting? For example, do you first consult with colleagues and supervisors? How can on-line research of court cases and laws support steps to resolve the dilemma? Is there an ethics committee at your workplace or a similar group in your professional organization?
5. How does your country's Code of Ethics for social workers, national laws, and the Code of Ethics of the International Federation of Social Workers influence ethical decision making in social work?

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CHAPTER 4

A DEVELOPMENTAL APPROACH TO SOCIAL WORK PRACTICE IN MENTAL HEALTH:

Building on Strengths

Len Spearman

Introduction

A seminal definer of social work practice is the twin emphasis upon people's problems, which are often conceptualized as deficits or pathology, and the importance of understanding and working with people's strengths. Historically, even the earliest social workers (e.g., Richmond 1917) articulated approaches that emphasized both working with deficits and strengths. This chapter is about understanding and developing the strengths of people who suffer from mental illness while recognizing that, in social work practice, this focus co-exists with a view that stresses treatment of deficits.

More specifically, the central theses of this chapter are that:

1. understanding people's strengths is a critical part of all practice, particularly in mental health
2. a strengths perspective leads to a developmental approach to practice
3. enhancement of social supports is one of two essentials in the treatment of mental illness and is foundational to the strengths perspective
4. social workers who practise in mental health settings can best define their roles by using a strengths perspective and a developmental approach

Deficits and Strengths

To discuss the differences and relationship between deficits and strengths, I will first distinguish between perspectives and approaches. A perspective refers to a particular way to view or understand part of the social and human world. It includes the concepts and theories that share the view and assumptions of the perspective. In social work, a perspective guides and shapes the assessment process. It establishes a framework for assessment.

An approach flows from a perspective and is a way to intervene or help people. Thus, this chapter argues that a strengths view (perspective) of the human world leads to developmental social work practice (approach) that emphasizes growth. Table 4.1 expands on these ideas by describing the connections. If assessment emphasizes and focuses on deficits, then intervention almost certainly becomes primarily restorative (restoring to earlier functioning). On the other hand, if assessment focuses on strengths, then the intervention that results from the assessment should be essentially developmental.

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Deficits and Social Work Practice

To begin, let's explore how we view the nature of the problems. In an effort to engage in problem solving with clients, do we emphasize people's deficits or strengths? And, as argued, the emphasis of assessment determines the type of approach used, which would be either restorative or developmental.

The concept of deficit is akin to the medical use of the term "pathology." (For examples of usage of the concept of deficit, see Cowger and Snively 2002; Goldstein 2002; and Saleebey 2002a). Essentially, understanding the pathology of a disease means understanding what is wrong. In medicine, it is widely viewed that if the pathology of a disease is known, then the disease is better understood and an effective treatment or even prevention is more likely to be developed. This is a powerful model, based on science that connects treatment with understanding causes (etiology) of an illness. The better the causes are understood, the more likely it is that effective treatment can be given.

Similar logic applies to the social work world. Emphasis upon deficit means that the worker attempts to understand problems by looking for and understanding "weaknesses" or "limitations." The focus, as in medicine, is on what went wrong. Once the deficits (what went wrong) are understood, the worker can then begin to take steps toward solving a problem. Hence, a view of practice that focuses on deficits is a social work construction of the medical model. Many helpers, including social workers, thus construct people's problems in terms of deficits or deficiencies.

Strengths and a Developmental Orientation to Practice

The heart of the strengths perspective consists of a core of ideals that guide practice. The strengths perspective and the development approach that results from it uses people's own resources in order to help them meet four goals: to grow as humans, to enhance quality of life, to develop their own problem-solving skills, and to deal with stress and adversity.

In order to meet these goals, the developmental approach capitalizes on people's own "capacities, vitality, abilities, talents, courage, and power" (Heinonen and Spearman 2001, p. 213).

The strengths perspective has been an important part of social work from the beginning of the profession, but until recently, it has been poorly articulated. This is now beginning to change. In 1992 Dennis Saleebey published a collection of writings (revised in 1997 and 2002) that he titled *The Strengths Perspective in Social Work Practice*. The work is important because it draws together a group of concepts, views, and ideas into a clearly articulated perspective. In the 1990s others (e.g., Anthony 1993; Degan 1988, 1996; Frese 1993; and Moxley 1994) promoted a view of psychiatric intervention in mental illness that emphasizes learning how to focus on quality of life despite a long-term mental illness. While these authors, whose background is in psychiatry or psychology, label this process "recovery," it is really a developmental approach to intervention based on building on patients' strengths.

Similarly, many of the concepts from other perspectives fit well within a strengths perspective. For example, empowerment, which is important in feminist social work and structural social work, is also at the core of the strengths perspective.

Developmental vs. Restorative Practice in Mental Health Settings

As implied in Table 4.1, professional intervention usually takes one of two forms. Probably the most common is restorative and is central to the medical model and problem solving. In a restorative approach, the helper (physician, therapist, social worker, etc.) attempts to return (restore) a patient or client to a healthy, "original" state. A physician does this when treating a patient for a disease. Many psychological and psychosocial therapies are restorative in nature.

A developmental approach to practice is fundamentally different. Instead of attempting to return the client to a former (healthy) state, the focus is on the promotion of growth. This type of practice sometimes holds that promotion of growth will, probably indirectly, enable the patient (client) to return to a healthy state; that is, attaining strength through growth will help fight the disease process.

Another proposition of a developmental approach refers to the concept of "recovery." Many times people are faced with long-term illnesses or injuries in which there is no foreseeable cure. However, this does not mean, as often thought, that the illness is an all-consuming factor in the person's life. A productive life and satisfactory quality of life can continue even in the presence of illness. It is possible to recover from the devastating effects of illness or injury. People are remarkably resilient. Recovery to a productive and satisfying quality of life is possible. The concept of recovery (Anthony 1993; Moxley 1994) is often used in this sense.

Restorative practice tends to assume that if a deficit is successfully treated, then the person will again be able to achieve a good quality of life. If medications for depression work, health is restored and one's quality of life will increase. Developmental approaches tend to assume the opposite approach. That is, if people's strengths can be increased, then their ability to handle deficits, stress, and adversity will also increase. For example, if a client successfully completes a training program that leads to a good job, then self-confidence may increase and the ability to handle depression and other adverse situations will likewise improve. In mental health, both restorative and developmental practice are important. One without the other usually leads to flawed intervention.

Developmental approaches are particularly suitable for use by social workers. In developmental practice, the role of a social worker becomes that of an enabler, teacher, counsellor, advocate, and supporter rather than that of a therapist who focuses on restoration. Empowerment is an important goal. The worker strives to help people take charge of their own lives because people, not professionals, manage their own illnesses and recovery. The role of case managers is not to "manage clients' lives" but to help them find ways to manage their own lives. Clients should, within limits (see the next section), be free to choose the type and kind of therapy, if any.

Principles of a Strengths Perspective and a Developmental Approach

An important set of principles that underpin a strengths perspective and developmental approach has emerged. The following is a brief summary of some of the most important.

Humanitarian and egalitarian ideals: First and foremost, the strengths perspective requires a deep commitment to and a profound respect for foundational social work principles, and the promotion of both humanitarian and egalitarian ideals. Humanitarian ideals are based on fundamental respect for the worth, dignity, and inherent rights of all people. They assume that all have the right to achieve their maximum potential.

The term "egalitarian" is synonymous with equity. All people are equal and should have the same rights and privileges as fellow citizens despite differences in race, culture, spiritual beliefs, sexual orientation, ability, gender, or other such defining characteristics. Explicitly, egalitarian ideals assume a democracy and the right of all to participate in the democracy. These two ideals are primary and fundamental to practice (also see CASW 1994; Heinonen and Spearman 2001; Mullaly 1997, p. 27; NASW 1997). All of the remaining principles flow from these two ideals.

All people have strengths: The strengths view holds that all people, families, groups, and communities have strengths, vitality, and assets. While at times these may seem hard to find, good practice requires social workers to vigorously explore and understand strengths with a view to helping clients maximize them (see Saleebey 2002a, p. 14).

Empowerment: This concept is in danger of becoming meaningless because of divergent interpretations, yet is a central tenet of good social work practice. Empowerment is not something someone can give. It is not an intervention or technique. Rather, it describes a process and a right of people. It implies that people take charge of their own lives, assume control, and make decisions from a set of reasonable choices. Practitioners can help people assume personal and social power. Empowerment practice assumes that social workers have a strong commitment to principles of democracy and emphasize growth and development (Dubois and Miley 1996).

Belonging and social support: Belonging is based on the knowledge and conviction that in order to sustain a good quality of life, people must not only be members of groups (including families) but must feel that they belong. Saleebey (2002a, pp. 10–11) calls this membership. The strengths view assumes that for humans to grow, it is necessary for them to form good quality, supportive relationships with other people.

This principle has enormous implications for developmental approaches. All people need supportive relationships. If people with serious problems lack quality social support, then recovery is difficult. Putting it in another way, to address their own problems, people require social support.

Relationships are the foundation of a developmental approach and are reciprocal: This principle is closely related to belonging. Most social work interventions hold that a trusting, mutually respectful relationship between worker and client(s) is necessary. Further, relationships are not one-sided. To be successful, all parties in the exchange must not only benefit from the interaction but must also contribute to it. Reciprocal relationships are necessary for people to gain a sense of belonging and membership. Further, this principle supports the tenet that helping best takes place when there is a collaborative relationship between client and worker (see Saleebey 2002a, p. 16).

Resilience: Resilience is the ability to "bounce back" from adverse and difficult life experiences. Far too often, professional helpers assume that people who have experienced stress or trauma are likely to succumb to the experience; that the "natural" reaction is pathological. Saleebey correctly argues that this assumption is faulty. People are inherently resilient. Consistent evidence (e.g., Saleebey 2002a, p. 11; Shulman 1999, pp. 67–73; Wolin 1993) shows that people are fundamentally resilient. A strengths perspective holds that good social work practice recognizes this resilience and promotes and builds on it.

Healing and wholeness: These two concepts directly connect to resilience. Healing implies wholeness. The natural tendency is to attempt to heal after one has experienced adverse situations (Saleebey 2002a, pp. 11–12).

Reframing: Reframing is a concept that alters the understanding of a problem. Framing refers to the spin or slant placed upon the definition or interpretation of a problem. It is how a problem is cast. For example, some may see poverty as the result of a faulty economic system. Others may see poverty as the result of individuals' deficits or failings. "[Framing] sets out preferences and prescribes limits based on ideologies and experiences, but refrains from the explicitness expected of a definition [of a social problem]" (Wharf and McKenzie 1998, p. 41).

Reframing refers to the social worker's attempt to change or alter the frame of a problem. This has specific utility in a strengths perspective. Reframing is used here to mean altering the frame of the problem from its conceptualization as a deficit to casting the problem as an opportunity for growth. Very frequently problems are cast as deficits. Often a primary task of a strengths-oriented social worker is to reframe the problem as a strength.

Reframing is closely tied to the principle that adversity and trauma may present opportunities for growth. Certainly, adversity can lead to damage and injury in a person. Most certainly, a deficit approach makes this assumption. However, Saleebey (2002a, p. 14) strongly argues that often adversity can lead to personal and social growth. Skilled social workers search for these opportunities.

A developmental approach strives to be consumer-driven: Consumer-driven means that the client (mental health service consumer) is in charge of the helping process. This principle is not absolute, particularly in mental health. Often workers are faced with situations in which they must make decisions for clients and apply methods of social control. Often this occurs when a client (or patient) is considered a danger to herself or himself or to others. A strengths view strongly promotes a consumer-driven approach, but is constrained by client's capabilities.

Within these limits,

> A consumer driven approach starts with the deeply held value, closely related to self-determination, that adults have the capacity and strength to make life decisions by themselves without interference from professional helpers. This is so even if the worker believes that the client has made the wrong decisions. Among other things, this means that clients can choose whether they need help, who is to provide the help, and how it is to be provided. The worker, while still an expert, is seen more as an advisor or consultant. (Heinonen and Spearman 2001, pp. 217–218)

The helping process is clearly client-oriented.

Assumes that the upper limits of a client's capacities for growth and change are not known: Many mental health professionals believe that they know what is best for clients; that their professional knowledge can recognize clients' capabilities and hence they can decide what is best for them. Often this is done to protect clients from failure.

A strengths perspective and developmental (growth) approach to practice seriously challenges this assumption. Too often, it seems, professionals use their expert knowledge to unnecessarily limit client goals and capacity for growth (see Saleebey 2002a, pp. 15–16).

Embedded in these principles is rejection of a focus on weakness, limitations, deficits, and pathology. Instead the focus of intervention shifts to development and growth. The view that "strengths" intervention is really a developmental or growth process helps to sharpen the distinction between restorative intervention and developmental or growth-oriented intervention.

The Strengths Perspective and Mental Illness

A central thesis of this chapter is that the strengths perspective is particularly suited for work with those who have a mental illness. This is so even though much of the work with mental illness involves limiting clients' rights.

Case Situation: Karl

This section uses a case example to illustrate the strengths perspective. The first part of the case shows a mostly restorative approach followed by a more extensive illustration of some of the principles of strengths and developmental approaches.

Karl was diagnosed with schizophrenia a few years ago. He is intelligent, has reasonably good insight about how the illness and medications affect his life, and desperately wants to achieve his goals in life. He calls it a way to "get ahead in the game." He sees his short-term achievement as getting a university degree. In the long run, he wants to be an accountant.

Karl's thinking is sometimes bizarre to others. Often his thought processes seem confused. This was first noticed by a high school language arts teacher, who could not really tell if Karl's essays were creative or the products of confused thinking. Either way the teacher could not understand his writing.

The teacher consulted with the school social worker, Nikki, who agreed to see Karl. The worker concluded that indeed he seemed to be confused and Karl, 17 at the time, admitted to hearing "something talking to him." This did not seem to alarm Karl because he thought everyone must experience this. The worker also retrieved Karl's recent school marks and could see a drastic decline in his grades, particularly in the past six months.

Nikki, who was beginning to sense a major problem in the early stages of development, received permission from Karl to talk to his parents. As the worker expected, his parents described their son as increasingly becoming a loner. He shunned his friends, some to whom he had been close for 10 years or more. Even more alarming to his parents was that Karl seemed "to be suspicious of everything, even the letter carrier." Karl would hide when he heard the dog bark, which signalled the arrival of the mail.

Nikki felt she had enough information to refer Karl to a psychiatrist. Karl's parents were supportive but perplexed. The worker received permission from Karl and his parents to make an appointment with a psychiatrist. Nikki was satisfied that with supportive parents and the help of a psychiatrist, Karl would improve. Karl continued in school, but did not see Nikki again. The only further action that Nikki took was to make sure that Karl kept his first appointment with the psychiatrist.

The psychiatrist diagnosed Karl as having a form of schizophrenia and placed him on a mild anti-psychotic drug. She also arranged for counselling from a psychologist. The thrust of the counselling was first an attempt to find out from Karl the factors in his childhood and relationships with his peers, parents, or others that could account for the pathological behaviour. Once understood, Karl could gain insight into his condition and thus work through past experiences that were traumatic.

The above interventions are restorative. Nikki's focus was on understanding Karl's deficits. The closest she got to understanding his strengths was to conclude that Karl had supportive parents. Nikki did not make much effort in understanding Karl's strengths nor those of his parents. If she had done this, the intervention may have been different. While the psychiatric referral was still very necessary, Nikki did not ensure that Karl's social support was continued and did not fall apart, which would have long-term consequences.

The psychiatrist, consistent with her training, saw the mental disorder as a pathology and prescribed medications. She also saw the need for further counselling, and chose to refer Karl to a psychologist. Like the psychiatrist, the psychologist also defined Karl's problems as pathology, but unlike the biologically oriented psychiatrist, defined the pathology in psychological and social terms.

Six months later Karl was much improved. He was restored to his former state of health. The psychologist had helped him understand his illness and its etiology. The medications had done their job and the psychiatrist began the process of dosage reduction. Karl's teacher now thought his essays were not only clear, but creative. His parents were relieved that he was no longer afraid of trivial events such as the arrival of the mail.

Two years passed and Karl was in his second year of university studying business management and administration. He had a few friends and was still living at home. His father was close to retirement, but was beginning to have health problems that increasingly became a strain for his mother. Karl no longer saw his psychiatrist. One evening, at a student party, he heard a voice somewhere in the background tell him he that he was in danger. This happened only two or three times, was not specific, and quickly disappeared. Nevertheless, it concerned the young man. The voice did not recur until about two weeks later.

Now, they told him that his classmates were evil and would not allow him to understand the exam. They wanted to outdo Karl so that when graduation time came, they would get the best jobs instead of Karl. Karl screamed, threw his papers on the floor, ran into the student lounge, and began throwing furniture. The campus police were called and Karl was hustled to the emergency ward of General Hospital.

The schizophrenia had returned with a vengeance. Karl was openly and severely psychotic. The only positive thing that happened to him that day was that he met with his old psychiatrist whom he had learned to trust. However, he was very agitated and his fear was increasing to the point that the psychiatric resident was considering using restraints on Karl if medications did not calm him down. Fortunately, the medications had a soothing effect.

Karl was placed on a regime of anti-psychotic medications that were more powerful and had more side effects than the medication he took earlier. Within a few days Karl was calm, showing neither signs of hearing voices nor fear of them. He was, however, very quiet and withdrawn. This pattern continued and deepened. He did not want to see his parents. No friends visited. This concerned the hospital social worker, Janice. She began to seriously worry about Karl's seeming lack of social support.

The physicians spent the next several weeks adjusting his medications. Karl's withdrawal began to wane. Most of his other symptoms were also disappearing. Karl told hospital staff he wanted to go home, but took no concrete steps toward that end.

Janice had been employed at the hospital for six years and had earned the respect of other staff. While she had a good understanding of the psychiatric and medical model and was well acquainted with diagnosis and prescriptions of medication, she was steeped in the strengths perspective and interventions that emphasized growth and development. She was able to show the medically oriented staff that building on strengths was an important enrichment to processes that addressed the pathology of illnesses. By providing and facilitating support and by enabling empowerment and growth in clients, she demonstrated that people with a mental illness could nevertheless develop a good quality of life, even if the illness affected them, in varying degrees, for a long time. Thus, rather than focus on treatment of illness and restoration of health, Janice concentrated on helping clients rebuild their lives, taking into account the effects of the illness even in times of remission and reoccurrence.

Applying the Principles of a Strengths Perspective and Developmental Approach

Reciprocal relationship: From the beginning of her work with Karl, Janice set out to establish a trusting, respectful, and mutually satisfying relationship with Karl. She did this by careful listening and showing Karl that she was willing to help him achieve his own goals. Janice held dear the social work adage, "Begin where the client is." At first this was difficult, but as the medications began to take effect, building a relationship with Karl became easier. Karl liked and respected his psychiatrist, which made taking medications a bit easier.

Empowerment, a consumer-driven approach, and reframing: The police had brought Karl to the hospital. He did not resist, yet there was the implied threat that if he did not co-operate, he could be forced to stay. There was an element of social control in Karl's hospital experience. To counter this reality, Janice emphasized helping her client attain his own goals and set intervention objectives with him.

About 10 days after admission, the head nurse on Karl's ward asked Janice to contact the university to explain what had happened so that, if Karl was able to at a later time, he could return to university. The nurse, reflecting on the opinion of Karl's psychiatrist, also made it clear to Janice that she did not think he would be ready to return for a very long time, if ever, but that just in case, the university should not close its doors to Karl. The nurse assumed that Janice would be better able to approach the university than Karl. Janice understood the problem and realized that it needed to be addressed, but she considered the nature of the request inappropriate.

The nurse clearly framed the problem as reflecting a deficit in Karl. In her view, Karl was not only incapable of contacting the university by himself, but likely could never handle university work. Janice decided to reframe the problem from a deficit to a strengths perspective.

Her first step was to talk to Karl about his plans. She discovered that he was planning to return to university the next term (about 45 days from now). Like the head nurse, Janice seriously doubted that he could achieve this objective. Karl would likely find the work at university so stressful that the illness would reappear. She began by taking a gentle approach with Karl. Janice tried to use her emerging relationship with Karl to gently steer him away from this direction. However, her attempt did not work. Karl continued to insist that he wanted to go back to university as soon as he could. Also, Janice realized her actions did not involve true attempts to reframe.

Janice considered Karl in charge; he was the consumer and needed to make his own decisions in spite of his illness. More was at stake here than simply contacting the university. Janice was keenly aware of the effects of hospitalization on Karl. The stay in the locked ward stripped some of Karl's person. Although it was a kind of prison for him, he also perceived it as a safe place. Karl's sense of personal control over his own life had been weakened. He had begun to lose personal power. His sense of empowerment was also diminished. Therefore, Karl needed to be able to make his own choices. If he lost his decision-making capacity, then he would likely embark on a long downward slide to a serious and debilitating, long-term mental illness. Janice began to define her primary role as an enabler. Along with regaining social support, Janice made it a priority to address how Karl could begin to take control of his life again. This would be an essential part of his steps toward personal growth. She would, to the best of her ability, help Karl make the most informed and best decisions possible, but in the end, Karl would make the decisions. Regardless of the decisions he made, Janice's role would be to fully support them and help Karl make them work.

Her decision was not without risk. Suppose Karl failed at university, or, even worse, suppose his attendance in classes increased his stress level to the extent that his illness became much worse? Janice decided that she needed to take her plan to the next team meeting.

The team, made up of a psychologist, social worker (Janice), psychiatrist, occupational therapist, and two psychiatric nurses, weighed the risks involved. If Karl was permitted to make his own decisions, the risk was quite real that he would decide on a course that would end in failure. If so, his illness might get much worse. Karl is now considering a reduced course load that, the social worker believes, might increase his chance of success at university. If he did not regain control of his own life and achieve a renewed sense of empowerment, then the team decided the risk was even greater. Therefore, the team agreed that Janice should proceed with her plan.

There are two subscripts to this decision. First, if risk involved true danger to oneself or others, the team's decision may well have been different. Second, even if the team disagreed with Janice's plan, she has succeeded in developing ideas that are alternatives to a restorative and medical model.

This example also illustrates the principle that the worker does not really know the upper limits of client's capacities for growth. Even though Janice felt that Karl would not likely be ready to return to university, in the end this was his decision to make.

Belonging and social supports: Over the first couple of weeks Janice began to suspect that Karl felt he did not belong. Where were his parents? His friends? She asked Karl for permission to talk to his parents. He was reluctant, but agreed.

Janice discovered that Karl's parents were preoccupied with their own problems. His father's health was failing and income was a problem. They had long recognized that Karl was having difficulties, but were unable to "talk to him." At home he was very withdrawn and almost uncommunicative. Karl had lost a key source of support.

During his illness while in high school, Karl's childhood friends had mostly abandoned him. In university, he had a number of "acquaintances," but no real friends except for one young woman he had dated about eight or nine months previously.

Karl was receiving support from Janice, his social worker, which he felt was very important. However, upon discovering that his community social supports were weakened, she realized that she must emphasize developmental intervention to help Karl rebuild his informal support network. So far the only clue Janice had to go on was the support that the young woman might provide. Soon, she decided, she needed to explore with Karl some possible sources of community and informal social supports.

Some of the above have been defined as deficits. For instance, Karl has lost key social supports. His sense of belonging has been impaired. Similarly, his feelings of power and control over his life have been compromised by both his illness and hospitalization. Janice's task is to turn these problems (deficits) into opportunities for growth and development; deficits were to be reframed as strengths. She must find ways to help Karl find a new sense of belonging and empowerment.

Many mental illnesses are long term with lot of ups and downs, remissions and surges. People who suffer from them need to discover ways to manage and experience quality of life while dealing with their illness. The strengths perspective is uniquely suited and a developmental, growth-oriented approach is a powerful way to help people meet the goals of living a quality life in spite of their mental illness.

The Essentials of Treatment of Mental Illness

Two fundamental interventions made a real difference in helping Karl. One is the medication that he received and the other is the social supports that enhanced his empowerment. Medications stabilized his mental condition. The hallucinations disappeared and he was no longer confused.

The social supports brought Karl along even further. The hospital staff helped him feel safe, provided considerable encouragement, and many, particularly the nurses, developed a trusting relationship with him. Overriding all of Janice's interventions was the support she provided in attempts to ensure that Karl would regain control of his life. Her professional relationship with him was supportive. When the team agreed with Janice's plan for Karl to make his own decisions regarding return to university, the goal was empowerment; the approach was to first support Karl in making the best informed decision possible and then to support him to facilitate success in whatever decision he made. Importantly, he then needed to restructure a supportive social network. Part of Janice's work was to help him accomplish that goal.

This leads to a hypothesis: The fundamentals of treatment in mental illnesses can be reduced to two broad essentials—biochemical treatment (medications) and social supports that enhance real and perceived empowerment. Without effective medications and social supports, recovery from mental illness is very difficult. Social supports are all the environmental resources that one can draw upon to enhance quality of life. This ranges from primary, intimate relationships to more formal institutional supports such as the available health services. Empowerment is the real and perceived sense of personal control over one's life.

The evidence for the effectiveness of medications in treatment of mental illness cannot be denied. While the use of some medications may be controversial, sometimes they may be misused, frequently side effects are severe, and sometimes they may even be counterproductive, but millions of people suffering from depression to schizophrenia have been helped by them. Probably most of us expect further advances in drug treatment of mental illness.

The evidence for the importance of social supports is more challenging to demonstrate. There is no doubt, based on my experience of 40 years working in and observing practices in mental hospitals, that patients who are there for the long term (years) generally have poor life skills and lack adequate community social supports. Relatively few long-term patients are there because they require hospitalization to treat their illnesses. Rather, they are hospitalized because they have no other place to go in the community.

Further evidence of the importance of social supports is apparent from the experience of the deinstitutionalization movement that began in the 1960s. The operative assumption was that resources like group homes and foster homes, along with out-patient care, would provide adequate social supports. Those programs that were successful did provide the necessary supports. Most of those that did not provide adequate supports did not succeed (Goering, Wasylenki, and MacNaughton 1994; Halpern, Sackett, Binner, and Mohr 1980; Rochefort 1993; Sommer and Osmond 1961; Wharf 1992).

Sullivan (1994), in an interesting qualitative study, used as subjects 46 seriously ill, long-term mental patients who were well into the recovery process and had not been hospitalized in the previous two years. Sullivan asked them to identify and discuss the factors that helped them most in their recovery. Medications topped this list, but running a close second were community and case-management supports. The most important component of these supports was a caring, supportive relationship of the professional helper. Sullivan, referring to his 1994 study, writes:

> For it was not the technical facility of the case managers or the specific programming offered by community-based programs that consumers identified as important; rather it was the strength of relationships and the caring atmosphere and protection these programs and

> persons offered. Case managers were valued for their friendship and companionship, and for the fact that they looked after their charges while providing constant encouragement. (Sulliven 1997, p. 166)

Similarly, Strupp (1995), as reported by Saleebey (2002b), shows that the most important element across various kinds of psychotherapy is a quality, supportive helping relationship. Simply put, an axiom of social work practice is that supportive relationships are necessary and essential to successful intervention.

Quality of life is presumed to be dependent upon social interactions. Systems and ecosystems perspectives assume that social support is necessary for human functioning (McMahon 1994, pp. 85–86; Meyer 1983, 1988; Wakefield 1996). Analysis of much of Saleebey's work reaches a similar conclusion regarding the strengths perspective.

The Strengths Perspective: An Oppportunity for Social Workers to Define Their Role in Mental Health

As argued throughout this chapter, the strengths perspective is part of good social work. It is part of our history and certainly flows from our values and ideology. The strengths perspective is an excellent way for social workers to define their roles in mental health settings and it is consistent with social work's emphasis on working with people in their environment.

Social Workers in Mental Health Settings

Importantly, most professionals in mental health centres have medical backgrounds or training in understanding the pathology of mental illness. Typically, social workers are an exception. Unless specially trained, social workers do not come from a medical background. Therefore, special attention needs to be giving to how social workers can define their roles in mental health settings.

Definition of Social Work Roles

In my experience, social workers usually define their role in a way that emphasizes working with the "social aspects" of a person's illness. This is consistent with a person-in-the-environment orientation of many social work education programs. However, often this definition of role lacks both clear goals and concrete referents. In order to be more specific, some social workers regard their main role as taking a social history or, in hospitals, discharge planning. Others define their roles as a liaison between the patient and community resources. While important, nearly any health care professional can accomplish these tasks.

While it is true that these tasks fit the orientation of many social workers, this view of social work roles does not permit the social worker to become an essential part of the mental health team. By itself, a person-in-the-environment orientation does not enable a social worker to claim a particular set of skills that can make a major contribution. The argument here is that a person-in-the-environment orientation—when coupled with a strengths perspective and developmental approach—gives social workers a more powerful frame to define their roles in mental health settings. Social work practice can be a truly indispensable part of a mental health service, even if the service is heavily medically oriented. Janice handled the problem by casting her role in terms of a strengths perspective and emphasizing the importance of Karl's relationship with others.

Conclusion: The Strengths Perspective and Social Work Roles in Mental Health

One of the strongest arguments for using the strengths perspective in mental health is that it establishes a set of roles for which social workers are uniquely suited. Our strong commitment to understanding people in their environment, or applying an ecosystemic perspective, is highly consistent with the strengths perspective. Nearly all agree that mental illnesses are often long term, that patients experience varying degrees of severity at different times, and that remissions and reoccurrences are common. Like those with physical disabilities, clients with mental illness often need to learn how to live with an illness that at times is debilitating. By emphasizing growth and development, social workers use a powerful tool that can help those suffering from a mental illness achieve a better quality of life. Attaining such a goal is a critical part in the recovery process of those who suffer from a mental illness.

This chapter has argued that in the treatment of mental illnesses, restorative action is essential. Medications are often very helpful and, with some illnesses such as depression, can restore many people to symptom-free status without other interventions. This seems to be particularly so if people have strong social (e.g., family) supports. For, some the roads to recovery also involve developing insight often through psycho or psychosocial therapy.

On the other hand, there is another necessary focus in the treatment of mental illnesses. This has been called the developmental approach, which focuses on growth and building a quality life while recognizing the ups and downs of many mental illnesses.

The responsibility of medically oriented professionals—psychiatrists, psychiatric nurses, and many psychologists—is to directly treat mental illness. The approach is restorative. They are specifically trained to do this.

Social workers must establish a different set of essential roles in mental health settings. Application of the strengths perspective and a developmental approach in the context of a person-in-the-environment frame offers a powerful means to define these roles. This is consistent with our heritage of diversity and commitment to a set of professional ideals. It is the strength of social work!

Reflection Questions

1. Think of a client or person you know with a mental illness. How could restorative and strengths approaches be helpful and how?
2. In Karl's situation, how important is the social worker's hope and trust in him? How does it affect Karl's options?
3. What is a developmental approach? How does it shape social work practice in mental health?
4. How important is a social worker's relationship in working with Karl and other clients who are mentally ill?
5. What are signs of growth in Karl that the social worker could identify?

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CHAPTER 5

PROBLEM DRUG USE IN THE 21ST CENTURY:

A Social Model of Intervention[1]

Julian Buchanan

Introduction

Working with problem drug users can no longer be regarded as a specialist role confined to the domain of drug agencies. Drug use is so widespread that social workers in all fields must now possess reasonable knowledge and skills to engage with this consuming and at times confusing social problem. This is especially important for social workers concerned with health, mental health, child protection, and criminal justice. In the past, help for problem drug users has been left to specialist workers, and too often dominated by a medical model of addiction. Based on 20 years of research and practice with problem drug users in Liverpool, England, the author presents a social model of intervention. Dominant approaches—such as the 12-steps program, the cycle of change, methadone maintenance therapy, in-patient detoxification, and the use of therapeutic communities—all have considerable merit and continue to be used with varying degrees of success for selective groups, but they remain heavily based upon physiological and psychological theory with the emphasis upon individual motivation and personal commitment. The social and cultural changes in the late 20th century, particularly in relation to risk and drug taking, have lessened the impact and effectiveness of these traditional approaches.

In the past two decades a growing hostility has developed, especially in the U.K. and the U.S., toward problem drug users, resulting in legitimized marginalization and social exclusion. This structural discrimination has become a serious debilitating factor for many problem drug users, hindering their opportunities for recovery. This chapter provides a rehabilitative framework that acknowledges these structural factors, one that promotes social reintegration, anti-discrimination, and traditional social work values. There are generally three types of drug users:

(1) recreational drug users who use illicit drugs in a controlled manner for pleasure without incurring social, psychological, and/or physical problems; (2) dependent drug users who use illicit drugs and have become psychologically and/or physically dependent (this dependence inevitably begins to have some impact upon their social, psychological, and/or physical well-being); and (3) problem drug users who use illicit drugs but have become heavily socially, psychologically, and/or physically dependent; this loss of control will have resulted in significant social, psychological, and/or physical problems; their lifestyle is also likely to pose difficulties for others. This chapter is concerned with this third group of drug users.

Societal Change, Drug Taking, and the Social Context

The last three decades of the 20th century saw significant and rapid social change, nationally and globally, including the widespread use of illicit drugs. Across the Western world experimenting with illicit drugs is now regarded as one of many typical adolescent risk-taking experiences. Standardized school-based survey research in schools in the U.K. found that 50 percent of school children in Scotland and 40 percent in England had tried at least one illicit drug (Parker, Aldridge, Eggington, and Measham 2001, p. 2). In the past, knowledge and understanding of the nature and risk of different illicit drugs among young people was poor. Today, largely through the development of widespread health education programs and mass communication, young people tend to be much better informed.

Choices: Alcohol, Tobacco, or an Illicit Drug?

It is widely accepted that recreational use of cannabis can be relatively unproblematic (Police Foundation 2000), while other drugs, such as heroin and crack cocaine, are more likely to lead to difficulties and dependence. What is interesting is that many young people today make "risk assessments" when choosing an illicit drug, with cannabis, amyl nitrate, and amphetamine being the most popular in the U.K. (Measham, Aldridge, and Parker 2001). In comparison to the dangers posed by other illicit drugs (and some legal drugs) these choices represent good risk-management decisions. However, there is a tendency to convince young people that all illicit drugs are dangerous and harmful. This stand against drugs inevitably leads to a loss of credibility and trust, which are key factors when trying to assist problem drug users.

In contrast to illicit drugs, alcohol and tobacco use have for many decades been legitimized and heavily promoted as appropriate and acceptable recreational drugs of choice. This dominant cultural perspective (seeing alcohol and tobacco as appropriate drugs for relaxation, socialization, and celebration) is being challenged. Sections of society are making informed risk assessments and selecting different recreational drugs, albeit ones that are currently categorized as illegal. Uncertainty, choice, diversity, and risk are now key themes of postmodern life. In this context it becomes easier to understand illicit drug taking as just one of many life choice options, each involving inherent risks, uncertainties, and benefits. Taking drugs is one of several choices in which there is risk, such as regularly using a mobile phone or eating genetically modified (GM) food.

Risks Created by Illegality

Interestingly, some activities and products in society are deemed "safe," and are promoted until they can be proven dangerous (cigarettes, mobile phones, GM food), whereas illicit drugs are deemed dangerous until research can prove that they are safe. Paradoxically, some of the most dangerous risks arise from the illegal status of the drug rather than from the substance itself. For example:

- using adulterated drugs that may contain rat poison, brick dust, or bleach, which is particularly risky if the drug is injected
- uncertainty regarding the strength of the drugs, risking possible overdose or death
- socializing with a criminal underworld that may lead to exposure to more dangerous illicit drugs and other illegal activity
- administering the drug in secret, in inappropriate and possibly dangerous and dirty places, such as derelict houses, under railway bridges, and isolated places

- being afraid to seek help or advice, fearing stigma and marginalization or even legal action
- engaging in a criminally defined activity, risking a criminal record and possibly imprisonment

Legalization has the potential to remove the vast majority of risk identified above. Ironically, it can be argued that many young people are choosing substances that are, if a clean legal supply could be obtained, far less damaging than the heavily promoted commercial substances of alcohol and tobacco.

Locking up Problem Drug Users: The Enemy Within?

Although the nature and context of drug taking has changed significantly in recent decades, the approach to the problem of illicit drugs has changed little. The war on drugs rhetoric continues. Anyone found choosing an illicit drug risks getting caught up in the criminal justice system. However, as illicit drug use becomes a mainstream activity, drug strategies such as those in the U.S. and the U.K., which lean heavily on the criminal justice system, inevitably create a spiralling prison population. In the war on drugs, drug users are portrayed as a threat and menace to society. Populist politics heighten this fear, then respond by getting tough on drugs. Society then becomes united, waging war against its "suitable enemies" (Christie 1986), and drug users are a convenient group to demonize (Van Ree 1997). This leads to marginalization, isolation, hostility, and distrust toward drug users with the emphasis not on rehabilitation, but on protecting others in society from the dangers of drugs and drug users. Once they are ghettoized, it is extremely difficult for recovering problem drug users to overcome this social barrier of stigma and exclusion. This exclusion must be appreciated and addressed by those seeking to effectively assist problem drug users. The war on drugs is a war on drug users, a civil war against an enemy within (Buchanan and Young 2000).

Case Situation: Mark

Mark is a White, unemployed male aged 22, the eldest of three boys. He was born and brought up in Boot Hill, a densely populated inner city area of Dockside. The area was blighted by high levels of unemployment in the 1980s (65 percent) and never entirely recovered. It also has poor housing stock, serious problem drug use, and high levels of criminal activity. Mark's parents both worked locally at the local factory until it was closed in 1985. Since then his father has been unable to secure permanent employment. His mother works as a cleaner at the local school. His parents separated in 1991 when Mark was just 11 years old. Mark still lives with his mother and two younger brothers, and has regular contact with his father. At the age of 11, like many of his peers, Mark began experimenting with tobacco. At 12 he started experimenting with alcohol, and at 14 he began taking cannabis. This illicit drug brought him into contact with a criminal network and introduced him to other illegal drugs. For the next four years he used cannabis regularly, and occasionally used amphetamine and ecstasy.

At 16, Mark officially left school with no qualifications. He was unhappy at school and actually stopped attending soon after his 15th birthday. He complains that he wasn't suited to school, didn't get along with the teachers, and preferred playing sports and studying practical subjects. His mother thinks he might have dyslexia, though an assessment has never been carried out. After a number of short training courses, Mark was pleased to secure a place as an apprentice plumber just before his 17th birthday. He enjoyed this work, but, sadly, Mark was laid off from his shipyard job just before his 18th birthday due to downsizing. Since then he has remained unemployed and dependent upon state benefits. The only employment he has been able to secure has been illegal, temporary work as a construction worker in a nearby housing development. When he turned 19, Mark began using heroin; within nine months this had escalated out of control, and soon after he acquired a criminal record for shoplifting, handling stolen goods, and theft from a motor vehicle. Mark says heroin gave him something to do each day, which was much better than doing nothing.

Mark's typical day begins with planning ways to generate sufficient income to buy heroin, otherwise he would face unpleasant withdrawal symptoms ("turkeying"). His day usually involves shoplifting from various large stores. Mark prides himself on the skills and techniques he had developed to steal (usually clothes) without getting detected, though shoplifting was a demanding and stressful activity. Mark referred to it as "grafting." Once he has acquired the goods, different skills were needed to barter and sell them quickly, sometimes for ridiculously cheap prices in local streets or pubs. Mark seemed to enjoy the adrenaline rush of stealing and selling. Once he had cash, he said he felt good, as if he'd earned it, but he never saw it as cash, just as a way to buy heroin. His next task was to find someone who can sell him nice (reasonably pure) heroin. The deal had to be properly managed otherwise he might place himself or the seller at risk of detection. It was also difficult because Mark, by this time, needed a fix and had no way of knowing whether he was buying brick dust or heroin. Once he had heroin in his possession, he needed to get home without being stopped by the police. He could then go to his bedroom, burn the heroin on silver foil, and inhale through a tube and enjoy the euphoric feeling the drug gave him. It was the culmination of a hard day's work and now he could relax and feel good. Each day was the same, a 24/7 treadmill. Not unexpectedly, Mark eventually got caught for some of his crimes, and just before his 21st birthday he was sent to prison for nine months following a burglary. Upon release from prison, he immediately started taking heroin.

A Physiological Approach to Problem Drug Use

Physical intoxication to a drug can be so debilitating that may be difficult for problem drug users to make rational choices until they become drug-free, a situation not uncommon with heavy long-term use of alcohol, heroin, or benzodiazepines. Abstinence-based workers therefore see the removal of all illicit substances from the bloodstream as the only viable option for recovery. Once addicts are detoxed, they become ex-addicts and their status can be regularly and randomly monitored by increasingly more sophisticated drug testing on blood, urine, saliva, or hair. One main abstentionist method is the 12-steps approach, which has its origins in Alcoholics Anonymous (AA), co-founded in the 1930s by Bill Wilson (Hartigan 2001). It emphasizes the importance of admission of wrongdoing, confession, repentance, humility, accountability, and yielding to an unspecified spiritual force (Alcoholics Anonymous 2003). The 12-steps approach has been popular and subsequently spawned a worldwide movement with a range of 12-steps programs to address a variety of personal problems (Bradshaw 1988). While AA concentrates exclusively on alcohol, Narcotics Anonymous (NA) is open to any illicit drug users.

The 12-steps approach is based upon a disease model of addiction in which clients must refer to themselves as alcoholics or drug addicts, even if they haven't taken anything for five years. Recovery can begin only when the client has hit rock bottom, recognizes his or her illness, and then commits to lifelong abstinence. This approach, which regards addiction as a disease for which the person cannot be held responsible, can be particularly appealing. The disease is seen as life-threatening, debilitating, and requiring drastic action. Lifelong abstinence is seen as the only viable option. A strength of this approach is the regular contact, support, and group meetings, which help to keep clients accountable and focused. Recent trends in the U.K. criminal justice system toward urine testing and abstinence orders reinforce abstinence-based models.

Case Study: An Abstentionist Approach

Mark is physically dependent upon drugs. The only way he can regain control of his life is to become and stay drug-free. Being in prison provided him with an ideal opportunity to remove the poisons from his body. Sadly, he went straight back on the heroin when he was released from prison, and will now have to hit rock bottom before he is likely to come to his senses and realize he is an addict who needs help. This relapse illustrates he has no control over his behaviour because he is an addict who is ill. Eventually, he may need to be an in-patient at a hospital detoxification centre followed by a lengthy stay at a residential therapeutic community away from the Boot Hill area. Until then he will behave like an addict, cheat, lie, and steal because he is gripped by a disease that needs treatment.

Limitations of the 12-Steps Approach

The 12-steps approach is suitable only for people who are ready, able, and willing to practise lifelong abstinence and are comfortable with a disease model that pathologizes their addiction and labels them. While it may be successful for those who join, there are many drug users who seek help, but may not be appropriate for the 12-steps model. Alcoholics Anonymous or Narcotics Anonymous are an option for one type of drug user and not the answer for all drug-dependency problems. A wider range of services is necessary for the many other drug users who are at a different stage or who are suited to a different approach. The notion of being cured or sick also tends to leave those that relapse in some difficulty. Once dry or drug-free, a person can feel proud and gain mutual support and affirmation in the group meetings. However, a return to drink or drugs, no matter how small or incidental, requires admission, repentance, and a renewed commitment to lifelong abstinence. Faced with this stark choice, people who relapse may quickly return to damaging patterns of intoxication.

Emphasis upon Physical Dependence

Abstentionists tend to regard clean legal substitute drugs such as methadone as an unacceptable alternative because the person remains physically dependent, and express concern because methadone is just as addictive as heroin itself (Robson 1999). While this is physiologically accurate, it is potentially misleading because it presents drug dependency as essentially a physical addiction. This has implications for policy and practice. To those who emphasize the physiological nature of dependence, it comes as something of a shock (as many drug users have testified) to discover that the cravings, stomach cramps, and sweats can all come flooding back once people return to the original environment in which they were exposed to the same cues and triggers, regardless of how long they have been away from the environment or how long they have been drug-free.

While the physiological aspect of problem drug use needs to be taken seriously, it is clearly just one component of drug dependence. It does not in itself provide an adequate understanding of dependence, and can lead to the exclusive promotion of abstinence-only programs, suggesting that harm reduction merely condones or prolongs drug taking. However, many problem drug users are able to live normal and healthy lives while maintained on legally prescribed substitute drugs (McDermott 2001), but sadly, access to clean legal drugs is severely limited, and many health suthorities (in the U.K.) are unwilling to provide clean injectable drugs. The preoccupation with physical withdrawal can also lead to a failure to recognize other crucial aspects of dependence. Drucker highlights this point:

> In an environment frightened with powerful moral and legal reactions to the use of drugs, the stigma attached to drugs may come to be a more important factor than the biology of addiction, the demonization of drugs and the criminalization of the drug user (i.e., the war on drugs) could be more damaging to the individual and society than drug use or addiction. (Drucker 2000, p. 31)

Reflection Questions

1. If Mark was physically drug-free in prison, why did he go back to using drugs?
2. To what extent is drug dependency a physiological problem?

Psychological Insights

Realizing that the physiological aspect of dependence is unable to provide a complete understanding of drug dependence, psychologists have usefully identified and introduced various cognitive behavioural theories to help understand drug dependence, including social learning theory, pro-social modelling, and cognitive behavioural therapy. Behaviour can be understood to be a result of behavioural conditioning, combined with the thinking processes. For example, faulty thinking can make unacceptable behaviour more likely to occur. A drug user may think, "I had no choice but to buy a bag of heroin." While factually incorrect, this statement removes choice and personal responsibility. A more accurate and helpful way of thinking would be: "I find it extremely difficult when I have money not to go out and buy heroin."

Motivational Interviewing (Miller and Rollnick 1991) doesn't persuade or manipulate drug users toward particular courses of action; instead, it attempts to empower drug users by assisting them to reflect upon their own situation as they perceive it. It also helps drug users review negative and positive aspects of their lives from their own frames of reference. This process can lead to an inner conflict that may stimulate problem drug users out of ambivalence and into action as they become motivated for change (Buchanan 1991).

The Cycle of Change (Prochaska and DiClemente 1982) recognizes that people who struggle with dependent behaviour tend to be in one of six stages: pre-contemplation, contemplation, action, maintenance, termination, or relapse. Identifying which stage a drug user is at enables a more appropriate response to be offered to the drug user. For example, if a person is at the pre-contemplation stage, then a goal-setting approach is likely to be a waste of time, possibly setting up the drug user to fail. The cycle usefully provides a framework for constructive intervention with problem drug users regardless of which stage they are at.

Case Study: A Psychological Approach

Mark has taken heroin so many times that he does it without thinking because he has developed a learned pattern of behaviour that is triggered by daily events. For example, each time he receives a £5 note, he automatically thinks of buying a bag of heroin. Mark has been assessed as a pre-contemplator. At this stage he is not ready or interested in giving up drugs. If confronted about his drug habit, he is likely to say what others wanted to hear because if he told the truth, people would be reluctant and unable to accept his stated desire to continue using drugs. Enforced detoxification would have no impact on Mark because his dependence is largely psychological, not physical.

Harm Reduction

Physiological and psychological understandings of drug dependence have significantly informed the treatment of U.K. problem drug users, but policy has also been influenced by the pragmatic strategy of "harm reduction" promoted by the U.K. Government Advisory Committee in the late 1980s (Advisory Council on the Misuse of Drugs 1988) and developed in the Netherlands (Buning 1990). This strategy was based on the premise that HIV posed a greater threat than drug use itself, therefore, agencies had to be prepared to accept continued drug use in order to develop relationships with the drug-using community and encourage safer practices to prevent the spread of infection to the non-drug-using population. Controversially, this involved the supply of free, clean needles and syringes, free condoms, and maintenance-prescribing of substitute drugs. Some clinicians even prescribed amphetamine and heroin to dependent drug users, sometimes in injectable form (ampoules). Harm reduction was reluctantly embraced as agencies felt obliged by their responsibility to protect the non-drug-using population from the risk of HIV/AIDS (Riley and O'Hare 2000). However, as the incidence of AIDS cases related to injection drug use began to fall significantly in the mid-1990s across EU countries (European Monitoring Centre for Drugs and Drug Addiction 1999), interestingly so did the prominence and practice of harm reduction. This is not surprising given that the United Nations Office for Drug Control and Crime Prevention (UNDCCP) has not accepted harm reduction. Hartnoll (1998, p. 240) identifies the problem of harm reduction for countries with a strong abstentionist views: "it lacks commitment to a drug-free goal, accepts or condones continued use of drugs, and implies a hidden agenda of decriminalization or legalization."

Case Study: A Harm-Reduction Approach

Mark has been using heroin for a while. He admits to injecting street heroin and has on occasions injected benzodiazepines. He doesn't share needles as a rule, but has used a needle that a trusted friend had used. He has little motivation to stop taking drugs. To reduce harm, it is best to listen carefully to what he is saying without moralizing or judging him. Mark needs to be shown how to inject more safely, be provided with clean needles, and given information regarding the risks of becoming infected with HIV, and hepatitis B and C in particular. He should be given a prescription for a daily supply of methadone ampoules. This would reduce many health risks and a significant amount of criminal activity. The greatest reduction of harm would be achieved if Mark gave up drugs altogether, but this won't happen (not yet anyway). This strategy is pragmatic, it seeks to reduce harm, maintain contact, and encourage an open and honest dialogue.

Physiological, Psychological, and the Harm-Reduction Approach

U.K. practice with drug users has been shaped by three separate frameworks of understanding: physiological dependence, psychological approaches, and the pragmatic philosophy of harm reduction. While the physiological approach tends to subscribe to pathological notions of dependence promoting ideas of the demon drink or drug, the psychological approaches also run the risk of decontextualizing problem drug users, suggesting that dependence can be controlled largely by internal adjustments in thinking, motivation, or the development of cognitive behavioural techniques. The promotion of harm reduction results in more accessible and appropriate user-friendly services for drug users, but the actual practice of harm reduction has tended to be limited and often confined to narrow health interpretations.

All three frameworks offer an important contribution, but each give limited attention to the social, political, and economic context of drug taking in postmodern society. Many socially excluded problem drug users in the U.K. struggle to break out of a drug-centred existence, even when they become physically drug-free and demonstrate considerable psychological insight and self-motivation.

Reflection Questions

3. Is being psychologically dependent upon illicit drugs any different from being psychologically dependent upon cigarette smoking? Explain your answer.
4. Can we justify giving Mark methadone ampoules, or is this increasing harm?

Drug Users and Discrimination

The war on drugs rhetoric has demonized, isolated, and discriminated against drug users. The institutionalized use of prejudice, power, and propaganda to promote discriminatory thinking toward people using illicit substances is highly questionable. Many groups such as Black people, gay/lesbian people, transient people, and women, have endured similar experiences and many continue to do so. Many of these discriminatory processes have been challenged and the damaging and offensive stereotypes exposed, though further work is still needed. Sadly, while progress is made to tackle discrimination against one group, new groups emerge, such as drug users, who are subject to personal, cultural, and structural discrimination (Thompson 2001). Like many other discriminated groups, some drug users have internalized the negative and harsh stereotypes imposed upon them, leaving them with poor confidence, low self-esteem, low aspirations, and little self-worth (Buchanan and Young 1996). Social work seeks to combat discrimination in all forms, but the experiences of drug users tend to go largely unnoticed and they are rarely mentioned as a discriminated group. Qualitative research studies (Buchanan and Young 1996, 1998a; Goldson, Kennedy, and Young 1995) involving a total of 200 known problem drug users in Merseyside illustrate how the war on drugs has legitimized and reinforced structural discrimination against drug users, and created a barrier that hinders their capacity to regain control of their drug habit. Common themes emerged from these three studies:

- the social dislocation experienced by problem drug users
- poor experiences of education and employment
- a lack of realistic legitimate opportunities

- separation and isolation from a non-drug-using population
- low self-esteem and a stigmatized identity

Many drug users who seek social reintegration have been unable to achieve it, not because of their inability to become stable or drug-free, but by a "wall of exclusion," a socially constructed barrier that separates problem drug users from mainstream society. Many problem drug users have accepted and internalized discriminatory identities as "smack heads" and feel socially stranded, forgotten, with little hope and few legitimate opportunities (Buchanan 2004). Many regard a drug-centred existence as their only option. It provides an all-consuming alternative, with each and every day involving the same demanding routine. Structural inequality and social exclusion tend to be associated with problematic (not recreational) drug use, and research has indicated that drug use generally is much higher in poor neighbourhoods (Foster 2000). Rarely, though, are these structural factors considered by those working with problem drug users. Treatment agencies are often poorly resourced and waiting lists are common. Helping problem drug users is not high on the political agenda. When problem drug users want to change, many lose heart, feeling trapped within a drug-centred life and wanting help, but seeing few legitimate options available.

Case Study: An Integrated Approach

Mark did well on his methadone maintenance program. He stopped injecting street gear (heroin), stopped sharing needles, used a safer injecting technique, and no longer committed crimes every day to pay for his drugs. His family has noticed a big improvement. Mark talks of wanting a proper job and of being bored sitting in the house watching TV. He is afraid of going out. He feels that people talk about him unkindly, and see him as a thief and a robber, even though he hasn't used any heroin for the past six weeks. While he isn't mixing with people in the drug scene, he is becoming very bored, isolated, and increasingly vulnerable to relapse. The Drug Dependency staff has conducted regular urine tests and are delighted with his progress. They don't see what he is worrying about.

A New Conceptual Framework

Much emphasis has been placed upon tackling the physiological and psychological aspects of drug dependence, and upon promoting health-based harm reduction. If rehabilitation and reintegration are to become realistic and achievable goals for problem drug users, the social context of drug dependence should be given greater prominence. As discussed earlier, the cycle of change model developed by Prochaska and DiClemente (1982), based originally on helping cigarette smokers give up, has proved effective in helping to understand the distinct stages of dependent behaviour. Significantly the identification of the appropriate stage has enabled drug workers to adopt the most effective and suitable intervention (Barber 1995). With good reason, it has dominated U.K. theory and practice with problem drug users, but it has led to thinking that problem drug use is merely a matter of individual motivation and psychological adjustments. These are important factors, but the social context and structural realities that problem drug users face must also be integrated. The social model below (Table 5.1) integrates the social, psychological, and structural components of drug dependence within a clear framework for recovery. Each of the stages is distinct and problem drug users will tend to work their way down the list. While it is possible to jump back as well as forward between stages, it is extremely difficult for problem drug users to get beyond the wall of exclusion. Some problem drug users may remain at one phase for many years, while others for only a short period.

Recognizing which stage the problem drug user is in is crucial as it enables a more appropriate response to be made. Accurate assessment of motivation is often hindered by agency staff's subtle coercive pressure on problem drug users to agree to a particular treatment regime, or to move faster toward recovery. The social model offers an alternative explanation to the long accepted view that problem drug use is a chronically relapsing condition because of the fluctuating motivation of the individual; physiological or psychological dependence; craving or physical addiction. Instead, the social model suggests that relapse is often due to the personal, cultural, and institutional discrimination that isolates and denies many recovered problem drug users the opportunity to socially reintegrate. This creates a ghetto for problem drug users and may lead to social exclusion that keeps them outside of mainstream society.

■ The Social Model in Practice

Case Situation: Mark

1. The Chaotic Stage: Mark did not see that he had a problem with drugs. When he began to achieve some realization, he was unwilling or not prepared to contemplate change. At times he was consumed and dominated by a drug-centred life. At this stage, those close to him tried to offer well-intentioned advice and coercion, but these attempts were usually met with a passive outward acceptance countered by an inward hidden rejection. This led to accusations that Mark could not be trusted and was becoming manipulative, though in reality he was never encouraged to say what he was really motivated toward. It may have been better at this stage to develop an honest and accepting relationship with Mark and avoid moralizing to enable Mark to speak without the fear of rejection. Within this relationship it is possible to offer realistic strategies that may reduce the risk of harm to Mark, his family and the wider community.

2. The Ambivalent Stage: During this stage Mark was beginning to consider the negative aspects of drug use, which at times led to a shift in his motivation. Now and again he considered tackling his drug problem. At such times his family and drug workers made concerted efforts to help, believing this was a golden opportunity. Mark valued the attention, acceptance, and support being offered, and obligingly agreed to treatment, but deep down felt coerced. He soon relapsed, which made him feel guilty for letting others down. Arguably, Mark had been set up to fail because he wasn't ready or committed to sustain such changes. Rather than force decisions, at this stage it would be better to provide Mark with opportunities to explore the pros and cons of his drug use and lifestyle without the family or agency staff projecting their own personal and/or professional views, values, choices, or interpretations. It is important for Mark to begin to openly explore issues from his own perspective, dealing with the competing priorities and values as they may trigger an internal motivation for change.

3. The Action Stage: At this stage Mark decides he wants to significantly reduce the harm from taking drugs. He knows that change will not occur overnight, but that it would be a long and gradual process. He wasn't ready to become drug-free, but wanted to stop injecting street gear and eventually give up injecting altogether. His first step was to make arrangements to enable him to obtain clean needles and syringes, and a clean supply of injectable substitute drugs. He knew that he would find it difficult to give up injecting street heroin, so he also began seeing a drug counsellor and talking to his probation officer. Unfortunately, as soon as they discovered he wanted to sort out his life, they pressured him to give up drugs altogether. While this was a positive aim, it was more than Mark could manage, and it caused stress in a relationship in which Mark was looking for support. Too often mistakes are made at this stage by the wrong pace of change. It is important that goals are appropriate, realistic, and manageable.

4. The Control Stage: During this stage Mark successfully gave up sharing needles; he stopped taking street heroin, and reduced his use of methadone ampoules from 60 mL to 50 mL of oral methadone. His criminal activity dropped significantly. While this was a real achievement for Mark, it was also a time of change and uncertainty because he was beginning to wonder what to do with his time. The 24/7 lifestyle, which had been so much part of his daily existence, had gone, and Mark was beginning to get bored. He wanted to engage in new activities, but he was extremely apprehensive about the idea of mixing with people who didn't take drugs. He was anxious too about meeting drug acquaintances, worried in case he would suddenly experience cravings or be offered heroin. His moods fluctuated, where one minute he felt vulnerable and the next overconfident. Mark's drug worker explored relapse with him, so that he didn't see it as a major setback but a potential learning experience.

The Wall of Exclusion: A successful transition depended largely upon Mark's ability and opportunities to move away from his drug-centred life and establish alternative routines. This was especially difficult because he had lost his self-confidence when among people who didn't use drugs. He wanted to get fit and thought about joining the local gym, but he felt anxious that people would see him as a smackhead and a thief. The wall of exclusion that social attitudes, government policy, and the media had constructed to exclude drug users like Mark from mainstream society was now hindering his chances of successful recovery. This was a critical period when Mark most needed encouragement from the non-drug-using population if he were to establish a new, alternative pattern of social and economic life, but it seemed to Mark that he wasn't welcome in mainstream society.

5. The Reorientation Stage: Three months after Mark had successfully controlled his drug habit, he was complaining of boredom. Although he recognized that he had tackled his drug habit, he hadn't managed to replace his lifestyle dependence, so he was left with a void that was made worse by the sense of exclusion. His drug worker referred him to the Buddying Scheme, and he was appointed a buddy/mentor. His buddy, Pete, had himself been a problem drug user and was acutely aware of what Mark was going through. Pete had a small budget to assist Mark in his reorientation. He met with Mark twice a week, once to engage in a social activity, the other to focus on reviewing Mark's progress and plans. Pete was available anytime by mobile phone to support Mark. Initially Pete and Mark went to a range of mainstream social activities that Mark didn't have the confidence to attend on his own. This included a meal in a pub, 10-pin bowling, going to the gym, and seeing a movie. Eventually, Mark established a routine of social, family, and educational activities that not only kept him busy, but helped him to socialize with the non-drug-using population. Mark was still anxious in case people found out about his past and rejected him.

6. The Reintegration Stage: In this final stage Mark makes a complete break from drugs, not just physiologically and psychologically, but socially. For many years Mark has been disconnected from mainstream activities, so normal day-to-day activities, such as engaging in further education, doing voluntary work, enrolling in a vocational adult education course, and applying for a job, were all quite difficult for him. Once he had successfully completed the supported orientation stage, his confidence and self-esteem grew and he felt more able to participate independently within the social and economical life of the community. Though he is still wary of judgmental attitudes from the non-drug-using population and concerned in case people discovered or referred to his past, Mark has developed resilience and a growing confidence. He is now able to engage actively in mainstream society. Without this purposeful activity and process of social reintegration, the risk of relapse would have been greater for Mark.

Conclusion

Many problem drug users have been disadvantaged and socially excluded prior to taking drugs, and for many the all-consuming drug-centred lifestyle is better understood as an inappropriate solution rather than a problem in itself. There is a tendency to concentrate on the drug problem and see harm reduction and physical and psychological dependence as the key issues. This chapter has argued that the main difficulty facing problem drug users in the 21st century concerns discrimination, isolation, and powerlessness. Social work has traditionally embraced the cause and plight of the vulnerable and the oppressed, and the profession's regard for human rights, empowerment, respect for diversity, respect for the person, fair access to public services, equal treatment, and self-determination (British Association of Social Workers 2002) are particularly important when working with drug users. Further, the enhanced degree and complexity of discrimination needs to be acknowledged when seeking to assist and understand the needs of Black drug users (Sangster, Shiner, Patel, and Sheikh 2002) or women drug users (Klee, Jackson, and Lewis 2002). Social work is ideally placed to articulate and highlight the oppression and discrimination that many drug users experience and to promote a social model to work effectively with problem drug users in a manner that embraces the structural context and seeks holistic solutions that offer them the best opportunity for well-being.

Notes

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CHAPTER 6

USING MUSIC TO FACILITATE SOCIAL WORK INTERVENTION

Alex Keen

Introduction: Why Music?

Music evokes some response from everyone, touching each of us at a profound level. By altering timbre, dynamics, tempo, and pitch, music has the ability to bind people together, send them into an emotional trance or aggressively into battle. Music can remove inhibitions, alleviate or induce sadness, arouse feelings of joy and confidence, and unlock creativity and hidden talents. Because music reaches people on emotional, intellectual, and physical levels, it can ease cultural and linguistic barriers while bringing people together in shared experiences. As such, the use of music in social work therapy provides a unique contact and a useful means of intercommunication individually, and in groups and communities.

Using Music in Therapy

Social work academics and practitioners alike are actively committing themselves to ensure that social work remains relevant, efficient, effective, accountable, and, importantly, sensitive to increasingly complex human conditions. Because music is a universal means of communication, it makes sense that professionals working to promote a sense of wholeness, healing, and well-being within individuals, groups, and communities tap into the vast natural resources offered by various forms of music. In more recent years, social work practitioners have increasingly seen the strength of using the creative arts. This has been particularly evident within the group work situation (Davies and Richards 2002). Unfortunately, the use of music as a tool in social work practice has not been adequately researched. In fact, as Anthony Storr (1994, p. 1175) wrote, "the deliberate use of music as a therapeutic agent, and the training of specialized music therapists, is a comparatively recent phenomenon in Western culture."

Music therapy is generally offered as a specialized professional course to appropriately qualified musicians who have strong musical abilities and who are dedicated to the study of music and its use for influencing behaviour changes. Extensive training that includes academic and experiential course work, clinical experience, supervised practica, and an internship are some of the requirements for a student desiring to graduate with a music therapy degree. Where this specialty has been developed, there are associations for music therapists where accreditation, ethical codes, and standards of practice have been set up. Social work practitioners who have an interest and desire to use music as primary means of therapy are therefore encouraged to confirm the appropriate course and association requirements for their work situation, and to ensure that they have suitable training.

Professional social work training ensures that students are skilled and equipped to intervene with clients in a variety of fields and situations. Drama, art, and music are increasingly viewed as useful techniques not only to establish and develop important relationships with clients, but also to enhance therapeutic intervention. Music therapy, in many parts of the world, is an established professional discipline. However, some human service professionals may use music as adjunctive to other forms of intervention. Professional differences and boundaries may determine who can formally refer to themselves as "music therapists." While it is understandable that suitable education, accreditation, and standards of practice ensure that clients are protected and that the artistic form being used is not regarded as a trivial or menial activity, there are ways that creative tools, such as music, can be applied in social work, provided that practitioners have appropriate knowledge and that effective supervision is available. In some cases, it is possible that interdisciplinary teams can work together to plan interventions and implement them with clients. Formal music accreditation is often required before music therapy can be implemented as a therapeutic means in itself (see, for example, the Web site of the Canadian Association for Music Therapy at www.musictherapy.ca).

Music therapists in the Nordic countries have established the *Nordic Journal of Music Therapy* to promote their profession and to foster research (see www.hisf.no/njmt/).

This chapter focuses on the use of music as a technique or tool within the social work therapeutic context. Music is a powerful technique that must not be used lightly. Thus, even the use and development of music as a tool in a practice situation necessitates careful consideration and appropriate supervision.

Music can be used in three main ways when dealing with clients: musical expression on instruments or with the voice, movement to music, or listening to carefully selected music. Because music has non-verbal, creative, structural, and emotional qualities, it can usefully be applied in the therapeutic relationship to facilitate contact, interaction, self-awareness, learning, self-expression, communication, empowerment, motivation, relaxation, socialization, rehabilitation, personal development, and fun! Music can be used with a wide variety of individuals regardless of age or musical background. In social work, it is usually an adjunct to more conventional methods. Situations and conditions in which music could prove to be a valuable tool for social workers include: acquired brain injury, HIV/AIDS, developmental disabilities, intensive care, emotional traumas, geriatric care, visual, hearing and speech impairments, neonatal care, obstetrics, oncology, pain control, palliative care, physical disabilities, substance abuse, teens at risk, and victims of abuse (Heal and Wigram 1993; Wigram, Pedersen, and Bonde 2002).

Use of a Cognitive Approach with Music

Cognitive approaches in social work treatment are based on the premise that a person's thinking—which is a conscious process and influenced by society, human relationships, immediate environments, and experiences—is the primary determinant of emotions, motives, and behaviours (Werner 1982). A practitioner using this approach therefore recognizes the importance of working with consciousness, helping clients to focus on their strengths and to achieve new perceptions of themselves and their situations (Goldstein 1982). Mental imagery, memories, and imagined images of forthcoming events are important aspects of cognitive treatment as the therapist works with the client to practise more appropriate thinking, feeling, and acting.

Goldstein (1983) identifies the importance and some of the difficulties of "starting where the client is" within a cognitive framework. In the initial stages of the helping process, clients may not present themselves as they really are in daily life. Self-disclosure is a risk that clients are willing to take only when they have developed trust in the worker. Cultural differences, in which meanings of words and sentences may be different between client and practitioner, may distort the practitioner's understanding of the situation. In addition, a worker's theoretical stance can restrict her or his full understanding of the client's state of being. Music can often be a bridge that transcends these difficulties and allows one to reach an individual's inner world (Priestly 1975).

Uses of Music in Social Work with Different Client Populations

Numerous opportunities for social workers exist with diverse populations and for helping people with various difficult life issues. A selection of these, described below, includes working with adolescents who experience problems related to health or mental health.

Adolescents

The child or adolescent with emotional problems may display behavioural problems such as suicide attempts, withdrawal from family, isolation from peers, anger, aggression, school failure, alcohol and/or drug abuse, and running away (Kasiram, Keen, and Naidoo 1996; Keen and Naidu 1992). Central to these difficulties is usually a lack of self-concept and self-esteem, and communication, which is vital in assessment of and therapy with these young people, is often blocked due to lack of a solid communication base. In my own practice, I have found that music is often the only therapy tool that opens and enhances communication with this population (Keen 2001). Because the nature of their "anti-social behaviours" frequently places troubled adolescent clients in conflict with parents, teachers, and other significant adult figures whom they view as demanding and critical, it is not unusual for them to be unresponsive in therapy, suspicious and antagonistic toward yet another "authority" figure. Further, adolescents may not yet be skilled in expressing their real feelings. In this situation, music facilitates the helping process by providing a means to interact with adolescents in order to gain their confidence and trust.

Adolescents generally relate to the music of their peer culture and therefore find music a familiar medium for them. Self-expression is often facilitated because of the non-verbal aspect of music. Thus, listening to and discussing songs are safe and non-threatening to the teenager and offer a pleasurable situation where projection of personal thoughts and feelings is facilitated in the situation because it is one step removed from their own experiences (Keen 2001). The therapeutic process is enhanced and may face little resistance because the adolescent client is "tuned in" to the music and not the therapist, who may subsequently become perceived as a safe and trusted adult.

Using music with adolescents can facilitate self-concept by affording them structured, successful experiences linked to specific reinforcements. It can enhance communication and self-expression by allowing the client the metaphoric use of song lyrics to promote expression. A great deal of information can also be gained by providing adolescents with the opportunity to write their own songs.

Because of its powerful socializing effect, using music in adolescent groups can provide a common ground and thus improve constructive interaction in individuals who have negative or non-existent peer relationships. Group improvization with instruments and/or voice not only enhances group cohesion, but also promotes relaxed feelings and can improve motivation, a greater willingness to work, play, discuss, and reflect together (Davies and Richards 2002). Group members can bring their own CDs with preferred songs to the sessions, which provides them with the opportunity to share feelings and invest in a concrete way in the group. Through discovering the ability and the language to express thoughts and feelings, the adolescent group members find more socially acceptable ways to vent anger, hostility, and rage. One recent study (Church 2001) found that music by Mozart, played as background music, could reduce disruptive behaviour in psychologically disturbed boys.

Music can be effective in helping children living in war-stricken and troubled communities (Sutton 2002). Nigel Osborne, professor of music at Edinburgh University, has spent much of the past decade in the Balkans. His opera *Sarajevo* has come to symbolize music's healing power. He is now musical adviser for the Pavarotti Music Centre in Mortar, Bosnia-Herzegovina, which helps traumatized children to put their lives back together. This centre promotes reconciliation through music. Within this war zone, children were brought together in shelters and cellars, in bombed ruins, and, when it was safe, in open spaces, to make and listen to music, to sing, to beat drums, to strum guitars, to act and react together through music.

Use of Music in Health and Mental Health

In Mental Health

In mental health, for example, the use of music can be used to stimulate association, affect, and imagery in ways that analytical, verbal processes cannot (Wigram and De Backer 1999). For those who are agitated or diagnosed with various mental illnesses, music, through its structure and order, can serve as a grounding experience. Simple, structured activities such as playing instruments or singing in a group can help even a severely disturbed or psychotic patient to focus better, develop social skills, relieve anxiety, and increase ordered thinking. Music can therefore be useful in the treatment of anxiety, depression, and mood disorders.

In Pre-and Postnatal and Infant Care

The use of music in obstetrics, both during pregnancy as well as at the time of labour and delivery, has answered some of the demand for choice and new alternatives in childbearing. The health care needs of this population have required techniques that help create a more pleasurable, more relaxed childbirth experience. Music in the neonatal intensive care unit can mask unpleasant sounds and promote pacification and stimulation of the premature baby within a soothing environment (Wigram and De Backer 1999a). In neonatal care, music has the potential to rouse lethargic infants, calm crying or anxious babies, and act as a natural sleep-inducer.

In childbirth, the "intrusive" qualities of rhythm, tempo, dynamics, and timbre (tone) in appropriately chosen music can provide a cognitive strategy for pain control and suppression of pain responses. Relaxation during childbirth, which is crucial in ensuring adequate oxygenation of vital areas and in minimizing both physical and psychological fatigue, can be enhanced by using appropriate background music and as a trigger stimulus for a previously learned relaxation response (Benson 1975). When chosen purposefully, carefully, and individually, appropriately paced music can be used to time rapid breathing during contractions, and as an almost natural physical response to support the breathing rhythms learned in antenatal classes and to induce a positive emotional state (Blood and Zatorre 2001).

In Palliative Care

The use of music in palliative care offers potentially rich experiences at the end of people's lives. Due to the special emotional, spiritual, and physical needs that arise in the lives of those for whom a medical cure is no longer possible, the skilled use of music within individual or group therapy can facilitate emotional self-expression, assist in resolving significant personal issues, as well as supporting life review while providing a supportive and non-threatening environment to confront fears and discuss present concerns (Aldridge 1998a). Within a group, music can provide members with opportunities for social interaction as personal experiences are shared with others, thus lessening feelings of isolation and loneliness. The use of religious music can provide spiritual comfort, reassurance, and support to some individuals. Family members can also find music helpful throughout the grieving process. It often allows time for personal reflection and provides opportunities to express feelings of loss (Pavlicevic 1999).

Music can be used within individual therapy or in a group setting with family, friends, or other patients to confront and deal with the fears and anxieties associated with terminal illness (Aldridge 1998a). Playing music with specially chosen lyrics, using percussion instruments to accompany chosen music, and writing songs all offer the patient an outlet for expression or discussion of personal issues that may have previously been difficult to talk about. Each person has a unique emotional attachment and response to music. Using music in this way can therefore reinforce identity and self-concept and promote a sense of normality, pleasure, contact, and independence. Retaining a sense of control is important for those who seemingly have limited choices left. Carefully chosen music enhances feelings of well-being, and compiling a collection of music memories and associating these memories with significant events in an individual's life can enhance the process of life review, thus providing the patient and his or her family with a sense of contentment and satisfaction. In all instances respect for the patient's needs and preferences is of utmost importance.

With Surgical and Medical Procedures

The therapeutic use of music has been shown to be effective in reducing anxiety and as an adjunct for pain reduction during dental procedures, with mechanically ventilated patients, coronary care patients, and patients undergoing a variety of surgical procedures and assessments (Aldridge 1996; Wang, Kulkarni, Dolev, and Kain 2002). Because of its broad appeal, the use of music is one non-pharmacological intervention that patients enjoy.

Developing a Music Kit

Choosing Music

The musical repertoire required by a social worker using music will depend on her or his musical training, understanding, and access to music resources, including individual skill and experience, and the kind of clients being treated and under what circumstances. Generally, music that expresses deep feelings or that contains evocative lyrics is useful. A practitioner could first listen to a mixture of light, classical, and popular music and then categorize them into various categories such as: rhythmic, relaxing, evocative, reassuring, and moods. Examples of rhythmic music are compositions with Latin American beats. For relaxing music, Mozart's *Clarinet Concerto* would be suitable. Evocative music could include Sibelius's *Violin Concerto in F* and Vivaldi's *The Four Seasons* would make a good choice for reassuring music. Brahms's *Clarinet Quintet in B Minor* comprises mood music (sadness).

Creating and Using Easy Instruments

In a group practice situation, members can make and play instruments. Simple instruments could include empty plastic containers filled with dry rice, large tin cans with rubber stretched and secured over them as drum heads, and/or two small squares of wood constructed to make clappers that sound like horses' hooves in action. Tambourines, maracas, triangles, chime bars, and bells are also effective and relatively easy to use (Keen 1989).

Music Fundamentals

Some essential elements of music are important to know. These include rhythm, harmony, and melody. Rhythm can have either a stimulating or depressing influence on the rhythmic systems of the body such as heart rate, breathing, and circulation of the blood. Heartbeat sounds, for example, can settle babies and even puppies! Young people may find studying easier with steady pop music playing; rhythmic drumming can fire up warriors; lively music can break tension and set feet and fingers tapping in time to the music. Harmony is the heart of music and appeals mainly to the emotions. Thus, proportionally spaced harmonies of the major common chords soothe and strengthen while the minor chords are useful to ease sorrow and encourage nostalgic reminiscing. Melody appeals most to the intellect because the flow of the music will be retained in the mind if one wants to follow the melody's pattern. Tension and relaxation of pitch in melody have an effect on the physical body of a singer, a person playing the music, and a listener.

Uses of Music in Therapy Situations

Singing and Discussions

The most common way in which music is used in the therapy situation is through playing recorded music and then having the individual or group members discuss the thoughts, emotions, and fantasies aroused. The music and lyrics stimulate clients' responses and encourage the expression of thoughts and feelings associated with the songs.

Playing Simple Instruments

Within various group work situations, playing simple instruments, which could have been made as part of the program itself, provides experiences for socialization, communication, and expression of emotions and feelings among group participants.

Guided Imagery

One could use guided imagery or identify a specific mood, such as joy, in one of the Strauss waltzes and help the client to sustain the mood. Another technique is to provide the individual or group with relaxation instructions and then allow them to relax while appropriate music is played. When relaxation has been achieved, one could suggest a suitable visualization such as: "Imagine that you are lying down, surrounded by beautiful scented flowers"; "Imagine you are a beautiful rose and that you are opening up to the sun, which is rising on a spring morning"; "Imagine you are walking through a forest." Such an exercise triggers feelings of a good experience, which acts on the brain almost as strongly as having had the good experience in reality, and thus the potential for regaining emotional health and peace of mind is enhanced (Wigram et al. 2002). As part of a musical exercise in a group with elderly people, one could suggest that instead of just raising their arms, they could "reach up to the stars!"

Visualization of a safe, peaceful place that the individual has either visited or created can be associated with a relaxing piece of music such as the slow movements of Mozart's *Clarinet Quintet in A*. While relaxing, individuals or group members listen to the music and imagine that they are in that place. After repeating this exercise several times, clients can begin to connect the sounds with the inner picture and the feeling of relaxation and, with the memory of the melodies, be able to induce a relaxed, peaceful feeling in stressful situations.

For those clients seeking success in specific areas of their lives—for example, writing an examination or going for a job interview—the practitioner can help them to imagine the successful situation and then to place this, in their imagination, at the top of a mountain. Music that rises to a climax, for example, Samuel Barber's *Adagio for Strings*, is then played and the client imagines ascending the mountain and experiencing the successful situation vividly at the climax of the music. Any doubt and despair experienced during the playing of the music can be noted and discussed.

To change a sad mood, one could go into the sadness with serious music and then turn to something lighter. Rhythmic music can be used to break tension, while anger or stubbornness can be overcome by choosing music with a quicker beat.

A cautionary note: As with all therapy tools, music used inappropriately or insensitively within a practice situation can be destructive, engendering moods of helplessness or intense anger. Using music to facilitate the therapy process is not always as easy as it may sound. It is therefore recommended that students and inexperienced practitioners use this medium under the careful supervision of someone who has strong musical and therapeutic abilities and who is experienced in the use of music as a means of helping.

Case Situation: Story of Jody

In the following fictional situation, Jody, a 29-year-old woman, was referred to me by her psychiatrist for supportive therapy. The referral letter indicated that Jody's situation included the following: major depression; decrease in her regular support systems; a recent marriage to a supportive husband; a recent motor vehicle accident; low self-esteem; and prescribed medication for depression.

Initial Consultation

During the initial meeting with Jody, as we discussed in more detail some of the above issues, it was evident that she was anxious. In such situations I usually play light, gentle music unobtrusively in the background as this helps to maintain a comfortable, unhurried atmosphere, particularly when a client is describing his or her difficulties and problems for the first time. It also allows for easier release of emotions. Music using a pan flute, classical guitar, or harp is often soothing and useful in this regard.

At our first meeting, Jody said she had been married for only 10 months. Just as they were returning home from their honeymoon, Jody and her husband were involved in a serious car accident in which a truck driver had fallen asleep and driven into them. Although their car was completely destroyed, fortunately, neither of them was seriously injured.

Jody's husband, Andrew, had been transferred to Durban from Cape Town (South Africa) a short while after their marriage. He had been working under enormous pressure as he had been transferred to Durban to establish a new branch of the computer company for which he worked. As a result of the transfer, Jody had to resign from a managerial position she had in her workplace because they did not have a position for her in Durban.

Another recent loss also affected Jody at the time. Her mother, with whom she had had a negative relationship for most of her life, had recently died without the relationship having been resolved in any way. A psychiatric diagnosis of major depression was confirmed as Jody experienced feelings of sadness, had nothing to look forward to, was aware of many failures in her life, had suicidal thoughts, was disappointed in herself, felt guilty much of the time, and was critical of herself for her weaknesses and mistakes. Jody also said she lacked the motivation and interest to do anything or see anybody, had difficulty in making decisions, felt unattractive, slept poorly, was constantly tired, and was frequently concerned about her physical health. Jody also had acute anxiety attacks on a daily basis. The physiological symptoms accompanying the onset of panic included heart palpitations, tightening in the chest, shortness of breath, a choking sensation, dizziness, sweating, trembling, and a tingling sensation in her arms and hands. The psychological reactions included an intense desire to run away, fears that she was going crazy, that she was dying, and that she would do something uncontrollable. A full-fledged panic attack is one of the most intensely uncomfortable states that humans are capable of experiencing. Jody was fearful of leaving her home, and when her husband finally was able to encourage her into the car, she usually covered her face with her long hair and kept her head on her knees for the duration of the journey. With the additional information that Jody provided, it became evident that besides the major depression she experienced, Jody was also dealing with post-traumatic stress disorder (American Psychiatric Association 2000).

Goals for Intervention

In social work sessions, the therapy goals that Jody established were: (1) to establish new friendships and support systems in Durban; (2) to be able to drive by herself; and (3) to find a job.

In order to achieve these goals, it was necessary for her to understand and manage her feelings of anxiety, to restore her self-esteem and self-confidence, and to manage or overcome the clinical depression. Her husband, Andrew, was included in this treatment process. He was understanding and supportive and thereby had a positive influence on Jody's situation.

Outline of Treatment Program

The treatment program established included physical, behavioural, emotional, psychological, medical, interpersonal, individual well-being, and spiritual/existential features. Not all of these goals can be addressed by a social worker since they require expertise in medicine, nutrition, or other areas. Team approaches can often be useful. The components of care in each area can be summarized as follows:

Physical

- Breathing exercises
- Regular practice of deep relaxation
- Regular aerobic exercise
- Nutritional improvements and vitamin supplements

Behavioural

- Coping methods to abort panic attacks at the outset
- Imagery and real-life desensitization to overcome fears of being in a motor vehicle

Emotional

- Learning to identify and express feelings
- Countering mistaken beliefs

Psychological

- Countering negative self-talk

Medical

- Taking the prescribed medication as prescribed for one year

Interpersonal

- Developing self-confidence by practising more assertiveness

Individual Well-being

- Developing self-esteem
- Working on her body image
- Overcoming her inner critic

Spiritual and Existential

- Pursuing her creative interest in art
- Locating a church near her home that suited her spiritual needs

In keeping with a cognitive approach, the treatment process was kept logical, clear, and relatively easy to measure when change took place. A weekly record was set up with daily tasks identified. The "Five Rules for Rational Behaviour," as outlined by Maultsby (1990, p. 12), were identified and discussed with Jody. In these principles, rational behaviour:

1. is based on obvious fact
2. helps you protect your life and health
3. helps you achieve your short-term and long-term goals
4. helps you avoid most undesirable conflicts with other people
5. helps you feel the emotions you want to feel

The Use of Music to Facilitate the Intervention Process

In the next section, an application of the parts of the treatment process in which music was used to facilitate change is described.

Relaxation

As most of the skills in the change process build on the capacity to fully relax, basic to this program is the regular, daily practice of deep relaxation. The relaxation response, as described by Benson (1975), involves a series of physiological changes that include decreases in heart rate, respiration, blood pressure, muscle tension, metabolic rate, oxygen consumption, and analytical thinking. At the same time, alpha wave activity of the brain increases as does skin resistance.

Jody was thus taught how to achieve a state of deep relaxation by using the methods of abdominal breathing, progressive muscle relaxation, visualization of a peaceful scene, and guided imagery. (These methods require that the practitioner have the requisite skill, knowledge, and supervision to perform them.)

Abdominal Breathing and Progressive Muscle Relaxation

Abdominal breathing and progressive muscle relaxation techniques were taught while soothing quiet music was played (Bourne 2001). Harp music, and sounds of the ocean and nature are particularly useful in this process. Music such as Bach's *Sheep May Safely Graze*, Myers's (1978) *Cavatina*, and Schubert's *Ave Maria* are examples of music that could be used. Music in this instance helps to prevent the mind from wandering and being distracted and to focus on the relaxation process.

Visualization of a Peaceful Scene

Jody designed her own peaceful scene. It is important that this scene is described as vividly as possible, and as appealing to as many senses as possible. Jody described a forest scene in which she walks along a path and notices, among other things, the trees, sky, sunlight, a clear mountain stream, fish, butterflies, and birds. Questions for the practitioner to ask include: What does the scene look like? What colours are prominent? What sounds are present? What time of day is it? What is the temperature? What are you touching or in physical contact with in the scene? What does the air smell like? Are you alone or with someone else? Music significantly aided the development of this scene as a piece was selected to accompany the visual image Jody created. As a result, the music created an association for her that she could draw on by playing the music in her own home or in the car as she travels. Jody chose Bruch's *Violin Concerto No. 1 in G Minor*, Opus 26.

Guided Imagery

This is a method that deliberately uses imagery to modify people's behaviour, the way they feel, and their internal physiological state. Appropriate background music often facilitates the guided imagery process in that it helps to focus thoughts as well as mask distracting outside sounds (Wigram and De Backer 1999a). Classical music, particularly movements identified as "adagio" and "largo," or nature sounds (such as the ocean waves, rain on a roof, a waterfall, or birds in a meadow) can be effective. Lowering anxiety and tension during the imagery can be achieved by playing music that has less than 72 beats a minute—that is, slower than the average heart rate. Examples are Pachelbel's *Canon* or the adagietto from Mahler's *Fifth Symphony*. If one wishes to infuse energy or to lift spirits, music that is faster than the average heart rate (72 to 92 beats a minute), such as the last movement of Beethoven's *Fifth Symphony* or *Ninth Symphony*, can be used.

Visualization or guided imagery was used with Jody to help her, over time, gain confidence about confronting and mastering her fears of being in a car, first as a passenger and then as a driver. Barber's *Adagio for Strings* was found to be very effective music as I guided her thoughts along the following lines:

> Take a few moments to imagine what you'll be doing and how you'll feel when you have successfully mastered your fear of a motor vehicle. See yourself fully involved in enjoying a trip in a car; doing what you want to do; feeling calm, comfortable, and confident. Notice what you're doing. Notice how your face looks. Feel the wonderful feeling of accomplishment you've gained from your success. Notice your husband and friends as they congratulate you.

Imagery and Real-Life Desensitization

One of the most effective ways to overcome a phobia is to face it (Bourne 2001). This task can be made more manageable if it is broken down into small, incremental steps. When using imagery desensitization, the client first confronts the situation in his or her imagination. Desensitization is the process of unlearning the connection that has previously been established between anxiety and a particular situation. In Jody's case, this was being in a motor vehicle. She was able to avoid the anxiety by not going near or in a car.

With imagery desensitization, Jody was helped to visualize being in a car while in a relaxed state. If she felt anxious, she could be taken away from the imagined fear and placed in her imagined very peaceful scene. Once this technique had been successfully mastered, real-life desensitization could then take place, where Jody would confront her fear of cars in reality and physically retreat to a safe place if her anxiety reached an unacceptable level. In both these situations, Jody had to unlearn the connection between being in a car and an anxiety response as well as reassociate feelings of relaxation and calmness with being a passenger and finally being a driver in a car. Repeatedly visualizing being in a car while relaxed, or actually getting into the car while relaxed, eventually allowed Jody to overcome the tendency to respond to this situation with anxiety. Jody was first helped to construct a hierarchy of her fear of cars in which together we created a series of situations that ranked from mildly anxiety provoking to very anxiety provoking. Beginning from the least difficult, these were:

1. watching from her home window as cars drive past
2. watching from her home window as her husband drives the car into the driveway
3. going to meet her husband and opening the car door for him
4. hearing her husband asking her to come with him in the car as he takes it to the gas station
5. seeing her husband open the passenger door for her to get in
6. getting into the car and putting on a tape of music
7. hearing the car being started, etc.

Jody was then helped in the therapy situation to first induce a state of deep relaxation, and then visualize herself in her created peaceful scene, walking along a forest path. She was then taken in her imagination to the first scene in her hierarchy, and allowed to fully relax and to feel confident and calm before being taken back to her peaceful scene, and then back to the first and then second steps on her hierarchy. During this process, Bruch's *Violin Concerto* was again used to help her maintain the association between the peaceful scene and feeling of being at ease before confronting each step of the fear hierarchy. Jody made a tape for herself to practise at home, first reading the hierarchy slowly with the music playing in the background. She was then able to use the music alone to facilitate feelings of calmness, and subsequently was able to use this tape in the car when she progressed to the real-life situation.

Countering Negative Self-Talk and Mistaken Beliefs

Adhering to a cognitive approach, what we say to ourselves in response to any particular situation largely determines our emotions and feelings (Maultsby 1990). For Jody, the realization that she could take charge of her thought processes, and thereby have greater mastery over her emotions and behaviour, was empowering for her. She was helped to confront thoughts and statements in her mind that began with the two words, "What if?" Statements that started with, " I should," " I have to," or " I must" were subjected to rational scrutiny (Bourne 2001) by using questions such as:

1. What is the evidence for this?
2. Is this always true?
3. Has this been true in the past?
4. What are the odds of this really happening (or being true)?
5. What is the very worst that could happen? What is so bad about that? What would I do if the worst happened?
6. Am I looking at the whole picture?
7. Am I being fully objective?

With Jody, positive counterstatements were then written out. These included:

> I am confident that I will be able to drive again; I can breathe deeply and let this feeling pass; I can handle this; I accept and believe in myself; and I acknowledge the progress I've made and will continue to improve.

Jody was asked to find a song that she really enjoyed and could identify with as she confronted her difficulties. This was to become her theme song, and one that she could play and sing each day as she dealt with the negative thoughts. Jody chose the song *Survivor*, sung by the group Destiny's Child (2000). Another example of a theme song is *Hero*, sung by Mariah Carey (1993). Unfortunately, much of Jody's negative thinking could be traced back to embedded beliefs or assumptions about herself that she had learned from her mother in particular. Some mistaken beliefs that Jody expressed were:

> I'm unimportant. My feelings and needs are unimportant. I can't cope with difficult or scary situations. The outside world is dangerous.

> There is only safety in what is known and familiar. There is something fundamentally wrong with me. To fail is terrible. I must be perfect. I should always be competent. It's important to please others.

Apart from helping Jody confront each of these mistaken beliefs, she was encouraged to write a letter to her mother in which she expressed the anger she felt toward her, confronted the mistaken beliefs that her mother had passed on to her, and, most important, to forgive her mother. When Jody wrote this letter, she played the first and second movements of Gustav Holst's *The Planets*, named *Mars, the Bringer of War* and *Venus, the Bringer of Peace*, respectively. Some of what she wrote included:

> Dear Mother,
> I'm going to suffer for you no longer. You tried to drive a wedge between me and myself. I was blind; only saw the bad things and not the good. I thought there was something horribly wrong with me. I was sorry that I existed. I'm a deeper person now. I'm holding the torch in the corner of your room and I want you to watch me dancing and laughing. I'm beautiful. My soul is freed, I can walk the streets with my head held high, and can allow my spirit to fly with the eagles. Thanks to so many things and people in my life I can forget about the past and live on. I hate you no more. I love you.

Jody was first helped with her music to go to her peaceful place and then was encouraged to read this letter out aloud. While she read, Bach's *Air on a G String* was played. A lot of deep feelings and emotions were expressed as Jody released herself from the bonds of many mistaken beliefs passed on to her by her mother, and in the process released her anger and bitterness. At the conclusion, the allegro from Vivaldi's *The Four Seasons* (*Spring*) was played to signify a new beginning.

Outcome and Evaluation of the Intervention Process

Although there were other difficulties dealt with in Jody's treatment program, the issues noted have been selected for discussion to show how music was incorporated into therapy. The use of music not only facilitated but also enhanced the change process. Within months, Jody had achieved all her goals for therapy. She had also developed new friendships. Many of these were made when Jody and her husband found a suitable church and became involved in its activities. Jody was painting again and had established friendships in an art group. She managed to find a job, and the final goal was reached when she drove herself to therapy! After Andrew was recently transferred back to his company's head office in Cape Town, Jody moved back too. She used the techniques she learned in therapy to sustain the gains she made and to tackle new challenges. Jody later informed me that she had stopped smoking, was coping well, and had learned to enjoy her life, including driving her car.

Summary and Conclusion

This chapter has attempted to demonstrate the usefulness of music within the therapy situation whether one is working with individuals, groups, or communities. Some of the benefits identified include: (1) better verbal communication; (2) improved relationships, including the social worker and client relationship; (3) greater awareness of emotions; (4) increased spontaneity; (5) development of a more creative approach to life; (6) enhanced feelings of belonging; (7) attainment of greater insight and awareness of oneself; (8) access to an enjoyable means of relaxation and stress management; (9) methods for managing pain; and (10) empowerment of clients through self-expression.

In Jody's situation, there was a good response to various kinds of music for different purposes during her treatment. She was helped to select music that suited her needs at a particular time and to make use of it to achieve her desired goals. In Jody's case, the application of music in treatment was helpful and enhanced its process.

As social workers, we need to believe in the change process and have a commitment to assist our clients toward healthy life adjustments. We need to ensure that we work with our clients so that their needs, goals, and aspirations are kept foremost in the intervention program. Music has a universal appeal and significance in people's lives, and social work students and practitioners alike may wish to consider its potential within the practice situation. There may be some practice settings, situations, and clients where the listening or performing music may not be helpful (e.g., those whose religious beliefs don't allow it or when clients prefer other methods). As an expressive medium, music holds a great deal of power and potential for work with clients. However, it is important that the practitioner is trained and supervised in the use of music in practice situations. Research to validate the use of music within the social work profession is also necessary.

Reflection Questions and Exercises

1. What are the advantages and disadvantages of using music in the therapy situation?
2. Identify a few of your favourite pieces of music. Listen to these and describe the effects on you.
3. React to the following statement: “It is necessary to have a strong musical ability to use music in practice situations.” Justify your rationale.
4. Does producing or playing music have universal appeal? For which client groups or in what practice contexts do you think that music would be helpful? How could it be applied?
5. Describe, with examples, how a social worker who is equipped to use music in his or her practice might make use of it in the following situations:
    - with a group of elderly residents in a retirement home
    - with an eight-year-old child who needs to be prepared for major surgery
    - with high school children whose school football team was involved in a major bus accident in which 10 members were killed
    - with a couple who are experiencing sexual difficulties after 12 years of marriage
    - with a community of homeless men
    - with a six-year-old child who has severe brain injury

Exercises

1. In small groups, each person brings a favourite piece of music to play for the group.

    After hearing each person’s selected music, discuss the effects of the music on you. Try to put each of them into these musical categories: rhythmic, relaxing, evocative, reassuring, and moods.
2. Using the search words “music therapy,” find a Web site that looks interesting.

    Bring material on ethics, qualifications, and accreditation to discuss in class.
3. Locate examples of at least three of the following types of music: jazz, operatic, pop, Asian cultural, Polish folk songs, African cultural, and New Age music. In small groups, identify what the music from each of the categories selected evokes in each member.

Discuss which of the above music examples you feel could be useful in one social work setting.

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PART B

SOCIAL ISSUES AND HEALTH EFFECTS

Health and well-being are affected by a wide range of determinants, including material resources and entitlements to social security and social welfare; the physical and social environments that characterize a person's life; societal-structural features such as social inequality, racism, and poverty; individual behaviour, including lifestyle and health preventative actions, health beliefs and health care seeking; and one's biological and psychological characteristics. In the following four chapters, the links between health and basic needs, such as food and safety, and between cultural expression and practices are explored. The thread that joins all these chapters is the importance of hearing each client's account and supporting his or her capacity to face and deal with life crises and difficulties.

CHAPTER 7

FOOD BANKS:
Food Insecurity in a Land of Plenty?

Bruce Bidgood, Stephen Krzyzanowski,
Laura Taylor, and Shelley Smilek

Introduction

This chapter provides the reader with a broad understanding of food banks and food insecurity and its implications for health, mental health, and social work practice. Using findings from our research study, it explains the increase in the number of food banks in Canada; defines food insecurity, food banks, and emergency food hampers; explores the extent and reasons for food insecurity; chronicles the experiences of food bank users; provides some recommendations to address food security; and considers the implications of food insecurity for health, mental health, and social work practice. It also includes a case situation of a food bank user who discovers first-hand about the food bank experience.

Food banks have emerged over the past two decades to meet a need in Canadian society. They started as a short-term response to feeding the poor, a band-aid solution to the problems of poverty (Riches 1997a). However temporary in their foundational intent, it is clear that food banks have become permanent fixtures in our society and a necessity in the lives of many poor families (Starkey, Kuhnlein, and Gray-Donald 1998). The existence of food banks illustrates to us the impact that policy decisions and program cutbacks have on people, particularly on marginalized populations. They are a concrete example of the necessity of the ecological approach in our profession, which "[embodies] the dualistic essence of social work, our legacy of perceiving and addressing personal troubles and public issues concurrently" (Landon 1995).

Case Situation: Nadia

Nadia is a 24-year-old single mother with two children, Alexis (age three) and Nico (age 18 months). She is a recent immigrant to Canada who came here for an arranged marriage. The marriage was difficult and got worse after the birth of the couple's second child when her husband became physically abusive. She left him and went to a women's shelter where she received help in finding a small apartment in which to live. The child-protection agency has conducted an investigation of her parenting, which is routine in reported cases of domestic violence. Nadia's husband is refusing to support the children and it could take up to one year for her to receive child-support payments. She is still waiting for her first social-assistance cheque.

Her doctor has prescribed costly asthma medication for Alexis. Nadia has no benefits from a prescription plan. The shelter worker recommends the local food bank so that she can remain independent from her abusive husband. The child-protection worker wants her to go to the food bank in order to adequately parent her children. The social assistance worker says that the food bank will help her survive until her first cheque comes. Her doctor directs her to use the food bank to maintain her own health and the health of her children. Nadia goes to the food bank.

What Is Food Insecurity?

People turn to food banks because they are "food insecure." Lack of food is an emotional issue; we are haunted by images of starving and malnourished Third World children. A wide range of terms describe dietary inadequacy: hunger, starvation, undernutrition, malnutrition, nutritionally inadequate. The problem with using terms such as "hunger" or "malnutrition" to describe the condition of food bank users is that they are culturally specific and open to differential, and often emotional, interpretations (Bidgood and Cameron 1992; Carlson, Andrews, and Bickel 1998; Riches 1997a). In this chapter we refer to the condition of self-sufficient dietary resources as "food security" and those diets that are deficient in quantity, quality, and/or variety as "food insecurity." Davis (1991, p. 5) describes food security as "a condition in which all people, at all times, have access to sufficient nutritious, safe, affordable food that is culturally and personally acceptable and is obtained in a manner that maintains human dignity." Food security, therefore, is understood to consist of four elemental food conditions: (1) sufficient quantity, (2) acceptable quality (culturally and personally), (3) affordability, and (4) accessibility. By extension, the absence of one or any combination of these elements represents food insecurity. For many Canadians, local food banks offer the only temporary solution to food insecurity.

In the study discussed in this chapter, food insecurity was operationalized (measured) using an instrument in the United States Department of Agriculture's Food Security Module (Bicker, Nord, Price, Hamilton, and Cook 2000), which records the degree to which individuals have had difficulty meeting basic food needs during the past 12 months. The study participants' responses are converted to one of four categories: food secure, food insecure without hunger, food insecure with moderate hunger, and food insecure with severe hunger.

What Are Food Banks?

A food bank is a charitable organization that collects and redistributes donated food (Oderkirk 1992). They are a type of import/export business. Some food banks provide food directly to consumers whereas others rely on a network of community agencies and charities to distribute foodstuffs to people in need. Such organizations are typically operated by a small number of paid staff and a larger complement of volunteers. Items that are donated by private citizens and corporations are collected, sorted, stored, and used to construct "food hampers." A food hamper consists of a variety of items designed to meet a consumer's dietary needs for three to five days. The content of a food hamper is adjusted to the size and developmental needs (i.e., presence of children) of the food bank user.

The first known food bank in North America, St. Mary's Food Bank, was established in Phoenix, Arizona, in 1967. In Canada, the first food bank to open its doors was in Edmonton in 1981, followed closely by the Regina and District Food Bank, founded in 1982. Since that time, food banks have rapidly proliferated. There was a 64 percent increase in the number of food banks in Canada from 1991 to 1994 (Riches 1997b). Today, there are more than 900 food banks in Canada located in 465 communities within every province and territory (Yadlowski and

Thériault 1998). In 1989, 1.4 million people sought food bank assistance, and this number had more than doubled by 1997 (Tarasuk and Beaton 1999). Recent estimates suggest that 2.4 percent of the Canadian population have at one point used food banks; regional statistics for poorer provinces are even higher (Tarasuk and Beaton 1999).

Why Are Food Banks Needed?

It is not as a consequence of inadequate food supplies that food banks are needed. The United Nations has declared that the overall supply of food in the world is adequate and it is instead the inequitable distribution of food that necessitates emergency relief (Riches 1997a). It is not because of a poorly performing economy that food banks are required. In fact, Canada is experiencing a period of remarkable economic prosperity with increasing personal income and spending and decreasing national unemployment rates (Statistics Canada 2000). There is evidence to suggest, however, that the benefits of a prosperous economy are not shared equally by all citizens. Paradoxically, the number of people living in poverty in the country is on the rise (Ross, Scott, and Smith 2000). Where is the prosperity going? The answer is in what has now commonly been called "the poverty gap," the increasing polarization of wealth between the rich and the poor. The rich are getting richer and the poor are getting poorer (Ross, Scott, and Smith 2000; Tam 2000).

The creation and proliferation of food banks, the rising numbers of poor people, and the increasing poverty gap corresponds to nearly two decades of erosion of the Canadian social safety net. The cutbacks in social programs have frequently been identified as a major cause of the increase in food bank usage (Canadian Press Newswire 2001; Riches 1997b; Yadlowski and Thériault 1998). The increasing utilization of food banks at the end of the month—when government cheques run out—has been interpreted as a sign that benefit levels of income-assistance programs such as social assistance (welfare), unemployment, old age, and disability pensions are inadequate (Che and Chan 2001). The withdrawal of federal contributions to employment insurance and reductions in transfer payments for health and social assistance, along with provincial cutbacks in education and welfare, have left the Canadian social safety net torn. The result of these changes has meant that many citizens find themselves falling through the net of social welfare into an abyss of poverty and reliance upon public charity, including emergency food service.

The published answers to why food banks are needed routinely focus on macroeconomic and/or socio-political explanations, including: changing labour market conditions (Dréze and Sen 1989; Riches 1997a; Yadlowski and Thériault 1998); governmental policies that contribute to wealth polarization (Riches 1997a); cutbacks in social spending (Canadian Press Newswire 2001; Riches 1997a; Yadlowki and Thériault 1998); and increasing costs of living in both cities and rural regions (Canadian Press Newswire 2000; Yadlowski and Thériault 1998).

Tarasuk and Beaton (1999) asked 153 women food bank users why they were using the service. Forty-three percent simply stated that they did not have enough money to buy food. Inadequate income, not economic or socio-political explanations, figured most prominently in the consumers' words to describe their reliance on food banks.

Who Uses the Food Bank System?

To date, there have been few systematic attempts to describe the characteristics of food bank users. An exception is the Daily Bread Food Bank (DBFB) in Metropolitan Toronto, which maintains recipient profiles on consumers. Their data suggest that the majority of food bank consumers are women, single parents, people with disabilities, and senior citizens (DBFB 2002). Children constitute nearly half of all people assisted by food banks (Yadlowski and Thériault 1998). The majority of households using food banks are also supported in whole or in part by social assistance programs (Tarasuk and Beaton 1999). Increasingly, individuals with post-secondary education also rely on emergency food assistance. Visible minorities, immigrants, people with an ethnic identification other than Canadian, First Nations, and Latin Americans are overrepresented among food bank consumers (Riches 1997b). Starkey, Kuhnlein, and Gray-Donald (1998) found that in Montrèal, more than 57 percent of food bank users were immigrants to Canada. Yadlowski and Thériault (1998) note that language and cultural differences, including food preference, are barriers to greater participation among immigrants and culturally diverse minorities. Some food banks have begun to supply ethnic foods and an expanded array of services at food banks in an effort to redress minorities' lack of participation (Yadlowski and Thériault 1998).

In summary, food bank users seem to include those who are more likely to be dependent on the beneficence of others, such as children, youth, the elderly, the disabled, and/or those who experience material barriers to labour force participation, including women, single parents, those with little education, and minorities.

What Is It Like to Use a Food Bank?

Most food bank users consider using the service as a humiliating experience. Food bank consumers are a stigmatized population; stigma is an attribute that is deeply discrediting (Goffman 1963, p. 3). Society tends to blame food bank users for their own plight and applies labels such as "uneducated, lazy drunks" who do not know how to manage their money (Yadlowski and Thériault 1998, p. 14). When describing their first visit to a Toronto area food bank, 84 percent of women voiced feelings of shame, embarrassment, degradation, and humiliation, and 17 percent were determined never to let their children know about their reliance on emergency food relief (Tarasuk and Beaton 1999).

How Adequate Are the Food Hampers?

Receiving a food hamper is a humbling experience in terms of the quantity and quality of the food provided. Husbands (1999) found that 55 percent of welfare recipients and 37 percent of other households required more food than was provided in the food hampers. Teron and Tarasuk (1999) point out that hamper size and family size are not necessarily related; over 50 percent of the households composed of four or more people received less than a three-day supply of food. In addition to quantity, the quality of food items in hampers is frequently less than desirable. Often damaged or outdated food items were found in the hampers (Teron and Tarasuk 1999). The limited supply of fresh vegetables and dairy products means that hampers are deficient in vitamins A and D (Teron and Tarasuk 1999). The substandard food that many people receive in emergency food hampers contributes to consumers' feelings of embarrassment, degradation, and disempowerment. Since food bank users have little choice and many can't afford the transportation costs to "shop around" for better food banks, they accept the inadequate provisions offered.

Experiences of Food Bank Users

In order to understand the experience of food bank users, people in the Kitchener–Waterloo region of Ontario, Canada, were asked to provide their perceptions of and experiences with the emergency food bank system (Smilek, Bidgood, Parent, and Thompson 2001). Table 7.1 provides a summary of the characteristics of these participants. As the table shows, the average age of the groups represented was 36 years. More than half of the participants were female; over half had completed a high school education; and almost a quarter had also completed some post-secondary education. Many participants in the study also reported that they had made ongoing efforts to upgrade their education in order to improve their employability.

Our food bank users came from a wide variety of family configurations. However, it is important to note that lone parents represented approximately a third of the food bank participants in the study. Over half of the food bank users were children. Participants' average monthly income was just over $1,000 per month. Food bank consumers' monthly and yearly incomes fell far below the Statistics Canada Low Income Cutoff Standards (LICOS) for every family size. Ninety percent of the study participants reported incomes below the national poverty line standards. The issues of food insecurity, poverty, and income insecurity were closely related. The most common sources of income for our participants were derived from some form of governmental assistance; of this sample, the most common sources were from social assistance and disability pensions. Only one-third of the study participants reported that their primary source of income was through employment (full-time, part-time, or contract).

The high cost of housing for our participants left little money in their budgets for food. In some cases rent was greater than the total monthly income. For one-third of participants, more than 50 percent of their income was spent on rent. A rental expenditure in excess of 50 percent of the monthly income is considered a "severe affordability problem" (cited in Bezanson and McMurray 2000, p. 38). As shown in Table 7.1, people from a wide variety of demographic profiles have come to rely upon emergency food services. Particular groups such as women, single parents, and children appear to be overrepresented among our food bank participants. The one feature that virtually all food bank consumers share is poverty. Food insecurity is synonymous with income insecurity.

Image not available

Are Food Bank Users Really Food Insecure?

Some people believe that many food bank consumers use food hampers to supplement already adequate diets. This is not what we found! We discovered that over 90 percent of the food bank consumers were food insecure. As resources become constrained, adults in households that are food insecure "first worry about having enough food, then they stretch household resources and juggle other necessities, then decrease the quality and variety of household members' diets, then decrease the frequency and quantity of adults' food intake, and finally decrease the frequency and quantity of children's food intake" (Nord, Jemison, and Bickel 1999, p. 15).

Eighteen percent of the food bank users were assessed as food insecure without hunger. This means that they had not yet needed to reduce the size of meals for adults or children within their households, but that they were concerned with the adequacy of their food supply and reduced household food quality.

Forty-nine percent of the study participants were food insecure with moderate hunger. This occurs when the adult members of a household begin to reduce their food intakes to the extent that they are repeatedly experiencing the physical sensation of hunger so that the children in the household can eat. Tarasuk and Beaton (1999) report that this is a common strategy used by women food bank consumers and was explicitly articulated by one participant, who stated, "I myself eat only what I know won't be eaten by them."

The remaining 24 percent of participants were found to be food insecure with severe hunger. These individuals repeatedly experienced extensive reductions in food intake. In households with children, the children's food intake has been reduced to the extent that they too are experiencing hunger.

Why Did Participants Use Food Banks?

The participants reported food bank usage was related to a combination of circumstances that led to their reliance upon the food hamper program. These included: (1) lack of income, (2) income insecurity, (3) social assistance cutbacks, and (4) the high cost of living. As one participant said, "Even with a job that pays anything less than $9 an hour, you can't pay rent, run a vehicle, and have money left over for food." Regarding hours of employment, another stated, "Some weeks

I have extra hours; some weeks there are not enough to survive on." Another study participant mentioned, "I used to get $1,800, then $1,400, then $995, all in the last eight months due to ... cutbacks to social assistance."

Some participants noted the high cost of transportation. One said "Lack of income after rent and bills ... it doesn't last, especially after transportation at approximately $20 a week to look for work. This seems like a waste when at the end there is no job found." Participants noted the high cost of heating and electricity. "We have a baseboard heater. This has been very, very expensive ... almost half of our monthly budget."

A number of study participants commented that they were unprepared for the costs of raising children, including diapers, clothing, and shoes, as well as medical expenses and school fees for extracurricular activities. "When I became a parent, I was unprepared for those expenses."

Patterns of Food Bank Usage

The length of time that participants had been using food hamper programs ranged from three months to 12 years with an average of 48 months. Most participants made use of food hamper programs six times per year; with a range from two to 24 times per year. Use of food banks was sporadic, seasonal, or chronic. Some participants received a food hamper sporadically once or twice a year, particularly when unexpected expenses arose. For example, one participant described a situation when she was ill and required medication. She had to use her grocery money to buy the medication, which meant that she then had to rely on the emergency food hamper program for food. For others, food hamper program use was seasonal. A self-employed tow truck driver explained that his work was very busy during winter and summer, but was slower during the spring and fall. During spring and fall he often didn't have enough money to buy food, so he had to use emergency food hamper programs. The third group of food hamper recipients were those for whom the use of food hamper programs had become chronic. This group included individuals on pensions that do not provide them with enough money to pay their rent and buy food. Other examples are a single mother whose ex-husband did not pay child support and a young man who worked at a minimum-wage job while repaying a student loan. For individuals such as these, emergency food hamper programs and the food that they provide have become a necessary part of life. It is important to note that the present study assessed only the frequency with which people made use of food hamper programs, and not the frequency in their use of other kinds of community food programs. Approximately half the participants interviewed had also used some other community food program, such as soup kitchens, children's breakfast programs, and church voucher programs. These additional resources were used to supplement what they received from food banks.

What Is It Like at the Food Bank?

There is a strong sense of stigma associated with using emergency food services (Starkey, Kuhnlein, and Gray-Donald 1998; Tarasuk and Beaton 1999; Yadlowski and Theriault 1998). The food bank consumers in our study described feeling embarrassed, guilty, conspicuous, ashamed, uncomfortable, and stressed about having to rely on food hampers. "I don't feel I can go to the food hamper programs in my own home town. If you sometimes want to treat your kids at the Dairy Queen and then someone sees you and they know you get food from the hamper program, you feel so guilty." Along with the embarrassment, a number of participants described feeling simultaneously relieved and grateful that they now had food: "There are no words to describe it—anger, but you don't know where to direct it—at your ex-husband, at society, at the courts. It's humiliating, but I'm grateful too." The stigma associated with using the food bank was the worst during the first visit. There was a consensus that the negative feelings associated with receiving food hampers diminished with continued use: "The staff get to know you; you don't feel like a stranger walking in." There was also a suggestion that the amount of stigma that consumers experience is lessened when food banks use a self-help approach in which consumers volunteer and participate in the administration of the program and attend a variety of additional programs. The participants who used the lone self-help type of food bank described more positive feelings about using the service: "Here we get a sense of dignity and a pride within ourselves for contributing to the community. And the friendships we develop are a wonderful support system." Some said they felt better about themselves because they were given the opportunity to assist in the administration of the program as well to develop new skills. "They encouraged my participation in other programs ... the skills I have can be used more effectively now. I started bagging food, but now I do computer work."

The relative benefits of the self-help model of emergency food delivery appeared promising for these food bank users.

The experiences of food bank consumers suggested that a number of the service delivery practices of food hamper programs can actually serve as barriers to food security. Over half of the participants reported that they were not always able to obtain food hampers when they were needed. They identified a series of organizational obstacles, such as rules limiting frequency of usage, transportation problems, limited hours of operation, and lack of physical accessibility.

Each member agency of the food bank determines the maximum number of hampers that they will distribute to any one recipient in a given year, which ranges from six to 24 hampers per year. Many consumers feared that if they reached their frequency limits too early, they would have to go hungry later on in the year. Some chose to forego food at one point in time so that they would still have hampers available to them later on the year in case things "got worse." Transportation, whether by bus or car, was costly for many. "When you have to take the bus, you're paying and it's defeating the purpose." Several single parents described the difficulties they had in trying to juggle a large box of groceries and two or three young children while on a bus. Other participants stated that because it took them so long to travel by bus to get to the food bank that they could not make it if they had other appointments on the same day. Often barriers to food bank use include limited hours of operation and lack of access for people with physical difficulties.

Case Situation: Nadia

Once Nadia got home from the food bank and sorted through the food hamper, she noticed that there were no dairy products or fresh produce. Everything she was given came in a box or a can. Nadia also noticed that some of the expiry dates on the canned products had long since passed. She was concerned about their nutritional value. Nadia could not use some of the items because of the family's cultural beliefs and her son's dietary restrictions.

Nadia lives in an apartment some miles away. It takes her several bus trips and hours, with children in tow, to get a food hamper. She really can't afford the bus. Nadia has used the food bank for three consecutive months. The volunteer at the food bank notifies her that this is her final food hamper for the year. It is only April. What will she do next month?

Many participants in the food bank study confided that the emergency food hamper quality and composition was limited. "We have so much Kraft dinner and pastas. Although it keeps for a long time, some of it is outdated and so I don't want to bring it back in case it is recirculated again, but I hate to waste it too." Participants particularly lamented a scarcity of fresh produce in food hampers. A number of food bank consumers also stated that they often received items that did not complement one another, thus making it difficult to prepare meals, for example, pasta without sauce. Such contents represent a legitimate challenge for recipients to produce nutritionally adequate meals. "If I could choose, I wouldn't choose the cookies, cake mixes, etc. [included in food hampers]. I like to give my child juices and healthy food."

Yet participants needed the emergency food program. Some stated that they would survive somehow if there were no food bank, but they were not sure how. For food bank users with children, the idea of their children going without food was unbearable. Parents stated that they would starve themselves in order to feed their children and were willing to go without food, beg, and borrow money from friends and family in order to feed their children. Some thought that they would even resort to desperate measures if it meant that they would be able to feed their children. "I try to live cleanly, but without the food program, who knows? I have to feed my child." Although originally established as temporary relief measures, it is clear that emergency food banks had become permanent fixtures in the consciousness and day-to-day realities of many hamper recipients and were considered an essential resource that prevented their lives from potentially deteriorating into deviance and destitution.

Case Situation: Nadia

Nadia had put off going to the food bank as long as she could. What would people think? Eventually, however, she had to go. Nadia went at noon, which is the busiest time of the day at the food bank. She became anxious in the noisy, crowded environment. A volunteer noticed Nadia and sat down at a quiet table to talk with her about her situation. Nadia explained that she had no food to feed herself and her children. The volunteer asked a number of questions to find out what food staples would meet Nadia's needs. There were a number of food restrictions as a result of her faith and culture. Nadia also needed products that did not have white flour in them because of her child's allergies. The volunteer explained that the food bank has difficulty meeting special dietary needs as they rely on donations and must stock foods that do not spoil easily. Nadia took what she was offered.

What Can Be Done to Address Food Insecurity?

Food bank consumers have historically been excluded from the public debate and policy deliberations about food security (City of Toronto Department of Public Health 1994; Olson 1992). Embedded in the stories of our participants, however, were numerous suggestions on how to improve the food security of vulnerable citizens. These ideas could be categorized into three central themes: (1) emergency food service delivery, (2) the causes of food insecurity, and (3) areas for new knowledge.

The participants made several recommendations on how to improve service at food banks and food hamper distribution sites. These include: abolishing limits on frequency of use and yearly caps on usage; increasing accessibility through access to subsidized public transportation to the food banks; improving the quality and complementarity of items in food hampers; providing other on-site services such as budgeting and cooking lessons; and finding ways to reduce stigma of food bank use, perhaps through staff training and public awareness campaigns. A number of suggestions were implied in the stories of participants to more broadly address the causes of food insecurity, including: provision of a guaranteed income; enabling sustainable employment; implementing government reinvestment in health, education, and welfare programs; and development of supports to food security (i.e., subsidized public transportation, affordable housing, publicly funded day care). Finally, a number of gaps in our knowledge of food insecurity and food bank users were identified that need to be researched further. Research is needed to study the prevalence of food insecurity in the general population, combined impacts of cuts to federal and provincial programs that have generally been viewed in isolation to one another, and an examination of the changing nature of employment. Implicit in the participants' observations was a recognition that food insecurity is a complex, multiply-determined problem that necessitates "acting locally and thinking globally."

Implications for Health and Social Work Practice

What is the relationship between food security and health? The connection between issues of food security and health are fairly obvious. Adequate quantity and quality of food is essential to the maintenance of healthy functioning. This association was explicitly referred to by one respondent: "The program [food hamper] is good, but it isn't the answer to all your needs. Foods like bologna and brownie mixes don't make people healthy." While we tend to think of starvation and malnutrition as being primarily confined to the poorest countries, there is a substantial amount of data to suggest that dietary inadequacy can also be found in our own wealthier nation. There is evidence to suggest that even moderate hunger (missing meals) and dietary inadequacy (chronic deficiencies in key vitamins and food groups) have a range of deleterious effects on physical and cognitive functioning (Bidgood and Cameron 1988). This is particularly true for children who are at special risk due to their developmental vulnerability. Studies have found that chronic undernutrition has negative impacts on the perceptual, cognitive, behavioural, and psychological well-being of even reasonably well-nourished children (Ashem and Janes 1978; Pelican, O'Connel, Lewis, and Byrd-Bredbenner 1982; Stevens and Baxter 1981). Food insecurity erodes the health of adults and robs children of their potential, so food insecurity is a serious health issue.

How is food security relevant to social work practice? We frequently think of food banks (private charities) and social work programs (publicly funded) as representing two distinct service traditions. This is erroneous. There is a tremendous overlap between the consumers of food banks and the recipients of social work services. Social workers at all levels of practice and across a broad domain of practice settings have clients who are food bank consumers. In fact, many social workers have come to rely upon food banks as a key component in the provision of services to poor, oppressed, and marginalized clients. The message is clear: food bank consumers are social work clients.

Maslow (1970) identified a series of needs (physical, emotional, intellectual, and spiritual) that are hierarchically arranged. His theory suggests that basic human needs must be met before an individual is able to pursue emotional and intellectual needs, including self-actualization. This perspective has been broadly adopted by our profession. Social workers recognize that food insecurity is a material barrier to the achievement of human potential, a need that must be met before working with clients toward more abstract goals of personal change, insight, affiliation, and/or self-actualization.

Social work also embraces a variety of methods that range from individual psychotherapy (casework) to group work and community development. Therefore, social workers are, by virtue of their person-in-environment perspective and broad interventive repertoire, uniquely positioned to address barriers to food security. Social work can play a role in awareness of food insecurity.

Finally, the eradication of food insecurity is consistent with social justice, one of the most fundamental values of the social work profession. The pursuit of social justice is a professional ethical imperative prescribed in the Canadian Association of Social Workers' Code of Ethics: "A social worker shall promote social justice" (CASW 1994, p. 19). The United States National Association of Social Workers' (NASW) Code of Ethics also contains specific recommendations about the social work profession's responsibility to promote social justice: "social workers should engage in social and political action that seeks to ensure that all people have access to the resources, employment, services and opportunities they require to meet their basic human needs" (NASW 1997, sect. 6.04a). Jerome Wakefield (2001) holds that the pursuit of some minimal level of social justice is the essence of our profession and what makes us unique from other helping professions. The pursuit of distributive justice, including food security, is not just a professional obligation. Social workers as promoters of social justice can work to eliminate food insecurity and advocate for the basic need of all in society.

Reflection Questions

1. Provide three reasons why food security is relevant to social work practice.
2. How is food security a health issue?
3. What are the three fundamental elements in the definition of food security?
4. Identify three groups of people who are overrepresented among food bank users.
5. What is the one condition that virtually all food bank consumers have in common?
6. Describe the four reasons for food bank usage discussed by study participants.

7. What are four barriers to acquiring emergency food described by study participants?

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CHAPTER 8

A HEALING RESPONSE:

The Role of Social Workers in Supporting Children Affected by Domestic Violence

J. Elaine Walters and Jeff Todahl

Introduction to the Problem

By any estimate, violence against women by intimate partners—domestic violence—occurs at epidemic rates all over the world (World Health Organization 2002). The sheer numbers mean that social workers will encounter victims and perpetrators in every work setting. In this chapter we will focus on one of the most tragic realities of this type of violence: the millions of children who live in the line of fire and how seriously it affects them.

Research suggests that between 11 percent and 33 percent of all children (Jasinski and Williams 1998; Straus and Gelles 1990) live in homes where their caregiver, most often their mother, is being assaulted by an intimate partner. Often, these children directly witness the violence and all are affected by it. Children exposed to perpetrators of domestic violence are also at extreme risk of being direct targets of abuse themselves. This may begin as early as pregnancy and can continue throughout childhood. Even when the abuse is not directed at the child, it can have devastating consequences for his or her emotional, physical, and social well-being.

Although we are learning a great deal about the impact of trauma on human development and functioning, we don't always know how to help. In this chapter, information about the impact of violence on children's health and development and about the overlap between domestic violence and child abuse is discussed. In addition, practices and recommendations for appropriate assessment, intervention, and support for children and their parents will be discussed.

Definitions, Incidence, and Prevalence of Violence in the Home

Domestic violence can be narrowly defined as intentional physical assault of an intimate partner (National Research Council, Institute of Medicine 1998) or more broadly defined to include a wider range of behaviours such as degradation, intimidation, and other forms of psychological abuse (Koss, Goodman, Browne, Fitzgerald, Keita, and Russo 1994), sexual assault (Ganley and Schechter 1996), and additional coercive or controlling behaviours (Jouriles, McDonald, Norwood, and Ezell 2001; Yllo 1993). In this chapter, domestic violence and intimate partner assault are defined as: a pattern of assaultive and coercive behaviours, including physical, sexual, and psychological attacks and economic coercion, that adults or adolescents use to gain and maintain power and control over their intimate partners. If there is no intervention, the violence can become more severe and/or frequent, sometimes resulting in murder and/or suicide.

By pattern, we mean violence that continues over time, has a particular nature and quality, and is rooted in a larger social context that helps to perpetuate it. The range of violent tactics used by any given batterer will vary depending on history, circumstance, and habit, but the purpose—to punish, abuse, and ultimately control the thoughts, beliefs, and actions of their victims—is consistent. The use of particular strategies to get and maintain control challenges the theory that someone who is battering is out of control. People who batter use their anger and rage as a means to exercise control. In fact, defining domestic violence as anger misses the point and may endanger survivors.

Though some women do batter men, and some women batter their female partners, it is widely agreed that the impact of male and female acts of aggression differ significantly. When assaultive incidents are classified by injury, women are the victims 94 percent of the time, while men are victims (injured) only 14 percent of the time, a 7 to 1 ratio (Stets and Straus 1989). Finally, it is generally believed that females rarely systematically engage in coercive control tactics that create an environment of oppression, intimidation, isolation, and terror.

Racism, classism, and other overlapping forms of oppression may be influential, but the gendered nature of most domestic violence can be explained by recognizing its foundation as sexism. The treatment of women as property and servants, for example, without equal rights or personhood has a long and prevalent history in many cultures throughout the world, including those considered to be the most modern. It is important, however, to dispel the myth that males are biologically predisposed to be violent or that women are predisposed to be victims. Domestic violence, like most forms of violence, is learned behaviour. In fact, men who batter their female partners have been conditioned often through exposure to violence by men in their own childhood homes (Dutton 1995) to expect adherence and to play out rigid and stereotypical gender roles with their female partners.

It must also be noted that domestic violence occurs in same-sex couples and that many of these couples have children (West 1998). Social workers need to be aware of and be prepared to deal with all kinds of families and individuals without making assumptions about them. In addition, understanding the dynamics of domestic violence in same-sex relationships can enhance our understanding of intimate partner violence in general. It provides further evidence, for example, that men can be (and are) victims and that women can also be (and are) perpetrators of domestic violence.

The Nature of Child Exposure

Children's exposure to domestic violence varies. Children may themselves be directly targeted, indirectly exposed, or both. The exposure may occur periodically or routinely and across a continuum of severity. Their experiences, funnelled through their young minds, are understood according to their cognitive development. What do children tend to experience? How do they experience it? And what do they do when faced with terrifying and untenable circumstances?

Research suggests that children exposed to domestic violence use three primary during-the-event response strategies: (1) distancing themselves from the event; (2) distracting themselves and/or the adults; and (3) intervening directly in it (Garcia O'Hearn, Margolin, and John 1997; Margolin 1998; Peled 1998). Children who distance themselves leave their homes, huddle in protective spaces such as closets, cover their ears, create distractions (e.g., television, music), and psychologically protect themselves by willing away the event and their feelings about it.

Betsy McAlister Groves (2002) in *Children Who See Too Much*, described her work with one child who witnessed the violent shooting of his mother. In the account, Groves discussed her efforts to engage the child, Daquan, in drawing the event. Daquan asked Groves for help in drawing a lady who was lying down. He then added red crayon to show blood, and tried to recall what happened.

> He told me that the man was wearing a blue shirt and that he talked loudly. He heard a big noise and his mom fell down. He then told me that he had gone upstairs to sleep in his bedroom. I now understood that this event was so overwhelming to Daquan that he had withdrawn to the world of sleep. Daquan drew very quiet and continued to look at the picture. He reached out to touch it and ran his fingers over the drawing of his mother. It was as though he were trying to touch her. (Groves 2002, p.15)

In Peled's (1998) study, the children who got involved in events took sides in arguments, protected their abused mothers by jumping into the middle of it, or called the police. Children may be assaulted or threatened while in their mother's arms. Abusive partners sometimes take children hostage to force the mother to return home, use children as a physical weapon against the victim, force the child to watch assaults against the mother or to participate in the abuse, and may use children to gain information about their mother's activities (Ganley and Schechter 1996). Abusive fathers also sometimes tell their children that their families would be together if not for their mother's behaviour and disclosure (Edleson 1999). Also, children who directly intervene to try to stop the abuse often become targets and may experience repeated failure in their efforts (Graham-Bermann 2001).

Children who do not act to stop the abuse face another kind of hardship. Groves (2002) described such an event, in the case of police who found three children watching television in the living room of a house in which a violent attack against their mother had just taken place. The police referred to the children as uncaring because they had not come out of the room during the attack and continued to watch television. Groves (2002), however, related that the children were actually very much aware of what had occurred, but they were both terrified and immobilized, using television as their only means of retreating from the horror. A nine-year-old child had stood outside his parents' bedroom door, but did not go in because he had been taught not to enter if the bedroom door was closed. Although he wanted to help his mother, he was afraid to break this rule and was afraid of his angry father. Groves commented that the boy experienced a painful struggle during the incident, and with his siblings, responded as children often do when they are terrified. This was costly for the child "because it left the children with considerable guilt at having abandoned their mother in her time of need" (pp. 19–20).

Children also face the weight and confusion of the aftermath of violence (e.g., visible injury in a mother, medical needs, or post-event emotional responses), an aggressive parent who is both violent and caring, visits by the police, displacement from their homes, and behaviours that ignore, understate, or dismiss the abuse.

Impact

For very young children, exposure to domestic violence directly threatens the sense of stability and security that is critical to healthy brain development. Preschool-aged children, who are developmentally egocentric, may believe that they are responsible for the violence and for stopping it. These children try to manage their emotions and soothe themselves, skills that require good modelling and healthy attachment to master. Mothers who are battered and consequently injured or frightened may find it particularly difficult to reassure and care for traumatized children. Young children exposed to violence may experience developmental delays or regression, aggression, difficulty bonding, eating, and sleeping, and symptoms of post-traumatic stress (Geffner, Jaffe, and Sudermann 2000; Graham-Bermann 2001). However, children tend to be resilient and, with appropriate intervention, can be helped toward healthy development.

Older children are developmentally focused on individuation and peer group acceptance. Exposure to domestic violence may cause damage or distortions to their self-esteem, confusion about gender and social identity, and an impaired capacity to create and maintain healthy friendships. They are more vulnerable to accepting the rationalization for the violence (e.g., "it's her fault," "she's a slut") and to being influenced by negative media messages about gender and violence. Adolescents are at increased risk of delinquency and violence in their dating relationships. Parent-teen conflicts, which are normal in many families, may become more pronounced and dangerous when there is a history of exposure to domestic violence.

Protective Factors

There is much variation in how domestic violence impacts children (Hughes 1997; Hughes and Luke 1998; Sullivan, Nguyen, Allen, Bybee, and Juras 2000), which can be explained by many factors: (1) limitations in the current research literature; (2) variation in the nature of the violence, such as in severity, degree, and length of exposure, co-occurrence, and a combination of violence and neglect; (3) the extent of additional stressors such as parental substance abuse and community conditions; and (4) protective factors (Edleson 1999a; Edleson, in press).

Protective factors are behaviours, conditions, and individual traits that moderate the degree to which children are affected by violence. Certain individual characteristics, sometimes referred to as a person's resilience (Luthar 1993; Masten, Best, and Garmezy 1990; Masten and Coatsworth 1998; Valentine and Feinauer 1993), may mediate the negative impact of violence. For instance, children who: (1) attribute responsibility to the aggressor and not their own conduct; (2) have a temperament that elicits social support; (3) have a sense of humour; (4) have an interest or talent they pursue; and (5) are pro-social, relatively intelligent, and optimistic tend to have fewer negative effects (Kumpfer and Alvarado 1998; Rak and Patterson 1996).

Social service and health care professionals are beginning to recognize the importance of protective factors in their work and in their clients' lives (Christensen, Todahl, and Barrett 1999; Pecora, Whittaker, Maluccio, Barth, and Plotnick 1992). Social workers can use almost any encounter with a child affected by domestic violence to identify and build on protective factors. Assessing children's exposure, how it has affected them, whether or not they are currently safe, who supports them emotionally, and the needs that children express must form the basis for further intervention.

Guiding Principles for Intervening

Any intervention designed to protect or rescue children from exposure to domestic violence necessarily involves the adult, usually their mother, who is being battered. Guidelines for interventions therefore apply to adults who are battered and to their children. Any intervention needs to consider safety first, be empowerment-based, promote advocacy, and hold batterers accountable for their violence (Ganley

1995). Intervention must also reflect and build on the strengths of each individual and his or her community, supported by an effective and coordinated community response.

To intervene safely and appropriately, those who help must be conscious in their efforts to identify the presence of domestic violence in the lives of their clients. Screening for domestic violence requires skill, thoughtfulness, routine practice, special care, and patience. A growing number of social service organizations now have protocols for screening clients for domestic violence, and many provide suggestions and training on how to do it. (See, for example, Chapter 12 in this book.)

Safety

Safety is the most important consideration when intervening. Attention must be given to emotional, physical, immediate, and long-term safety. Once domestic violence has been identified, there are opportunities for social workers and others to be extremely helpful in increasing safety for adult and child survivors. Safety planning with both children and adults is a practical intervention that may mean the difference between life and death. It occurs through conversation with survivors about self-preservation and protection of children when living with or escaping from a perpetrator of domestic violence. While the social worker can offer guidance and facilitate the conversation, it is the survivor who ultimately develops and implements a plan. She is intimately familiar with her aggressor's thoughts, actions, and responses, and she has the information and ability to assess risk and lethality. She must also be supported to work through age-appropriate safety planning with those children who are able to understand and communicate.

Agreements between mothers and children about how to stay safe or escape a violent situation (such as what to do, where to hide, who to call, where to meet, etc.) need to be coordinated whenever possible. However, social workers and other helpers can make sure that any child who needs a plan in place will get one, with or without the mother's support. Effective safety planning requires social workers and others who help to be familiar with available local resources, such as legal assistance, court-ordered protective and stalking orders, supervised visitation and access (an international Web site can be found at www.svnetwork.net), housing, advocacy, and financial support, among others. For a sample "script" for a safety planning conversation, see www.endabuse.org/resources.

Empowerment

Judith Herman (1992) identified disempowerment and disconnection as the core experiences of psychological trauma. Domestic violence, she argues, can be equivalent to enslavement and captivity, including an increasing elimination of autonomy. This can be true for both adult and child victims. Obedience, loyalty, and accommodation to the abuser are prioritized over one's own choice, individuality, and self-determination. Empowerment not only supports survivors in their recovery from domestic violence, it is critical to their survival in the first place. It is imperative that survivors define their own terms, assess their own safety, create their own plans of action, and are supported to make their own decisions.

Well-intentioned helpers who create and attempt to promote or enforce their own plans can put adult and child survivors in grave danger. A simple example is the use of authority to make survivors leave their batterers. Survivors know, based on experience, that leaving is the most dangerous time. It is the time when a batterer may actually be most likely to murder or seriously hurt them (Walker 2000). Given this potential, any social service intervention should actively solicit the opinions and wishes of child and adult victims and should base service planning on them.

Advocacy

Combined with an empowerment-based approach, advocacy with child and adult survivors of domestic violence requires a partnership, rather than simply doing things for them. In practical terms this may mean, for example, documenting the domestic violence in confidential records and letting survivors know what we're doing and how they can view records about themselves. It may mean we support survivors to contact child-protection services themselves while we sit with them instead of making the report directly. Advocacy, in an empowerment style, also means that we allow ourselves to be clumsy and human and to make mistakes sometimes. If we don't know how to help, we can support survivors to find those who can. If we don't know anything about the service we're referring someone to, we will take the time to learn about it, sometimes together with the survivor.

Advocacy work to end domestic violence and to support survivors in general must also include challenging the systems, structures, and beliefs that tolerate, support, or promote violence against women and children. It means actively taking a stand, questioning our own practices and procedures, and keeping the voices and needs of adult and child survivors present in our interventions.

Accountability

People who batter are responsible for their own behaviour, no matter what the circumstances, how they were hurt as children, or their stated or unstated reasons for violent behaviour. Individuals who behave violently often justify their actions and displace responsibility. This dynamic may also be reflected in the community, where non-offending parents (usually mothers) are blamed for their child's maltreatment. Recognizing this, many non-offending parents do not seek help, fearing they will be held accountable for what, in reality, is someone else's behaviour (Schechter and Edleson 1999).

Perpetrators of violence, not their victims, are accountable for their violent and coercive actions. Domestic violence diminishes everyone involved, including the perpetrator. A system of accountability and intervention, properly placed, can help stop people from battering and can assist them in learning how to develop and maintain egalitarian and respectful intimate relationships. Moreover, communities must be organized so that adult victims of domestic violence have real choices, both for themselves and their children. This includes a delivery system that provides financial support, education, housing, child care, and culturally appropriate and accessible services. Moreover, statutes and protocols in the justice system need to effectively identify violence and lead to convictions and consequences whenever appropriate. In this way, domestic violence survivors can reliably anticipate support, and individuals who behave violently can expect real consequences.

A Strengths and Client Competency-Based Orientation to Practice

Historically, social services have operated according to a deficit orientation, in which assessment criteria emphasize illness and symptomatic behaviour. A different trend, however, is emerging. Influenced by feminism and social constructionism, professional practice is increasingly focused on competencies, strengths, and exceptions to problematic behaviour. Hubble, Duncan, and Miller (1999), in an analysis of literature on counselling effectiveness, argued that environmental factors contribute most significantly to positive outcomes. Recognizing this, therapists, advocates, social workers, and others are increasingly intentional in their efforts to stress and thoughtfully support the mobilization of clients' own naturally occurring resources. People are seen as experts of their own situations. "What do you believe is important?" "When you've been in this situation before, what were all of the things you did that were useful?" "What do you believe you need?" "How can I assist you?" These questions are consistent with a strengths-based orientation.

Coordinated Community Responses

Domestic violence is a community responsibility. The education, health care, social service, religious, criminal justice, child protection, legal, political, and business communities, among others, all deal with domestic violence on a regular basis (Schechter and Edleson 1999). Coordination within and across these various systems can increase consistency and responsiveness, properly place and address accountability, create earlier intervention and safety-based protocols, and enhance prevention efforts. Every individual in the community—professional, para-professional, and otherwise—has a responsibility to understand the complexities of domestic violence and its impact on children, to be familiar with community resources, and to participate in or otherwise support local coordination efforts. Including survivors in the design, implementation, and evaluation of any effort or service to address domestic violence will directly influence how successful they will be. Coordinating outreach and networking efforts directly with survivors can prevent isolation and, for those who are already isolated, can reconnect them with communities.

A Healing Response

Domestic violence includes degradation, violation, domination, humiliation, oppression, and injury and its threat. It is painful and leaves emotional and physical scars. Thinking about domestic violence and its impact on children brings up strong feelings for many of us. Beyond the general protectiveness many of us feel, some of us have been directly exposed to violence in our own lives and families. Though we are often taught to suppress our personal responses to what we see in our professional lives, these experiences directly influence our ability to respond. It is necessary, therefore, to deal with our own feelings and experiences in order to do our best work with clients. In practical terms, this requires us to build in the time for self-care and for our own healing. This is especially true for social workers and other helpers who will come into direct contact with survivors in their daily work. Taking care of ourselves models what we want for our clients, and keeps us more able to do the work over a long term. Many of us remember a time when one person made a significant difference in our lives. You may be that person for a child or adult living with domestic violence. Do not minimize your own importance.

Given the right conditions, child and adult victims of violence not only can and do heal, many heal completely and go on to thrive. Social workers are often in a position to be extremely helpful in this process, whether the contact lasts only one minute or goes on for years. Based on the above principles, there are many simple and practical ways to support healing and recovery, and some that are deeper and more complicated. What we say and do absolutely matters, but *how* we say and do it may be even more important. Our tone, body language, and willingness to listen can make the difference between a healing response and one that pushes people even further into isolation.

Healing, naturally, is a process. Its fruits are evidenced when, among other things, the trauma and its echo no longer command the central part of one's life (Herman 1992). With healing, survivors learn to claim and reclaim their ability to determine their own goals and actions. Although time can heal to some extent, it is not, on its own, adequate. In order to heal, children who have witnessed domestic violence or who have been directly targeted for abuse have a need for interventions that: (1) support their parents to heal and be non-violent; (2) allow them to talk openly about their experiences; (3) help them to understand that the violence is not their fault; (4) help them to learn that violence is not okay; (5) help them to learn respectful ways of relating; (6) dispel myths about woman abuse; and (7) establish safety plans.

The need for safety cannot be stressed too often. It is very difficult, perhaps even impossible, to heal while in the midst of danger. Therefore, efforts to facilitate and support safety are crucial. In addition to the need for practical safety plans, attention must also be given to emotional safety. It is important, for example, to prepare children and adults to discuss traumatic memories so that the discussion itself is not unduly traumatic. Preparation can include: (1) predicting the possible emotional and physical responses, such as anxiety and vivid memories associated with discussing the trauma; (2) development of relaxation and coping strategies (self-soothing) so as to deal with the natural responses to discussing the trauma; and (3) agreements regarding the pacing and content of the discussions. A relationship that is collaborative, yet places control of the recovery process in the hands of clients, is fundamentally safe.

In all cases it is critical to stay open and interested when a child or adult is talking or expressing feelings about their experiences related to domestic violence. Children may draw pictures, use very short sentences, play-act, or use ways of communicating that are often dismissed by adults. Social workers can empower these children by paying close attention to their many ways of asking for help and expressing themselves. While maintaining a non-judgmental and non-reactive stance, actively listening to children (and adults) immediately destroys isolation and reasserts the existence and value of the speaker. It also communicates caring and compassion, often contradicting the messages given to them by batterers. In this environment, survivors can be vulnerable, take risks, remember and review painful details, and mourn. Further, active listening brings us face to face with the details of our client's particular situation, including beliefs about himself or herself, his or her significant others, and relevant events.

In this context, our explanations and key messages can earn credibility. For instance, when a victim takes the blame for a perpetrator's actions and, due to our previous listening, we know something about the events or messages that led to these misperceptions, we can offer credible alternative explanations. At the same time, communicating key messages such as "it's not your fault"; "no one deserves to be abused"; "you aren't alone"; and "there's help available" can be meaningful and effective. In this way, listening and reframing are intimately tied. Supporting the reconstruing or reframing of memory and beliefs about the events surrounding the violence and about oneself, often systematically and deliberately distorted over time by the perpetrator, is essential to healing for both child and adult victims.

Victims of domestic violence become isolated from their own interests and identities, their social network, and their community. Often, those who use violence to control convince child and adult victims that their allies have forgotten or betrayed them. Not unlike political prisoners in solitary confinement, domestic violence perpetrators deliberately isolate their victims from social support, access to information, and alternative points of view. The perpetrator's power gains strength in isolation. Healing, therefore, is fundamentally about reconnection with oneself, one's right to self-determination, and with one's community. Therefore, regardless of our particular professional role, every encounter we have with child and adult survivors of domestic violence is an opportunity to create a healing context. Even in places such as mandated service settings and courts, we can facilitate healing by behaving in a manner that communicates the respect and value we have for each client.

In many cases social workers may never know the outcome of their interventions. Survivors move their children away to safety, change their names, go into emergency shelters, and seek help and support in many other places. In these cases, success can be measured only in the quality of the interaction. We can ask, "Was there a good connection?" "Did the child and/or adult feel heard?" and "Would the client be more likely to reach out again because of how things went?" Every interaction with child and adult survivors is important. Each person along the path toward safety and healing has a role to play. Assume that you make a difference in the lives of those affected by violence, because it's true.

■ Case Situation

Scene 1

Lucy and Joel live with their two-year-old son Joey in an apartment in a small town. Lucy is six months pregnant. Early one evening the police were called by neighbours who heard crashing sounds and screaming coming from their home. When the police arrive, Joel is sitting calmly on the front steps with a packed duffle bag at his side. As they approach him he stands, smiles, and extends his hand to greet one of the officers whom he knows. The officer declines to take his hand and instead asks him what's going on. The other officer, a woman, sees Lucy looking out the window and speaks with her.

Although Joel denied the use of any physical violence, Lucy had numerous injuries, including red marks on her abdomen and neck. Her two-year-old son, Joey, was crying and clinging to her legs. Joel was arrested and spent 48 hours in jail before being released with an order to stay away from Lucy and Joey until a court hearing was scheduled 30 days late. The police report, including photographs of Lucy's injuries, was forwarded to the child-protection service. You are the social worker at the child-protection service assigned to work with this situation.

Reflection Questions

1. Assuming empowerment, safety-focused, and strength-based guiding principles, what are the most important things to do? What are the things one would not do?

   While collecting information from Lucy, you include the following questions, among others:

   > "Please tell me, from your point of view, what happened the other evening. I've read the report and want to know what it was like for you." "What are you most concerned about?" "What are your ideas about what would help you and your children?" "What would you like to have happen?"

   During this discussion, Lucy vaguely describes the incident. She tells you that Joel is under a lot of stress and gets carried away at times. She reassures you that Joel loves Joey, would never hurt him, and that Joey doesn't hear their disagreements. Her basic position is that Joel is a good person, is making changes, and doesn't want to hurt her.
2. What are all of the factors that might be influencing Lucy's basic position?
3. Given the guiding principles outlined in this chapter, what position will you take with Lucy? What will you say to her? How will you say it?

   At that point, you decide to assess the risk to this client and her child should they return to live with Joel, and to develop a safety plan.
4. What is the most important information to gather in a risk assessment?
5. How will you use the information gathered in the risk assessment to inform the safety plan in this situation?

Scene 2

Lucy Simmons has come to the Mental Health Clinic for counselling services with her two children, Joey, age four and a half, and Mary, age two. At her intake appointment Lucy acknowledged that both children have witnessed violence since birth. She said her ex-husband, Joel, continues to harass her and she feels confused about what to do. Despite the known history of abuse, the court awarded Joel unsupervised visitation every other weekend with the children. Lucy said the children are more violent with each other and more emotionally withdrawn from her after visiting their father. She occasionally sees bruises on Joey, but neither he nor the father will tell her what happened. Joey's primary exhibited behaviour has been aggression, most recently toward his sister and the family dog. He was unable to stay in his most recent preschool because he bit and pinched other children. Mary does all right in day care, but doesn't seem to be progressing developmentally. She suffers from continual diaper rash after a regression to bedwetting again.

Reflection Question

6. What are your biggest concerns about this situation? How will you talk with the children about this? How will you talk with mom about this if the children are present?

Scene 3

Joey, now 13, has had ongoing difficulty in school. He does well socially, although his grades are low and he has a growing record of truancy. Teachers generally regard him as a nice kid who doesn't apply himself to schoolwork. One afternoon, in the hallway, a teacher overhears him say to a friend, "You know she wanted it. They'll tell you they don't. Sometimes you've got to whip them into shape." The teacher, upset by this, reports it to you, a school social worker. You decide to meet with Joey. You know nothing about his background, including his history of domestic violence exposure.

Reflection Questions

7. What is your personal response to this account? Given the guiding principles, how will you approach your conversation with Joey? What are the most important messages for Joey?
8. Will you involve his mother in the conversation? If so, how will you involve her?

You decide to call Joey's primary guardian, his mother. You introduce yourself and say the following: "Joey was overheard saying something that upset one of our teachers. I wanted to tell you about it and to ask for your help. I'm thinking I will talk with him, and would like your advice and input before I do that. And, perhaps there's another approach to take. Can we discuss this now?"

Lucy is concerned about Joey's comments and is very engaged in the conversation. She gives you some important background information and has several suggestions. Together, you plan an intervention and agree that your primary goal is to help Joey think through his statements and to imagine their impact. Lucy tells you that Joey's uncle, Brad, who is non-violent, is very important to him, as is Mr. Solberg, Joey's history teacher. Lucy arranges to have Brad talk with Joey about his views about women and how he treats his partner. You create a similar plan with Mr. Solberg.

Reflection Question

9. How will you preface your comments to minimize Joey's possible defensiveness? In your work with Joey, how will you balance empowerment and accountability?

APPENDIX A

Intervention and Treatment Needs for Children and Parents Affected by Domestic Violence

Children

- Key messages
- Safety planning
- Basic needs
- Every attempt to keep children and non-offending parents together
- Frequent contact with parents if in substitute care
- Protection of confidentiality (i.e., children's disclosures are not shared with the offending parent)
- Consideration of children's wishes when making decisions regarding visitation
- Supervised-only visitation with offenders

Advocacy, therapeutic, and educational approaches that

- Address safety concerns as a first priority
- Help children understand they are not responsible for the domestic violence, cannot change it nor control it

- Teach them to identify feelings and express them in healthy ways
- Work with them to build self-esteem and sense of self-worth
- Directly address trauma

Parents

- Safety planning
- Basic needs
- Every attempt to keep children and non-offending parents together
- Frequent contact with children if in substitute care
- Protection of confidentiality (i.e., survivors' disclosures are not shared with the offending partner)
- Adult survivor's wishes considered when making decisions regarding visitation
- Supervised-only exchanges and visitation between children and offenders

Advocacy, therapeutic, and educational approaches:

- Address the safety needs of adult survivors
- Teach alternative, non-violent methods of discipline, limit setting, and communication
- Provide opportunities to resolve their own experiences of violence and trauma
- Hold perpetrators accountable for their violence while offering intervention groups and parenting support and education when appropriate

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CHAPTER 9

VIOLENCE AGAINST WOMEN DURING PREGNANCY:

Issues, Risks, and Intervention

Deborah Walsh and Wendy Weeks[1]

Introduction

Domestic violence has been referred to as a violation of one of women's most basic of human rights—that is, the right to be safe. Statistics report that from 10–50 percent of all women in societies around the world are estimated to have suffered physical violence from their male partners (Heise, Ellsberg, and Gottemoeller 1999, p. 9).

In a number of contexts the terms "violence" and "abuse" are used interchangeably to mean both physical and psychological violence (MacDonald 1998), while in other studies the use of the term "abuse" is assumed to mean only verbal or psychological abuse and the term "violence" to mean actual physical assault (MacDonald 1998).

This chapter will discuss the contentious issues regarding definitions of violence and abuse, and their impact on women and service delivery. The term we prefer is "violence against women," which includes both physical and psychological acts that establish and maintain power and control over women. In this chapter we will confine ourselves to physical and psychological violence against women by their intimate male partners.

Definition of Violence Against Women

A review of the literature on violence reveals an enormous variation in the terminology used. In Australia the terms "family violence," "spouse abuse," "wife battering," "battering," "violence against women," "criminal assault in the home," "intimate partner violence," and "domestic violence" are all used. Upon closer examination it becomes clear that these various terms cannot be used interchangeably, as each is characterized by varying assumptions and each refers to substantially different phenomena. Weeks (2000, p. 276) argues that, "Different terminology and concepts are not simply linguistic debates but contain different assumptions, perspectives and experiences and lead to different responses to the extent and nature of violence against women."

Further evidence of this definitional dilemma can be found in research literature on the occurrence of violence by intimate partners. While physical violence is often assumed, what is being measured varies widely. For example, Hegarty and Roberts (1998, p. 48), in their review of research on domestic violence studies from around the world, found that violence affected from 2–28 percent of the female population depending on the definition used in each study. To make sense of any of the studies, it is critical, then, to understand whether there are underlying assumptions in the concepts applied and exactly what each study aims to measure. It is important, for example, to know whether the research measured recent actual physical assault resulting in actual bodily harm. Identifying the definitions and concepts used in some studies can be an investigation in itself, for as MacDonald (1998) found, definitions of concepts (including their operationalization) are sometimes not discussed in research summaries, abstracts, or reports, leaving readers uncertain as to the applicability of study findings.

It is reasonable to assume that if research varies in the definition of terms and contributes to a lack of clarity, then the wider community will reflect this confusion, with implications for women's health care services. If certain violent behaviours are considered normal and women do not seek assistance, they may risk their own health and that of their unborn children. This is further confounded by the fact that many human service agencies also define violence differently. MacDonald (1998) cites a situation in which a woman was being assaulted by her 29-year-old son and was refused assistance by a domestic violence service because she was not being assaulted by a partner. It appears that the workers defined domestic violence as spousal abuse, which excluded other forms of family violence. These are, unfortunately, the realities of definitional dilemmas as they translate into practice and affect the experience of women who require help. It is important for social workers to be aware of the operational definition of violence used by human service agencies use before service users are referred, so exclusion can be avoided.

Cook and Bessant (1997) argue that we need to operate with an inclusive understanding of violence against women, including all its subtle forms, as a first step in responding to and preventing violence. Women's stories of violence have been a topic of feminist research and have generated discussion about the extent and forms of violence against women. Cook and Bessant (1997, p. 8) state: "This non-naming of certain behaviour as violence makes it extremely difficult if not impossible to redress it." It is critical that each of us is clear about what we mean, particularly in our practice. A useful definition of violence against women needs to encompass an appropriate range of responses.

Violence against women in families is defined as intentional violent, threatening, coercive, or controlling behaviour in intimate relationships. It includes not only physical injury, but direct or indirect threats, sexual abuse, emotional and psychological torment, economic control, property damage, and enforced social isolation. It is an abuse of power, one that is socially constructed, not biologically determined and is a violation of human rights, opposing safety, dignity, integrity, equality in the family and before the law (Walsh 2001).

While men are the actors in the majority of documented incidents of domestic violence against women, violence is not exclusive to intimate heterosexual couples. Social workers need to be aware of how they define terms, and be open to challenge this. It can assist them to develop a more inclusive view of violence, one that includes relationships between siblings, children and parents, elders, gays and lesbians in our service user population. Exclusiveness conflicts with social work ethics and principles of practice.

This chapter reviews some of the literature on violence experienced by women when they are pregnant. The implication for women and children's health is enormous and while difficult to calculate the resultant health cost, it is reported to run into the billions of Australian dollars per year (Cox and Leonard 1991; KPMG Consulting 1994). It has also been noted that much domestic violence goes unreported and undiagnosed (Cox and Leonard 1991; KPMG Consulting 1994).

In Australia, professional responses to the occurrence of violence against women in the medical and social work field have become important. It is particularly necessary for professionals to address this issue in their practice as it has been found that if a first disclosure or an attempt at disclosing is not handled appropriately, it may be many years before the woman tries to seek help again (Atkins 1995). With pregnant women such delays can lead to serious injury and after-effects that affect both themselves and their children (Bullock and McFarlane 1989; MacFarlane, Parker, and Soeken 1996a; McFarlane, Parker, Soeken, and Bullock 1992; Quinlivan 2000). To aid in the work with victims (who are also survivors) of violence, a suggested guide for practice is outlined with a case scenario that might be seen in social work situations.

The Australian Context

Since the early 1970s, violence against women has been highlighted by the Australian women's movement as an issue of serious concern and a violation of women's fundamental human rights. Its international significance was recognized when the United Nations appointed a special rapporteur in 1994. The first Australian women's shelters were established in 1974. During 1988, the government launched a National Agenda for Women, giving priority to violence against women, and funded a three-year community and professional education campaign. In 1991 the Labour government initiated a National Committee on Violence against Women. A decade later, in 1997, the federal, state, and territory governments endorsed Partnerships against Domestic Violence, an initiative between the commonwealth, the states, and territories, to work together toward the common goal of preventing domestic violence across Australia through action research (Strategic Partners 1999). Following 30 years of development by the feminist women's health and welfare service sector, this initiative provides Australians with a unique national framework in which standards of practice are now being developed in a range of professional areas of health and welfare. Many themes have emerged through women speaking out about their lives, one of which is violence during pregnancy. Practice experience, together with current research, has identified the fact that many women disclose they have experienced either their first assault, or assaults that escalated, during pregnancy. This issue has grave implications for the health and welfare of women and children.

The issue of violence against women during pregnancy has only recently gained attention here in Australia, legitimated by the findings of the Australian Bureau of Statistics' (1996) Survey of Women's Safety. To date only two states (Queensland and New South Wales) have implemented state-funded detection and intervention strategies as part of antenatal health care (Irwin and Waugh 2001; Stratigos 2000). There is still much advocacy work to be done in this area in the other states.

Violence against women is a violation of human rights and a serious issue for social workers to address and has led, in the 1980s and 1990s, to the development of women-centred practice in social work following the leadership of feminist women's health and welfare services. This has further prompted the development of policy and guidelines for some social work and human service organizations.

Violence Against Women During Pregnancy

Pregnancy is a time when women, friends, family, and health and welfare professionals expect the partner's support to be focused on the health and well-being of the pregnant woman and the unborn child. It is hard to imagine that anyone, let alone the father of the child, would intentionally harm or injure his pregnant partner, thus jeopardizing the health of the woman and the life of the unborn child. International studies and, more recently, two Australian studies on domestic violence occurring during pregnancy reveal a very different picture (McFarlane et al. 1992; Muhajarine and D'Arcy 1999; Quinlivan 2000; Webster, Sweett, and Stolz 1994).

International research predominantly focuses on physical assault as the main form of violence against women by intimate partners and as the criteria for inclusion in studies. It is, therefore, with caution that we view such statistics as they may significantly under-report the actual numbers of women who experience both physical and psychological acts of power and control. Focusing on physical violence, an American study found that 21 percent of pregnant women had experienced violence, with 9 percent experiencing violence during their current pregnancy (Helton 1986). The women who participated in this study formed a random sample of 112 women interviewed during their routine prenatal clinic appointments (Helton 1986). Larger studies of violence against women (Gazmararian, Adams, Saltzman, Johnson, and The Prams Working Group 1995; Gazmararian, Lazorick, Spitz, Ballard, Saltzman, and Marks 1996) found that physical violence was experienced by between 4 percent and 8 percent of the pregnant women. Cokkinides and Coker (1998) determined that nearly 11 percent of newly pregnant women (less than 12 weeks) were experiencing physical violence from their partners.

Common sites of the body treated for injury during pregnancy are the abdomen, breast, and genital areas where damage caused by blunt trauma or assault without a weapon are seen (Stark, Flitcraft, and Frazier 1979; Walker 1979). These injuries tend to be more frequent during the late second trimester and during the third trimester of pregnancy (Stark and Flitcraft 1996; Stark, Flitcraft, and Frazier 1979). Pregnant women who experience physical assault are more likely to have multiple trauma sites than non-pregnant women experiencing violence (Helton and Snodgrass 1987). Between 40 percent and 45 percent of women who experience violence reported that sexual assault accompanies physical abuse (Campbell and Alford 1989). In the U.S., trauma from domestic violence was reported as the leading cause of injury for pregnant women who presented at hospital emergency rooms (Poole, Martin, Perry, Griswold, Lambert, and Rhodes 1996).

From 1987 through 1991, medical examiners' records in New York revealed that domestic homicide caused by injury from a domestic violence episode was the single most significant cause of death by injury for pregnant women (Dannenburg, Carter, Lawson, Ashton, Dorfman, and Graham 1995). Women who experienced violence in pregnancy were found to be four times more likely to have miscarriages and four times more likely to give birth to infants with low birth weight (Bullock and McFarlane 1989; McFarlane, Parker, and Soeken 1996b). Higher infant mortality has also been noted among women who had been physically assaulted during pregnancy (Vasilenko, Marshall, Fournier, Gwizdala, Lehman, and Bigelow 1998). Further, pregnant women who experience domestic violence appear to be socially isolated (Muhajarine and D'Arcy 1999).

Australian research on this issue is only just beginning. The Australian Bureau of Statistics in the Women and Safety Survey (1996) found in their national sample of 6,200 women that 20 percent who disclosed violence from a previous partner stated that the onset of violence occurred during pregnancy. In Queensland, Webster et al. (1994) found that women who experienced violence in pregnancy had more miscarriages and neonatal deaths (babies born alive who die soon after birth) than women who did not experience violence. This study also noted that abused women had low birth weight infants, suffered more injuries to the abdomen, were more likely to abuse substances, had an increase in late trimester bleeding, and experienced more infection and premature deliveries than the non-abused population (Webster, Sweett, and Stolz 1994). While this information is shocking, it may be only the tip of the iceberg.

In Western Australian research (Quinlivan 2000) on the impact of domestic violence on infants, it was reported that the incidence of domestic violence among pregnant Australian teenagers was higher than that experienced in the general community. Concern about the health of unborn babies was the focus of Quinlivan's study (2000), in which it was found that babies born to a group of young, abused pregnant women were diagnosed with significantly more neonatal problems than a non-abused group. These babies had smaller head circumferences and a range of other health problems not found in the control group (Quinlivan 2000). The results of this study confirm findings reported in other studies on the incidence of low birth weight among babies of women who experience violence (McFarlane, Parker, and Soeken 1996a, 1996b; Murphy, Schei, Myhr, and Mont 2001; Newberger, Barkan, Lieberman, Yllo, Gary, and Schecter 1992; Webster, Chandler, and Battistutta 1996). Quinlivan's (2000) study is important as it points out the health effects of violence against pregnant women in Australia. Although it is necessary to draw attention to the health risks to babies of women who experience violence, it is equally important to act in ways that are empowering to women. Quinlivan (2000, p. 57) asserts that: "removing any pregnant woman from an environment of abuse may be as critical for the future of her infant as any other possible intervention in modern obstetrics." Although removing the woman from a dangerous situation would protect her and her baby, it is difficult in practice to remove a woman from an environment of domestic violence without denying her freedom of choice and decision making. Further, such action, although it may enhance the safety of both the mother and infant, raises several practice questions. Could it occur without the woman's consent?

Much of our social work education centres on empowerment models of practice that include provision of information, support, and resources so that clients can make positive changes in their lives. As feminist practitioners, we see service users as experts in their own situations and, thus, respond to and respect their choices. Empowerment in social work goes against making decisions for others without their participation. It would be inappropriate for a social worker to remove a woman from a violent home, even if it might be safer for her. If the focus is only on the baby, then there is a danger that the intervention may overlook the rights of the mother. What about the perpetrator's role and his (usually this person is male) responsibility for the violence? Who takes responsibility for the consequences of violent behaviour and the risk of long-term health implications for the mother and the infant?

The spotlight on violence against women requires a wide-angled lens to bring the perpetrator into the picture. Placing blame and responsibility on the woman is not appropriate. Feminist social work practice, on the other hand, reframes blame and places responsibility for the violence onto the perpetrator. It explores the legal, economic, and social consequences and enables the woman's access to a range of resources. A feminist social worker assists women as they explore options and make the most appropriate choices for their lives, and may serve as a role model for the woman survivor.

Impact of Violence on Women's Health During Pregnancy

The overall psychological effects of domestic violence on women have been compared with the effects of being a prisoner of war and a victim of torture (Condonis, Pariossien, and Aldrich 1989; Herman 1992), involving short-, medium-, and long-term effects, some with serious outcomes for women's health. Women experience a range of responses to violence that include a sense of helplessness, powerlessness, and a total loss of a sense of self (Dutton 1995). They also endure hyper-vigilance, hyper-arousal, sleep disturbances, memory impairment, concentration problems, irritability, sudden outbursts of anger, exaggerated startle responses, and depression (Dutton 1995). Herman (1992, p. 35), in her landmark work on trauma, explains that: "After a traumatic experience, the human system of self-preservation seems to go onto permanent alert."

Many women experiencing violence present to health and social welfare professionals with a range of issues that often exclude discussion about the violence. Many women do not believe that they are experiencing violence unless it is chronic, enduring, and includes serious physical assaults (MacDonald 1998), not recognizing the seriousness of the trauma inflicted on them by the associated psychological violence. It has been argued that emotional abuse is the most prevalent form of domestic violence and has been described by women as the most devastating of the traumas they have experienced while living with a perpetrator of violence (Geffner and Rossman, 1998). This issue is of concern for women who are pregnant. If a baby in utero is exposed to high levels of the stress hormone cortisol, it can retard the development of the infant, thus affecting both birth weight and the infant's ability to fight infection after birth (Quinlivan 2000).

Maternal complications in childbirth have been found to increase if the mother has been exposed to domestic violence. These include puerperal sepsis, postnatal depression, and acute situational crisis affecting the development of mothering skills, these often in combination (Quinlivan 2000). If professionals ignore the cause of the issues that women face, an opportunity to provide support, information, and referral options, and to prevent future injury to women may be missed. It is, therefore, necessary that health care and social welfare professionals know how to assist and support women in an empowering way. So that professionals can adequately and confidently address issues of violence in their practice, domestic violence, including its health and mental health effects, needs to be included in core professional courses.

The general human service and health care system also suffers by ignoring violence. It has been estimated that the health and welfare cost of domestic violence in the general community is extensive (Cox and Leonard 1991; KPMG Consulting 1994) and in the adolescent pregnant population it was found to be 2.5 times the cost of the Australian average antenatal care (Quinlivan 2000). There has not been an independent costing on the impact of violence against the pregnant adult population. While the costs of health and welfare can be estimated, it is difficult to know the psychological cost to the individuals involved. How can the cost of a woman's lost opportunities, quality of life, identity, integrity, safety, and sense of self be determined? Is it possible to measure the loss of a woman's dreams and aspirations for herself and her children? We hold that is not possible.

Professional Responses to Disclosures of Violence Against Women

Many health and human service professions have direct contact with women who experience violence. It is useful to explore the issue of violence from the perspective of the medical and social work professions, since these are most likely to be directly confronted with the pregnant woman experiencing domestic violence.

Medical Encounters

For otherwise healthy women, reproductive health issues lead to more frequent and regular contact with medical and other allied health professionals than at any other time in women's lives. Evidence, however, suggests that medical professionals (including physicians, nurses, and midwives) have considered the existence of domestic violence in their patients as trivial, minor, or non-existent, and that they fail to respond to women who disclose (Easteal and Easteal 1992; Stark and Flitcraft 1996). The need for medical professionals to be sensitive to issues of violence has now been highlighted, particularly during pregnancy (Bullock and McFarlane 1989; Campbell 2001; McFarlane 1993; McFarlane et al. 1992; McFarlane et al. 1996b; Muhajarine and D'Arcy 1999; Parker and McFarlane 1991; Quinlivan 2000; Webster, Chandler, and Battistutta 1996).

It is useful for health care professionals to ask patients about domestic violence due to the potential of early identification and early intervention strategies that can help to reduce injury and chronic illness associated with domestic violence (Lawler 1998; Parsons, Zaccaro, Wells, and Stoval 1995; Sherin, Sinacore, Li, Zitter, and Shakil 1998; Stratigos 2000). Sherin et al. (1998) and Mazza (1997) argue that while domestic violence is an important health problem affecting women, physicians often do not recognize it. In fact, the majority of obstetricians and gynecologists do not inquire about current or past abuse for fear of opening "Pandora's Box" (Parsons et al. 1995; Sugg and Inui 1992). Surveys of medical professionals have established a number of concerns that doctors have about initiating discussion on domestic violence (Sugg, Thompson, Thompson, Maiuro, and Rivara 1999). These include time constraints, lack of comfort about the issue, fear of offending patients, a sense of powerlessness, lack of confidence, and poor access to management information and training (Easteal and Easteal 1992; Sugg et al. 1999). It has also been argued that if medical staff do not have access to, or perceive that community resources are not available to them as backup when they offer assistance, they may avoid altogether the topic of domestic violence with their patients (Sugg et al. 1999). Sugg et al. (1999, p. 306) state that: "nearly half of clinicians seldom or never ask about the intentionality of an injury when examining a patient … [therefore] a critical opportunity to diagnose domestic violence and potentially prevent future injury or death has been missed."

Scutt (1990) asserts that in Australia, many women have received hospital treatment following violence with little or no attention given to the cause of the injuries. Scutt's study showed that 7 percent of women in the research sample specifically mentioned experiencing violence during pregnancy. Some of these women had experienced premature deliveries and miscarriages as a direct result of the violence (Scutt

1990). Other research indicates that women who disclosed violence to doctors were usually referred to a psychiatrist and/or were prescribed tranquilizers (Head and Taft 1995; Women's Coalition against Family Violence 1994).

The use of standardized tools and the routine screening of women for psychosocial problems during antenatal care is increasing. It acknowledges the awareness of domestic violence and its impact on women and their infants. The development of a range of screening tools evaluated and tested on various antenatal populations have recently been discussed in the literature (Irwin and Waugh 2001; Lawler 1998; McFarlane and Gondolf 1998; Stratigos 2000). Some argue that routine and universal screening in antenatal care is in itself an intervention that acknowledges the gravity of violence and reassures patients that it is not acceptable behaviour (Stratigos 2000). Lawler (1998) recommends routine screening as an effective and efficient attempt by the health care sector to address issues of violence; however, it is also important to recognize that women will more readily disclose violence within a trusted relationship. Although routine screening may prompt health professionals to take action that they would not have done prior to the screening requirement, the health care environment may pose barriers for women who wish to disclose any violence they are experiencing. Routine screening in antenatal care not only requires the use of screening tools and standardized methods, but also needs to include the creation of safety, comfort, and trust between women and practitioners in the health care setting.

There are a number of difficulties with the concept of routine and universal screening, in addition to disagreement about what constitutes violence, such as determining who is and who is not an abused woman (Yllo 1990). Further, there is controversy about the lack of adequate training that may lead to misunderstanding about appropriate responses and effective ways to intervene without harm (Taft 2001). We are sympathetic to the viewpoint expressed by Taft (2001, p. 45), who summarizes the issues as follows:

> The use of "screening" and "screening tools" are problematic strategies with which to respond to complex psychosocial issues, including intimate partner violence and abuse. Any mistakes in our implementation of offering help to victimised women in health care settings could be very costly to the women and children we seek to support.

The Social Work Profession

In the literature on family violence intervention, there is a great deal of interest in the training and educational requirements of medical and primary health care staff, particularly in some areas of the U.S. (Alpert 1995; Warshaw and Alpert 1999). Australian schools of social work vary in the extent of curriculum attention to violence against women, and whether all offer relevant theory and practice material on the topic has not been studied. Most social work schools need to attend to this issue as it represents an important area of knowledge required by all social work students. They will likely encounter, and need to provide help, for women and families affected by violence during their professional careers.

Social workers and counsellors have faced criticism for ignoring, overlooking, and averting their gaze from issues of violence against women in their practice (Healy 1984; Hansen and Harway 1993; Women's Coalition against Family Violence 1994). Australian social workers have attempted to address this issue by providing social work-specific training to a range of social work professionals (Thorpe and Irwin 1996; Walsh 1999; Weeks 2000). In the health care system, social workers often receive referrals when women are in crisis as a result of domestic violence. This requires the social worker to conduct a safety assessment, assist in the development of safety plans, be familiar with domestic violence legal provisions, and refer women to appropriate services (see Mackay and deMello in this book). All these skills require continued professional education as new knowledge becomes available and as regular changes to criminal and protective legislation occur.

In health and human service agencies, social workers may be confronted with a disclosure by a woman who may not be in immediate crisis, but may require support, counselling, and assistance in exploring her options. These activities draw on particular skills and knowledge that are critical in promoting the safety and survival of the woman and any children she may have in her care. Women across all phases of the life span are at risk of experiencing intimate partner violence. It cuts across all socio-economic and ethnic boundaries (Family Violence Professional Education Taskforce 1994; Women's Coalition against Family Violence 1994). Regardless of where social workers practise, it is our contention that they will be confronted with issues of violence in their client population and, therefore, will require the knowledge and skills to appropriately address it.

Social Work Practice

As in all areas of social work practice, beginning "where the service user is" also applies in situations of responding to violence. This can be difficult particularly when women experience violence at home, are given information and assistance to discuss their options, and then choose to stay in the violent relationship. To respect a woman's choice in such a situation and to support her in whatever decision she ultimately makes is critical to her empowerment and her human rights. In social work practice, it is important to believe and listen, as these are powerful in practice.

Of the various tools developed for health care professionals, one of these (Alpert 1995) uses the acronym, RADAR, to outline key aspects of intervention:

- Remember to ask the question.
- Ask it directly.
- Document what you find.
- Assess the patient's safety.
- Refer to needed resources.

While RADAR is not considered routine screening, it is a tool that reminds practitioners to ask women about experiences of violence in their relationships, and it paves the way for those women who wish to disclose violence in their lives to do so and to obtain assistance.

The following guidelines (Walsh 1999) have been developed and adapted by a domestic violence specialist social worker and trainer who has found them useful for practice:

- See safety as a practice priority.
- Do not be judgmental.
- See the woman as the best expert in her own situation and support her to take control of decisions.
- Do not denigrate the violent partner, but focus on the violent behaviour. Saying something derogatory about the partner may be viewed by the woman as a personal insult, causing her to defend the behaviour and the partner.
- Be clear about confidentiality, including any limits to it, and ensure that the woman is aware of these (e.g., mandatory requirements to notify authorities about violence toward children or adults).

- Do not give advice, but do outline options. Giving advice may be disempowering and takes away a woman's control and decision making.
- Ask permission to provide written material about domestic violence for her to read, so it is not experienced as pressure. If she agrees, then offer the woman an opportunity to read it at your office in case her partner finds it and reacts. Let her know that you are aware it might be risky for her to take this home. (Some partners routinely go through belongings, including handbags, as part of ongoing surveillance.) It may place her at risk if the material were found.
- Anticipate women's sense of loss and grief.
- Respect the woman's decisions.

(See www.rwh.org.au/casa for an example of an approach to working with women survivors of violence.)

Many women see themselves as failures if intimate relationships break down. It is our observation that an intense grieving process is often experienced after the breakdown of a relationship, which can be exacerbated by the trauma of violence and sense of betrayal often reported by women. These are important issues to address in counselling when working with women. Recovery from violence takes time, and support is often a critical component of this. Assisting the woman to develop a wider range of support systems is critical for this healing process (Herman 1992).

Case Situation: Mary's Experience of Violence in Pregnancy

An example of one woman's situation will help to highlight and apply the practice principles for working with women who have experienced violence. Social workers encounter violence that occurs in a range of circumstances. Women may present with injuries to an emergency room at a hospital, and often find it difficult to disclose the cause of their injuries. Women who live with partners who are violent may visit a community-based health care practitioner, who may refer women who disclose violence to a social worker. The following example describes a scenario that takes place between a social worker and a pregnant client in a community-based health centre.

Part One: Mary

You are a social worker employed in a community agency that provides counselling and social work assistance to families. The agency often receives referrals from physicians and nurses who identify psychosocial concerns in the course of patient care. A woman service user is referred to you.

Mary, aged 29, is married, 32 weeks pregnant, and has a three-year-old daughter, Mia. She has been referred to your service by her obstetrician, who states in the referral that Mary is suffering from prenatal depression and is not coping well in caring for her young daughter, nor is she dealing well with her pregnancy. The doctor is reluctant at this stage to prescribe medication because of the pregnancy and has referred Mary to you for counselling.

Mary tells you that she cries a lot and finds it difficult to leave the house. She adds that she was once very "house proud," but struggles at the moment to do anything around the house, which causes more friction in her relationship with her husband, John. He expects to come home to a clean, well-managed, and happy household and gets upset that Mary can't manage to provide this. Mary was a teacher before giving birth to Mia, the three-year-old, and states that she misses the contact with her peers.

Mary describes how John tends to discourage contact with her family as he worries about her family's interference in their relationship. Mary agrees that sometimes her family can appear to interfere, but they mean well. She starts to cry a number of times during her first session with you.

Reflection Questions

1. How would you proceed at this point in the session?
2. What do you think are the key issues here?
3. What questions would you ask at this point and why would you ask them?

Part Two: Mary

Later, you ask directly about violent behaviour, and Mary breaks down crying, stating that her husband has beaten her in the past and is terrified it will happen again. Mary says that she tries hard to meet her husband's high expectations, but she just gets too tired and can't do all the things he expects her to do. He will not listen to her "excuses" and when he starts his verbal abuse, Mary cannot help crying, which makes him even angrier.

Mary recalls that the last assault occurred a few of months ago when he hit her in the stomach. He had insisted that she couldn't cope with another baby because she was crying and not listening to him. He blamed her for the abuse, saying that she should have been listening to him. However, Mary insists that "he is not a violent man" and that she would never consider leaving him, particularly now because she is pregnant and believes that children need their father. After assessing the situation further, you focus on developing a work plan with Mary, noting the areas to be addressed.

Reflection Questions

4. How would you talk to this woman about her safety?
5. What issues need to be addressed in continued work with Mary?

Part Three: Mary

You assure Mary that emotional and physical abuse is considered violent behaviour and is an issue for many women. You suggest that there is no justification for such behaviour, and that responsibility for violence rests with the perpetrator of the violence. You and Mary discuss the risk of physical and psychological harm caused to children who witness their father's violence toward their mother. You also listen to Mary's account of how sad she feels at times in her relationship and how she wants this pregnancy to go well and for her baby to be healthy. You affirm her courage in discussing such intimate personal issues and her feelings of hope, gently explaining that Mary can receive continued support and assistance from the agency and from other services if needed. You ask Mary who in her informal network would she feel comfortable relying on if she needed some help urgently. Another important task is to identify and highlight Mary's resilience, strength, and skills, especially those used in the past, as these could be drawn upon again now.

Together, you and Mary develop a safety plan, going over what Mary would do and how she might react if John were violent again. You provide information about the range of people and services, including a women's shelter, that Mary could contact should an emergency escape plan be required. Together, you and Mary review the plan carefully, considering a range of backup options in case the primary plan could not be implemented. With Mary's permission, you discuss the issues with her doctor and the social worker at the hospital where Mary will deliver her baby, as these professionals would be available to provide continued physical and psychological support.

Reflection Questions

6. Why is follow-up important in this scenario?
7. How, in Mary's case, are physical and mental health issues connected?

As illustrated in the case situation above, it is critical that all health and human service professionals be cognizant of the impact of violence on women's lives throughout the life span and particularly in pregnancy. Service users such as Mary and her family often come to the attention of practitioners who require the knowledge and skills to adequately and confidently address the effects of violence for those who are most affected.

Conclusion

Research on violence against women has increased beyond the topics of incidence and causation to include themes on various forms of violence and their effects and intervention strategies to address them. Another more recent topic within this research is violence against women during pregnancy. This issue has emerged because of the public abhorrence of violence toward women at a time when their health and well-being is of particular concern. While there appears to be an increase in the focus on violence, there is, however, no indication that the occurrence of violence has decreased. Intervention remains primarily focused on crisis management with less investment put into the attitudinal changes needed to prevent violence against women in general. Domestic violence as a health issue has been explored in relation to medical and social work responses. Both professions have been criticized in the past for attitudes and practices that have ignored or minimized domestic violence and its effects. This has had serious implications for women and, in particular, women who are pregnant. The feminist movement has challenged such inadequate responses in health care and human service provision and, in Australia, this has led to significant changes in the past three decades.

Women-centred practice, a development of the women's movement, has emerged as an appropriate approach to violence against women. Most perpetrators of violence deny, minimize, or blame the victim for the occurrence of the violence (Augusta-Scott 2001; Stark and Flitcraft

1996) and it was not long ago that many health care and human service agencies reflected this attitude. Women-centred practice challenges this traditional orientation. Women-centred practice primarily focuses on enhancing women's sense of control and coping skills, resists pathologizing (defining as a disease) women's behaviour, and recognizes that women's problems may be caused by social structures and views that are oppressive.

Nations around the world need to address the issue of domestic violence in pregnancy within their health and welfare systems. Violence against women affects the health and well-being of millions of women and children on a daily basis throughout the world. How violence against women is defined shapes how social welfare and health care systems respond, including the services provided and the ways in which women can use them.

The economic costs of domestic violence, including the health care provided, are incalculable and the community is the poorer for its occurrence. Women who are continually violated are unable to reach their full potential, and their children, whether currently being carried in the womb or those already born, are also seriously affected, often bearing emotional and/or physical scars for life. This is a tragic loss to all communities worldwide. Change needs to occur at a structural level in a systemic, collaborative, and coordinated way that includes ongoing research and evaluation. While this requires commitment and adequate funding, it is a vital step toward addressing this critical issue. Anything less is shameful in the face of the evidence.

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* * *

This chapter is dedicated to the late Associate Professor Wendy Weeks,
who died suddenly on July 31, 2004. Wendy's passion and
commitment to women's rights was well renowned,
and she will be sadly missed around the globe.

Wendy Weeks
November 3, 1943–July 31, 2004

* * *

CHAPTER 10

CULTURALLY COMPETENT SOCIAL WORK PRACTICE IN HEALTH:

A Focus on Urban Aboriginal Populations

Grace Elliott, Ron Levin,
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Cultural Competence

Cultural competence is defined as “the ability to integrate cultural knowledge and sensitivity with skills for a more effective and culturally appropriate helping process” (Weaver 1999, p. 217). It requires the social worker to be aware of personal biases and to be committed to an ongoing process of continuous learning. To be culturally competent, the social worker must: be aware of his or her own cultural limitations; be open to cultural differences; possess a client-oriented style; make use of clients’ cultural resources; and acknowledge the client’s cultural integrity (Devore and Schlesinger 1996). Cultural competence is important for social work practice in health care. Devore and Schlesinger (1996) note: “in situations involving health and illness, the ethnic reality forms an integral part of peoples’ responses to their health problems and also becomes an integral component of resolution” (p. 312). Also, “an understanding of the interplay between ethnically derived attitudes toward health and illness and bio-psychosocial factors is critical to accurate assessment and intervention” (p. 308). Dean (2001) questions the ability of one person to be truly competent regarding the culture of another, and proposes a model based on “acceptance of one’s lack of competence in cross-cultural matters” (p. 623).

Acknowledging that no one can ever fully understand another’s cultural reality, this chapter focuses on effective practice with Canadian urban Aboriginal health care users and suggests that some themes can be extrapolated to social work with many indigenous peoples and the principles applied to practice with diverse ethnocultural populations.

Issues

There is evidence that Aboriginal peoples in Canada, the United States, Australia, Europe, and elsewhere are more likely to suffer from hypertension, heart disease, diabetes, and other chronic illnesses than their non-Aboriginal counterparts and are reported to have poor levels of overall health (Lowe and Kerridge 1995; Shah, Hux, and Zinman 2000; Shah and Farkas 1985; Yukl 1986). They are therefore disproportionately represented on hospital in-patient lists and out-patient health care services. Since most health care providers are not Aboriginal, there is almost certainly some degree of cultural dissonance that affects how services are used and experienced by Aboriginal peoples (Mokau and Fong 1994; Sanchez and Plawecki 1996; Weaver 1999). Further, there is consensus that urban Aboriginal patients encounter tremendous obstacles related to availability, accessibility, and acceptability of services in their encounters with the health care delivery system (Gagnon 1989; Mokau and Fong 1994; Shestowsky 1995; Willms, Lange, Bayfield, Beardy, Lindsay, Cole, and Johnson 1992).

Levin and Herbert (2001) have pointed out that the knowledge, skills, and attitudes of health care providers are often unsuitable to meet the needs of urban Aboriginal clients, who consequently report high levels of dissatisfaction with their experiences in urban health settings. Further, their research identified treatment areas such as obstetrics/gynecology, emergency, and psychiatry as particularly problematic. In addition, cultural issues are compounded by the problems of poverty, which is the lived reality of many urban Aboriginal peoples. Social workers, encouraged to be holistic in their approach, and as part of multidisciplinary health teams, have the potential to play a key role in ensuring that the needs and concerns of Aboriginal heath care clients are addressed. They may also be able to influence other professionals to respond in ways that are appropriate and culturally sensitive.

Context

Aboriginal peoples, prior to the arrival of Europeans, had evolved a successful society well adapted to life on this continent. The initial relationship between Aboriginal peoples and the first Europeans was often characterized by a spirit of partnership and collaboration, as these two peoples found mutually respectful ways to work together. In many instances, it was clear that the first immigrants to Canada could not have survived without the active support and advice of the Aboriginal peoples they encountered. Yet over time, Aboriginal peoples were subjected to systematic colonization and domination when they came to be regarded as obstacles to European intentions. Federal policy in Western countries ranged from policies of assimilation, through such means as residential schooling, to a policy of extermination (Miller 1996). The experience of oppression continues to affect Aboriginal individuals, families, and communities today.

Our capacity to fully appreciate the history, traditions, and values of Aboriginal peoples and the impact of these experiences is limited and the challenge to practitioners who work with Aboriginal peoples is daunting. We must acknowledge the fundamental limitations of any one group to enter into the experience and culture of another. All Aboriginal peoples are not the same. There are important differences to be acknowledged between different language groups, tribal groups, and geographic settings. Aboriginal peoples in North America alone represent 600 First Nations with over 50 languages and dialects (Chaimovitz 2000).

This complexity is compounded when the differences in assimilation are taken into consideration. Practitioners have to distinguish between traditionalists and assimilated Aboriginal peoples, and those who may have found a way to bridge both the traditional world and the modern reality (Morrissette, McKenzie, and Morrissette 1993). There are many differences within and between First Nations and between individual members of First Nations, and a further distinction must be made in relation to urban Aboriginal peoples, who have been described as more assimilated into mainstream culture and less identified with Aboriginal culture (Frideres and Gadojz 2001). There are, however, common themes that can be conceptualized in relation to a "world view" or framework. An Aboriginal world view has the following features: wholeness; balance or interdependence; harmony within the person and in relation to other living things; and healing and growth (Hart 1999). This world view contributes to an interconnected and cyclical view of life as well as an appreciation of the delicate balance between all things. It emphasizes harmony, natural laws, and rhythms of nature. It also sets the context for a group of values that can include: self-determination; a focus on the present rather than the past or future; an emphasis on oral tradition; adherence to traditional healing practices; and recognition of the validity of individual experiences and beliefs (Hart 1996).

These dominant characteristics continue to influence the lives of many Aboriginal peoples. They also fit with social work practice in which the practitioner adopts a holistic view in working with people, emphasizing physical, emotional, mental, and spiritual factors. In contrast is the Cartesian dichotomy between mind and body, which continues to dominate Western thought. It also shapes a compartmentalized and segregated approach to the delivery of health care services. In this orientation, the body is seen as separate components to be treated by different medical specialists. We suggest that this makes it difficult to recognize the full story or the entire person behind the diagnosis and can result in diminished attention to the social work values of self-determination, egalitarianism, and respect for the individual.

A Framework for Social Work Practice with Aboriginal Consumers of Health Care

There is a need for increased sensitivity on the part of social workers and other professionals in response to the documented dissatisfaction on the part of Aboriginal consumers of health care services (Levin and Herbert 2001). The social work profession, as an integral component of multidisciplinary health teams, must take responsibility for its part in the dissatisfaction by critically reflecting on and reconceptualizing traditional social work practice frameworks and making adaptations that optimize the potential for more positive outcomes for Aboriginal peoples. It is a daunting challenge to balance the dictates of a complex medical institution with the resolve to provide culturally appropriate services for Aboriginal patients.

The proposed framework, while borrowing from generalist practice traditions, recognizes Aboriginal contextual factors and emphasizes cultural strengths, both historical and contemporary. It builds on the problem-solving process (Compton and Galaway 1999), acknowledging the need for an empowerment perspective in assessment and intervention. The target of change is not restricted to individual patients, but includes the different systems within their contextual reality (familial, community, and societal, as well as the health care setting). Use of this framework requires social workers to be willing to critically assess their own cultural attitudes, biases, and limitations.

As illustrated in Figure 10.1, the layered model depicting the proposed practice framework includes a historical underlay, reflecting insight into the lingering effects of colonization, domination, and oppression. Social workers applying this model will be open to viewing mainstream reality through another lens and will honour collective history as well as individual experience. This model also acknowledges a distinct Aboriginal world view, emphasizing balance through inclusion of the physical, mental, emotional, and spiritual components of the medicine wheel. The social worker is encouraged to address spirituality, a dimension often ignored in social work practice, by exploring and acknowledging the patient's spiritual beliefs, values, and traditions.

The problem-solving process (Compton and Galaway 1999), which is sometimes criticized for defending the "status quo" (Mullaly 1993, p. 32), has been adapted for application within this model. The steps of this process are seen as overlapping and recurring rather than sequential, and include engagement, assessment, planning, intervention, evaluation, and termination or disengagement. The patient is not seen as separate from family, extended family, or community, and the environment is seen as a pivotal component of the model, since improving the health of Aboriginal peoples necessitates addressing and attempting to influence the environmental factors associated with health, such as poverty, unemployment, and inadequate housing. Also central to the model, the concept of Aboriginal empowerment (Morrissette, McKenzie, and Morrissette 1993, p. 91) is consistent with the social work value of self-determination and is essential in ensuring that patients (clients) themselves play a major role in making decisions that affect their lives. The social worker is encouraged to be responsive to diversity in such elements as language, cultural traditions, and healing practices.

The following section includes an example of a case situation, a description of the contacts between the social worker and her client, and a discussion of practice to illustrate operationalization of the suggested model. (Key terms used in this chapter are defined in our glossary.)

Case Situation: Nadine

Nadine, aged 18, is a young Aboriginal woman who came to live three months ago in a large city, 300 km from her home reserve. She presented at a large tertiary care hospital when her baby, who was three months old, refused to eat and was in distress. The baby was diagnosed with a bowel obstruction and required immediate surgery. The surgery was successful and prognosis is good. This case was referred to the social worker on the pediatric unit to assess the situation.

Nadine reported that she was very upset by the baby's illness and the surgery and very anxious about the future when she had to care for her son on her own. She said that she was still uncertain about her responsibilities in treating the baby after discharge and felt unable to communicate with the many doctors and other health care providers who were involved in the baby's care. Nadine is living with her mother in a small inner city apartment. There is no phone. She receives government financial assistance, as does her mother. Their joint income is barely sufficient for food and other needs. At the time of her pregnancy, Nadine was attending an upgrading course with the hope of entering a training program as a teacher's aide. Her mother has worked intermittently as a food services worker, but is currently unemployed.

Nadine no longer lives with the baby's father (Wilfred, age 22) who is still living on her home reserve. Wilfred had been physically abusive to Nadine in the past, particularly when he was drinking, but had been more supportive recently and had visited the baby regularly. Nadine and her mother have no friends or family in the city. She told the hospital social worker that she and her parents are "traditional" in maintaining their culture and had asked the medicine man from her reserve to give them medicine for the baby. However, the nursing staff at the hospital had discouraged her from giving this medicine to the baby. Nadine was also upset because the nurses had complained to her about the number of visitors who came at all hours to see her and the baby (Nadine stayed in the baby's room most of the time). While Nadine was pleased to see her family and friends and welcomed the support they provided, the staff maintained that this interfered with their work and was disruptive to other patients and families. Nadine said she had contacted her financial assistance worker to make her aware of the situation and to tell her that she would need a phone and assistance for baby food and transportation once the baby came home. Nadine said the worker was abrupt with her and did not treat her respectfully.

A Social Worker's Intervention

As the social worker, Marjorie, walked to the room in which Nadine was staying with her baby, she tried to recall what she had learned about working with Aboriginal peoples. When she opened the door to her room and discovered that it was full of Nadine's relatives, it confirmed her understanding of the importance of extended family to Nadine. Marjorie made a mental note to discuss Nadine's family support and to explain traditional healing approaches to skeptical nursing staff, who had expressed some concern about "interference" from Nadine's friends and relatives, and their introduction of strange medicinal substances to the hospital.

Nadine shyly introduced the hospital social worker to her mother, two of her siblings, and three cousins who had just arrived from their rural community, along with several somewhat lively toddlers who seemed to have the run of the room. Marjorie recognized that rushing into her own agenda would be seen as impolite, and spent a few minutes chatting with Nadine's relatives, who seemed to be sizing her up to determine if she was a social worker who could be trusted, or if she was one who might use her authority in ways that were not to their benefit, as had happened with a cousin who had two of her children placed into the care of the child welfare system.

Marjorie was warm and friendly as she began to inquire into the nature of the problem as Nadine and her family understood it to be. She also explained that her role in the hospital was to assist Nadine and her baby while her baby was hospitalized and to help them acquire the kinds of supports they would need in the inner city community where they now lived. This appeared to reassure Nadine and her family, who began to warm to Marjorie's non-threatening approach and her genuine willingness to really hear what they had to say.

Nadine's family was sensitive regarding their intergenerational experience of discrimination and domination in mainstream Canadian society and was finely attuned to the slightest indication that such an experience might be replicated in the hospital setting. Marjorie described how she might feel in a similar circumstance if it were her child who was suffering, and this self-disclosure helped to establish her as a warm, accepting person. As Marjorie communicated her view of the helping process with this family, she defined her relationship with them as ideally a partnership. She demonstrated this relationship as she spoke with them. This seemed to be an unexpected experience for Nadine and her family, one that seemed to maintain their sense of dignity, gave them confidence that their views would be respected, and they would have a say in what was to occur.

During a subsequent visit, while Nadine sat in the hospital room with her mother and her baby, Marjorie asked further questions about how Nadine felt about the condition of her child and her ability to cope. Nadine fell silent and averted her eyes from Marjorie's gaze. Marjorie began to imagine what it might feel like to be in her situation, and attempted to reflect on her understanding of the difficulties Nadine was encountering, suggesting that it must be difficult to cope with her strange new surroundings and how she might miss the closeness of her home community. Nadine agreed with this comment, adding that she was very worried about returning with her baby to the unsafe environment surrounding her apartment in the city, where women were involved in street prostitution and drug abuse and men made rude comments to her as she went to and from the hospital. Marjorie suggested that perhaps they could work on finding a place to live where she would feel more secure, at which Nadine brightened up considerably. As Marjorie prepared to leave the room, Nadine's mother got up to shake her hand, and expressed appreciation for the support that she was providing.

As Marjorie walked back to her office, she sensed that she and Nadine seemed to be off to a good beginning. The first thing she wanted to do was to investigate potential new accommodation for Nadine. By concentrating on this very concrete need, she was confident that their work together would begin on a solid footing. As she pondered the next steps, Marjorie realized that although she had learned some things about Nadine's life, she had much to learn, and she still had very little knowledge of the issues that were most important to Nadine. She knew that Nadine had no financial resources and lived in a deteriorating, crime-ridden neighbourhood, and she suspected that like many Aboriginal peoples she had known, Nadine may well have been affected by the legacy of her ancestors' residential school experience, which may have affected their cultural identity and preparation to parent. She also realized that she knew very little about this young woman's strengths, and resolved to explore her client's strengths and capacities the next morning, and to determine where she and her family might be in their healing journey. Marjorie knew that the reality of this busy hospital environment would dictate that Nadine's baby would soon be discharged and there was much work yet to be done to prepare for this and other needs of Nadine and her family.

As Marjorie entered Nadine's baby's room the next morning, she found Nadine holding her baby and appearing sad. Marjorie said, "It must be very scary for you to be here," which unleashed a torrent of tears from Nadine as she described how alone she felt when her family had to return home because they could not afford to stay longer in the city. Nadine missed them terribly already. As she calmed down, Marjorie asked her what had led her to the city, and Nadine began to describe her life on the reserve, her sexual abuse by an uncle, the parties that began with social drinking and deteriorated into bouts of violence, the loss of her favourite cousin to suicide, and her mother's inability to fully relate to her because of the childhood abuses she had encountered in residential school. Marjorie listened attentively to her story, making mental notes of the difficulties faced by this remarkable young woman who continued to strive so hard for a better life.

Marjorie commented that Nadine must be very strong to have survived all of this and still be working to improve her life and that of her child. Marjorie said, "You must have had some good things in your life as well to have come so far." Nadine seemed pensive and thought carefully about this comment, and said, "Yes, I guess I did, but no one has ever asked me about this before." She went on to describe the faithful love and devotion of her beloved grandmother, who had always been available to her. She told Marjorie about how safe she felt when surrounded by her favourite aunts and uncles, and how much they enjoyed going to pow-wows together, where they could again enjoy their cherished dances and meet friends and relatives from miles away. She told Marjorie about the work she had been doing in a healing circle to understand what effect her mother's experience in the residential school had on her own life. Nadine's mother had come to realize that she had never learned how to parent because she had never been parented properly herself. Nadine had vowed that she would find a way to break the cycle by not allowing this to harm her children in the way that she had been affected.

Marjorie was profoundly moved by this woman's passionate determination to make a difference in her child's life and was determined to help her. She asked Nadine what she could do to help her achieve her goal. Nadine looked at her intensely for what seemed like an eternity without saying a word. Finally she said, "I have seen many social workers in my life that have promised to help me, but they never did. How do I know that I can trust you?" Marjorie thought for a while, and finally replied "I have no way of providing you with any guarantees, but if you will take a chance, I will do the best that I can." Nadine nodded and stated that she had no money, but that she hated to be dependent on welfare benefits. Marjorie gently explained that she may not have a choice for the moment, and offered to advocate with the welfare worker to ensure that her immediate financial needs were met. Nadine agreed that this would be helpful in dealing with the negative response she has received to her request for assistance with food and shelter. Marjorie also explained that she might want to explore the future possibility of returning to school and learning some skills that would enable her to earn a living wage for her family. Nadine thought this was a good idea, and shyly told her that she had always thought of being a social worker. Marjorie gave her information and encouraged her to look into potential funding by her band for educational and training opportunities that could help her pursue this goal.

As they discussed the exciting possibilities, Nadine suddenly seemed somewhat sad and remote. When Marjorie asked her what was wrong, she replied that although she did not wish to repeat the pattern of abuse that had occurred in her family, she was afraid that she would end up doing so anyway. Marjorie asked her if she had any thoughts on how this night be addressed, and she replied that the healing circle she had attended at home was very helpful, but she was not sure if this would be available in the city. Marjorie responded that she knew of some groups that operated through an agency in town, and that she would be happy to provide her with this information. She also wondered if Nadine might be interested in one of the parenting groups that she knew about. Nadine was unsure about this until Marjorie told her about some groups that had been established for Aboriginal parents.

As their conversation drew to a close, Marjorie felt close to this young woman who had demonstrated such courage and told her as much. Nadine said that she felt much the same way. They both realized that they had done a great deal of work that day, and agreed to meet the following morning prior to the baby being discharged. At that time, Marjorie and Nadine reviewed the discharge plan for the follow-up care of the baby and the referrals to resources in the community. Nadine consented to Marjorie contacting her financial assistance worker and Marjorie made arrangements to accompany her to a subsidized housing agency and to an intake appointment at the local Native Friendship Centre.

Discussion of Practice

Preparation

Prior to the first meeting with the client, it is important for the social worker to lay some groundwork. In a general sense, workers such as Marjorie are encouraged to take every opportunity to raise awareness about culturally competent practice by participating in courses, seminars, in-service training, and workshops. They are also encouraged to develop a high level of personal insight and self-awareness through ongoing self-reflection and feedback or supervision. Social workers must be aware that, by virtue of their position in the hospital and their professional title, before they even have the first meeting they are already in a one-up position of greater power in the relationship with the client. Sensitivity to this power differential is important before making attempts to engage with the client. Workers must understand how their own position of privilege may have an effect on their understanding of and ability to work with oppressed clients (Mullaly 1993). It is essential for social workers to prepare to see the client's reality through more than one lens.

In our case, Marjorie could prepare ahead by getting as much background information as possible in order to minimize surprises in the first meeting. This can be accomplished by such basic activities as reading the referral sheet and the medical chart and talking with staff when appropriate. It is also important for Marjorie to try to imagine what it would be like to be in Nadine's position, while being careful not to make assumptions. All social workers must be sensitive to direct and indirect discrimination that their Aboriginal clients may be experiencing both inside and outside of the medical system in relation to their ethnoculture and factors such as age and gender.

Engagement

Engagement with a client requires empathy from a social worker. Empathy means putting all other considerations aside and fully attending to what the client is saying, not only the words, but the non-verbal communication and the unspoken messages conveyed. Aboriginal peoples have conveyed the essence of this capacity in the traditional proverb "One should never judge another person until one has walked in that person's moccasins for at least one moon [month]." At this stage one must withhold judgment, as the most important consideration is to understand as fully as possible how the client sees the situation. This can be difficult to achieve in a busy medical setting that requires a social worker such as Marjorie to make rapid assessments and interventions to meet the hospital's discharge deadlines. However, experience over time will demonstrate that bypassing this important step can lead to false starts and inappropriate or unhelpful case plans and less effective work with the client.

Achieving a common understanding between the social worker and the client promotes engagement in which the worker and the client make explicit their respective definitions of the problem as they see it and agree on how they will approach it. It also leads to a clear understanding of what they can expect from each other. When the relationship established with the client is one of partnership focused on strengths, it can be an empowering source of change for the client. The notion of client empowerment is always an important consideration for social work, but in work with clients who belong to an oppressed group such as Aboriginal peoples, it calls for increased sensitivity to any power differential between the worker and the client. A power differential can interfere with the development of a working partnership when clients perceive their social workers to be similar to their oppressors. Social workers are better off being open and frank, and discussing the power they hold, rather than not speaking about it.

Assessment

Assessment activities can be adversely affected by a lack of cultural sensitivity and care must be taken to avoid misinterpretation of client communication. With the first contact, the social worker's own cultural biases can begin influencing the focus and accuracy of assessment.

The main source of information should always be the client, and the assessment should reflect that input. However, useful information can also be obtained from other family members, from hospital staff, and perhaps from others who have worked with the client. As a general rule, no information should be included in a written assessment without the client's knowledge, and the client's permission should be obtained prior to speaking with other agencies or family members. An exception to this rule may be when there is genuine concern about a child's welfare or a criminal act.

The information for an assessment must be collected and recorded in a factual and non-judgmental way, using descriptive language and taking into consideration the cultural context of the client's situation, and the client's world view, which may be very different from that of the social worker and other hospital staff.

In working with Aboriginal clients, it is important to assess each situation in terms of strengths within the client, the family, and the community, available resources, practical planning for discharge, and other factors. The assessment should include the client's socio-economic situation, including housing and employment, early life experiences that may affect coping ability and/or offer skills and strengths, understanding and knowledge of child care, values that reflect the client's degree of identification with his or her cultural background, spiritual beliefs and practices, current level of self-esteem, and problem-solving skills.

In our case, a vital part of Marjorie's assessment is identifying Nadine's strengths and resources and not only the obvious limitations in Nadine's life, such as her youth, poverty, lack of employment, and inadequate housing. If the social worker does not develop a broad understanding of the client's situation, including both strengths and challenges, it is unlikely that the social worker's interventions will prove helpful.

The Service Covenant

Once the client and social worker have established an initial relationship, agreed to work together, and come to a common understanding of the issues, contracting, which is a more formalized goal-setting phase, occurs. Devore and Schlesinger (1996) define contracting as "the process by which workers, clients, and others engaged in the problem-solving activities come to a common agreement concerning the respective work to be done, objectives sought and means by which these objectives are to be attained" (p. 208). Authors who write about the problem-solving process (Compton and Galaway 1999; Heinonen and Spearman 2001) point to important limitations when the concept of contracting is applied to some practice situations. Primary among these is the power disparity between worker and client, which belies the notion of an agreement between equals. Often a client has no choice in selecting a worker and cannot hold the worker accountable. Devore and Schlesinger (1996) hold that the notion of contracting has evolved from a Western, rational conception of reciprocity and an assumption of trust in formally organized institutions. The fact is that many do not share this trust, but, on the contrary, are suspicious of the health care and social welfare service delivery systems.

Compton and Galaway (1999) stress that the service agreement calls for negotiations between worker and client, which define the problems for work, identify mutually agreeable solutions, and determine an action plan. Miller (1990) has extended this notion further in a "covenant" model, which focuses on the "gift" aspects of professional identity and the unbound commitment of worker to client. She articulates this as "a commitment to staying with the client throughout the client's journey in working through his or her troubles" (p. 165).

In working with urban Aboriginal clients, establishing the service covenant and setting goals must be a collaborative and respectful process. With Nadine, rather than the social worker forging ahead with her own agenda, which is a hazard of the trade in a busy health care environment, Marjorie approached each meeting with Nadine carefully, observing her client's direct and indirect communication and encouraging her active participation. The opportunity to have input into their working agreement was empowering for Nadine. Both Nadine and Marjorie agreed that while the baby was in hospital, they would continue to work together to address the following priorities:

1. Practical planning for discharge including care and follow-up of the baby
2. Help with housing and telephone communication with Nadine's current financial assistance worker for needed funds
3. Career training or upgrading options for Nadine

4. Implications of Wilfred's frequent visits to the baby, considering his history of violence and concerns regarding potential future abuse
5. Nadine's social isolation in this new urban environment

Nadine and Marjorie had reached a mutually determined agreement or covenant for their work together that would provide community linkages to resources and support and follow-up after the baby's discharge from hospital.

Intervention

Depending on the nature of the person being helped and that person's individual life circumstances and cultural context, a hospital social worker working with Aborginal peoples will place more or less emphasis on particular interventive roles at different times. The success of all these roles is based on social workers' ability to form relationships with those who need their services.

Social broker: In addition to health care, a client may need financial assistance, housing, or child care, all of which will require careful and thorough referrals to a variety of community agencies and subsequent follow-up. Marjorie acted as a social broker in linking Nadine with housing alternatives and making referrals to education facilities, the public health nurse, and other community agencies.

Advocate: Often urban Aboriginal peoples are not accustomed to dealing with complicated and impersonal bureaucracies such as health care services, and the social worker may need to be vocal and active on their behalf. In the case example, Marjorie was a vocal advocate for this vulnerable young mother who needed help in dealing more assertively with her financial assistance worker and hospital professionals.

Mediator: The urban Aboriginal client may take a position based on cultural and personal considerations that contradicts the judgment of the health care team about what is medically advisable or in the patient's best interest. Part of the social worker's mediation effort is to sensitize the team to the rationale for the client's stance and/or acknowledge health-related concerns while also respecting the client's wishes. In this case, Marjorie acted as a mediator between Nadine and the other hospital staff, who thought Nadine was incapable of caring effectively for her baby at home.

Counsellor: This traditional supportive role that social workers fill with many clients can be especially useful with Aboriginal clients in health care settings. In the role of counsellor, Marjorie demonstrated her warmth, empathy, listening ability, and support to Nadine.

Teacher: Many urban Aboriginal clients will require considerable information about being in a hospital, ongoing health care needs, living in the city, existing community standards of child care, opportunities for furthering education, and other important needs. Marjorie took on the role of teacher in providing Nadine with information to prepare her for discharge from the hospital.

Case Manager: This coordinating role includes overseeing all the services the client will need to secure and ensure that there is no duplication or gaps. An important tool for case management is the case conference, which involves bringing together in one room all of the people providing services, in order to plan the best ways to meet the client's needs. The client should always be part of this process.

This approach may find the social worker engaged with key people such as extended family members and community Elders, and may necessitate encouraging medical professionals on the team to adapt to what may seem unconventional inclusion of cultural practices such as smudges and sweetgrass ceremonies. Because of the complexity of this situation, the case manager role was important for Marjorie to take on to ensure that multiple needs of Nadine and her baby were effectively met by all of the different professionals and services involved.

Evaluation

Evaluation enables the client and social worker to track their progress toward achieving their goals and to discuss any adjustments required to their plans. Evaluation in a hospital setting, which often requires a need for rapid assessment and intervention, is still a vital component of the helping process and is a continuous and often informal activity. In the case example, Marjorie checked with Nadine to make sure she was in agreement with each part of their mutually defined work together. In working with Aboriginal clients, the evaluation process is particularly relevant because it underscores the primacy of the client's judgment as to the effectiveness and appropriateness of service and assures the client that he or she is heard. An important purpose of evaluation is to continue improvement of practice skills for future work with diverse clients.

Ending

Endings in hospital social work are often determined by the client's medical status and the need for ongoing treatment or services outside the health care facility. Often the social worker provides a vital service for the patient and team by asserting the importance of psychosocial and cultural factors in effective discharge planning. Contacting community-based service providers to initiate and ensure that the referral has been successful is particularly helpful in the case of urban Aboriginal health care clients who may have to contend with transportation difficulties, child care needs, and other challenges. They may, due to previous experiences of perceived racism and disrespect, be wary of those who determine service arrangements for them. Follow-up by the social worker is stressed since, from an Aboriginal perspective, once a relationship is established, there is an expectation that it will continue. This is in contrast to many hospital social worker-client terminations, where the contact is stopped and the relationship ends immediately upon discharge.

Although, in this case, the health care setting dictated a rather abrupt termination process upon discharge of the baby, it was important for Marjorie to follow through to provide essential emotional support and to ensure that Nadine actually received the services and support she needed in the community. This responsibility is implied in the service covenant between Marjorie and Nadine.

Conclusion

There is general agreement that currently, social workers in all practice settings need to have some understanding about the cultures of diverse client populations. Nowhere is this more important than in urban health care settings, where the cultural background of patients may be in contrast with mainstream Canadian culture and model of health care delivery.

Although the problem-solving approach, so commonly utilized by social workers, can be the basis for effective intervention with urban Aboriginal patients, it is imperative that the model be expanded to include genuine understanding and acceptance of historical, cultural, spiritual, and familial factors that may profoundly affect how health care is experienced. It is important for social workers employed in urban health care facilities to improve their own understanding of historical factors and cultural differences, in order to effectively help this potentially vulnerable client population.

Reflection Questions

1. How would you, as a critically reflective social worker, systematically examine personal values, attitudes, stereotypes, and biases that might interfere with your cultural competence (without assuming that you already understand how to work competently across cultures)?
2. How does the experience of racism affect access and use of health care services and what is its impact on the individuals and groups affected?
3. In health care facilities you know of, what factors would help ensure more culturally competent health care services?
4. How might Marjorie have tried to influence the hospital system to be more responsive to Aboriginal consumers?

Chapter Glossary

Elders: Aboriginal peoples who are respected and consulted for their experience, wisdom, knowledge, background, and insight. Elder does not necessarily equate with aged.

First Nations: Used interchangeably with "Indian band" and refers to all the people of a particular Indian community. It is also used to imply the First Nation Council.

Indian Reserve: Reserve land is owned by the Crown (Canadian government), and held in trust for the use and benefit of an Indian band, for which they were set apart. Indian bands have the rights, stipulated under the Indian Act, to the indefinite use of the reserve land and to receive the beneficial interest derived from those lands (called reservations in the U.S.).

Nation: Refers to a sizeable body of Aboriginal peoples with a shared sense of national identity that constitutes the predominant population in a certain territory or collection of territories.

Pow-Wow: Aboriginal peoples getting together to join in dancing, visiting, renewing, sleeping over, and renewing old friendships and making new ones. This is a time to renew thoughts of the old ways and to preserve a rich heritage.

Smudge: A universal component of all ceremonial practices. The grass was gathered when long, and plaited into braids. Before and at frequent intervals during every ritual, a bit of dried grass was broken off and placed onto live coals. The resultant aromatic smoke was regarded as a purifying agent used to dispel a mundane atmosphere and substitute a pleasant odour.

Sweatbath: While not common to all ceremonies, the sweatbath was often utilized. It could be taken for pleasure, as an offering to a spirit power, or as a ritualistic cleansing preliminary to any ceremony. The sweatlodge was built, and stones were heated and passed inside. Sweetgrass was burned inside the sweatlodge and a pipe offered. Then the lodge was closed and water sprinkled on the hot stones. A set of four songs was sung and then the cover was lifted a little and the bathers rested. Participants sang two or three sets of songs in all and then came out of the lodge; they lay on the ground to cool off. The sweatbath continues to be in use today.

Talking Circle: In a circle, all members honour and listen without comment or interruption to the story of each speaker. The speaker takes all the time needed. When the Talking Stick is passed to the next person, that person does not comment on the previous story, but speaks only from his or her own truth. In other words, non-interference was practised as each story was accepted and honoured as a teaching and a truth from the individual speaker. Each person had the right to his or her own truth in an atmosphere of sacredness and safety without risk of criticism, shame, and judgment from others.

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PART C

STRUCTURAL AND INSTITUTIONAL CHALLENGES AFFECTING HEALTH AND MENTAL HEALTH CARE

Social workers who provide services to clients in health and mental health agencies and facilities work in particular settings and locations that tend to shape their mandates and practices and the supportive resources available to them and their clients. The following five chapters address the barriers and possibilities in working in mental health and health care settings, describe social work interventions that can be effective in these settings and with some groups of clients, and discuss collaborative work with professional colleagues, both social workers and other health care team members. These chapters raise questions about how social work can be more effective, how resources can be further developed, and how social work practitioners can enhance their services for the benefit of clients.

CHAPTER 11

PSYCHIATRIC REHABILITATION IN A REMOTE COMMUNITY

Glen Schmidt

"David" (not his real name) is a 19-year-old male who lives in a remote First Nations community in Canada. When he was about 17 years old, he began to hear voices and believed that people were making fun of him. He attended the local high school where he was a good student. However, David stopped going to school and withdrew from his friends and family. His parents became very concerned and took him to see a doctor. After meeting with the doctor, David was sent to see a psychiatrist based in a community 200 km to the southwest of his hometown. David was hospitalized for observation and subsequently prescribed anti-psychotic medication. The hallucinations and paranoid thinking cleared and he was discharged from hospital. He returned to live with his family and resumed attendance at school. Community mental health services were unavailable in David's home community and he was advised to consult with the nurse and doctor at the local health unit.

Introduction

Social work, like other professional disciplines, relies upon models or paradigms to guide and inform practice. The ecological or "person-in-environment" model, the structural model, the feminist model, and the strengths-based model are a few contemporary examples. The social work profession is also very adept at incorporating approaches from other disciplines. This is an asset as it represents flexibility and adaptability, particularly within practice environments that emphasize the importance of interdisciplinary and multidisciplinary methods. However, in adopting models of practice, it is important to consider the origin and context of the particular model or approach in question. For example, almost all of the contemporary practice models have their origins in urban-based settings. This is not surprising given that the vast majority of the world's people live in cities. Social work education and practice research are predominantly urban in application and consequently students and practitioners are exposed to paradigms that are usually developed in an urban environment. This is not necessarily a bad thing, but social work practitioners must consider the geography of place and location when they look at application of a particular approach or model.

In the field of mental health, the psychiatric rehabilitation approach is a good example of a progressive model of practice that has been widely used by social workers employed in the field of mental health. However, the origins of the model are distinctly urban and we have to carefully consider how this model might apply to the case of David.

Psychiatric Rehabilitation

Anthony (1979) defined psychiatric rehabilitation as a process of ensuring that people who experience a psychiatric disability have every opportunity to learn and perform the physical, emotional, social, and intellectual skills to live and work in their community with the minimal amount of professional help. The psychiatric rehabilitation approach helps people to develop goals along with the necessary skills and supports to achieve those goals (Anthony 1998). Divisive arguments about etiology are less important as most service providers, family members, and consumers can agree that rehabilitation should be an optimal goal, especially rehabilitation that emphasizes the strengths of the person who experiences a serious mental illness. The approach strives to ensure that people having a mental illness can be active citizens and members of the community.

Psychiatric rehabilitation is urban in origin and the beliefs and assumptions related to the approach have to be understood as arising from that environmental context. For example, psychiatric rehabilitation is premised on the assumption that communities have a range of housing options available for people with mental illness

(Carling 1995; Trainor, Morrell-Bellai, Ballantyne, and Boydell 1993). There is also a belief that the employment market is diverse and has many opportunities that just need to be liberated for consumers of service (Chandler, Levin, and Barry 1999). Finally, in the discussions of building support networks, there is a belief that services such as psychiatry, recreation, hospitals, social work, and nursing are readily available, though again these services need to be made more accessible and accountable to those with mental illness (Anthony, Cohen, and Farkas 1990).

Unfortunately, these beliefs do not always hold true for isolated and remote settlements. This is especially true for a country like Canada.

The Canadian North and Service Organization

Although Canada is described as a northern country, 75 percent of the population live in a narrow band along the border with the United States (McVey and Kalbach 1995). The Canadian population is overwhelmingly urban and the political power base is closely attuned to the needs of urban voters. The terms “northern” and “remote” are relative and somewhat imprecise (Schmidt 2000), but include a range of characteristics such as latitude, climate, lack of economic diversity, limited services, distance from major population centres, a sparse and widely dispersed population, and primary dependence on a single resource-based industry. All of these factors create relative isolation and limit the extent and range of services.

Health and social services in the North have been organized in a manner that can be described as “vertical,” meaning that programs and funding arrangements are controlled from a central urban point. This vertical structure creates problems for northern people because programs are often designed with a southern, urban population in mind. Urban service delivery tends to be highly specialized whereas health and social services in small northern communities have typically employed workers and offered programs that are less specialized and more generalist in their function (Collier 1993; Lee 1998).

Widely dispersed populations make it difficult to support highly specialized services that are used by only a handful of people. For example, it is difficult to justify and fund a drop-in centre for people with severe mental illness if the community is tiny and has only two or three people who might use this type of resource. A second reason for the provision of generalist services relates to the fact that it is difficult to recruit specialized workers for employment in the northern environment.

Stigma may be attached to mental health service organizations and the people who require such service. This is true for urban as well as northern locations. However, the problem for residents in small northern communities is that their activities are highly visible to friends and neighbours, and accessing a service in a way that is discreet and confidential may present challenges (Delaney 1995).

First Nations peoples are a significant population group within northern Canada and among them there are differing definitions of mental health, a fact that further complicates service delivery. Elias and Greyeyes (1999) conducted an environmental scan of First Nations' mental health needs in every part of Canada. The scan demonstrated that serious mental illnesses requiring psychiatric rehabilitation are not usually seen as urgent a problem as other issues such as substance abuse, sexual abuse, and the various effects of residential schools.

Various structural elements further complicate matters for northern residents. The cyclical nature of resource-based economies places northern people at periodic risk for unemployment. For example, in northern British Columbia, the market for forest products is heavily dependent upon the United States and key Asian countries such as Japan. Downturns in these economies or trade disputes quickly close mills and put people in northern British Columbia out of work. This difficulty is even greater within First Nations communities where unemployment and poverty are at unacceptably high levels.

How Well Does an Urban-Based Model Work in a Non-Urban Setting?

In exploring this question it is important to talk to people who receive and deliver the service—in other words, consumers like David, family members, and service providers. An isolated community in northern British Columbia was selected to consider how the model of psychiatric rehabilitation is applied and how well it works. The research proposal was first reviewed by the chief and council of the selected community, who provided their permission and support to proceed.

Ten subjects were purposely selected to examine the issue of urban model application and its fit in a remote setting. The subjects included three reserve-based service providers, one itinerant service provider, two family members, two people with a psychiatric disability (one with schizophrenia and one with bipolar disorder), and two Prince George-based service providers. Prince George service providers were interviewed because Prince George is the regional centre, the closest "large" community, and the location for specialized mental health services, including psychiatry and hospital services. The education and professional background of all the service providers included two social workers (one MSW and one BSW), one social service worker (two-year community college diploma), two registered nurses, and one licensed practical nurse. Each person was interviewed using a semi-structured interview guide. The interviews were tape-recorded and transcribed using a code to identify participants. The transcriptions were analyzed using a thematic content analysis (Krippendorff 1980). Five theme areas emerged from the interview responses: (1) service delivery; (2) housing barriers; (3) employment and education barriers; (4) community attitudes; (5) identified needs.

Results

1. Service Delivery

An issue that was addressed by all of the service providers related to referrals between resources or services. Respondents' comments and concerns described a disconnected service system. This disconnectedness appeared to be due to a number of factors, but clearly geography and the challenges of vast distances are at play. For example, one person said that clients who are dealt with in Prince George don't connect with resources back in their home community. This service provider speculated that the reasons for this might include lack of transportation and lack of knowledge about where to go for help. In the North, transportation is expensive and availability of public transport is poor. The type of public transportation that many consumers rely upon in urban centres is virtually non-existent.

Geographic distance and resulting transportation problems create other problems that interfere with rehabilitation planning. When people are ready for discharge from a specialized urban treatment resource, it is difficult to know what the person may be returning to and whether or not the situation is appropriate. This happens because discharge planning assessments are not always reliable. This problem is exacerbated by the fact that it is very difficult for family members to travel to visit a hospitalized family member and participate in discharge planning. One community-based service provider said that financial and transportation difficulties restrict interaction with a mentally ill family member.

"Family normally don't go to Prince George to visit because there's nowhere to stay. There's no funding for compassionate travel, so especially if an adult family member is on income assistance, they won't have a vehicle, they won't have money for meals, and they won't have money for accommodation."

The disconnectedness and the distance between communities also seem to have a negative impact on information exchange. A service provider indicated that it was difficult to maintain reliable and up-to-date information on contacts in the remote communities. This person said that staff turnover appears to be higher in remote communities, which makes it very difficult to develop reliable and knowledgeable referral resources. The service provider reported that many staff in remote communities may be in their first job and they lack experience.

"Quite often we have new people who are in their first position—they're right out of school. And sometimes I even wonder if they know anything about mental illness."

At the local community level there is another lack of knowledge and this relates to understanding and recognizing mental illness. For example, most First Nations reserve communities employ National Native Alcohol and Drug Abuse Program (NNADAP) workers. However, the NNADAP workers generally have very limited training in recognizing mental illness. This is unfortunate as the NNADAP workers are one of the local resources that may have first contact with a person experiencing a mental illness. One service provider stated:

> I met a young woman from a First Nations community and it was clear that something was going on. She had spoken to two counsellors—one was a community counsellor and one was a NNADAP worker and they didn't know what to do with her. The idea of a mental illness was remote so she'd never had a referral to a GP to explore that further.

Follow-up resources may be located in an adjacent community rather than in the reserve community itself. One of the service users interviewed indicated that the community mental health resource that they were using was located in a larger community 50 km away. This person's family did not have a vehicle, which made access to the service very difficult as public transportation schedules made it impossible to arrange necessary travel in a convenient and affordable manner.

2. Housing Barriers

Housing is a key component of psychiatric rehabilitation. Affordable housing can certainly be an issue in urban locations, but the availability of housing in remote northern communities is even more limited. For example, the community in this study had a population of just over 600 inhabitants and 90 of those inhabitants were on the community's waiting list for housing. A service provider noted: "It is fair to say that the housing shortage makes it difficult for healthy individuals to get housing. If you have a disability, like a psychiatric disability, it is even more difficult."

The psychiatric rehabilitation approach typically relies upon a range of housing options, including group homes, adult care homes, supported independent living, co-operative living arrangements, and independent living as well as other variations. This variety or range of options is simply not available in remote First Nations reserve communities. Housing stock is made up of small, detached bungalows. Overcrowded conditions are common and a house might be shared by several family units. One service provider noted that people end up being discharged from hospital into a household where there are often many children and limited privacy. This service provider stated that: "people might be discharged into very crowded living conditions with associated higher levels of stress and concerns about safety." One of the consumers in this study stated that crowds created discomfort and this person reported a need for privacy and quiet.

3. Employment and Education Barriers

Work options in isolated northern communities are largely confined to the single resource industry or the service sector. The relatively small size of the community under examination limited work prospects in the service sector while the resource sector is always influenced by fluctuation in market demands for wood. Community officials estimated unemployment at 55 percent of the employable population. Clearly, high rates of unemployment restrict possibilities and options for those with a psychiatric disability. One service provider stated:

> There's nothing. We have to find a position for them [mentally ill people] that would be a job-shadowing model with a structured growth pattern, and there's nobody who is willing to take that on. We have one person who is developmentally delayed, not a specific disorder, just a very slow person and they work as a janitor alongside another person and that is as far as people are prepared to go.

Life skills training is an important component of preparing people for the employment market. However, this is a fairly specialized service. All of the service providers who were interviewed, as well as the family members and consumers of service, described a total lack of life skills training.

One Prince George-based service provider indicated that life skills training is critically important for many people with persistent and severe mental illness. If there was a base for life skills training, this provider believed that it would make a tremendous difference for many people with serious mental illness from remote First Nations communities. However, the provider noted that life skills are often taught within the context of things like day programs and in smaller more remote communities, this raises a concern about economies of scale. If there are only two people in a community in need of life skills training, then an approach other than a day program is required.

4. Community Attitudes

Community support and acceptance are important aspects of the recovery process. One person reported discomfort as a result of a family member's mental illness. This person stated that many people don't understand and don't seem to want to understand what is involved with a mental illness. The family member said, "They're either afraid or confused."

One local service provider said, "Some people believe in curses or bad medicine. It depends a lot on what's going on. If a person becomes violent and then suddenly changes, there are those in the community who think that this is some kind of witchcraft or something."

A family member said, "The community reaction to mental illness is very negative, even cold. People don't want to have anything to do with you, or it's always your fault and you're just a bad actor. It's a very poor attitude."

Several service providers indicated that among some community members, mental illness has the stigma of bad medicine or a curse attached to it. Beliefs in bad medicine remain very strong in a number of First Nations cultures, and people with mental illness may be shunned and marginalized because they are thought to be cursed.

Consumers as well as service providers all spoke of the need for community education about mental illness. One service provider stated that mental illness is generally seen as the same thing as mental retardation. There is no differentiation in the minds of many community members. This service provider stated: "Mental illness, brain injury, and mental retardation are all placed in the same pot and viewed as the same thing."

5. Identified Needs

One suggestion related to community education. Consumers of service, as well as service providers, described a need for more community and public education about mental illness in order to deal with the myths and stigma.

Service providers on reserves also talked about the need for supportive housing options. However, they noted that a supportive housing project would have to include people with a range of disabilities besides a psychiatric disability as the population base simply did not warrant separate construction.

Service providers saw life skills training as being critically important in developing skills for independent living. There is a lack of knowledge about mental illness and life skills trainers are also seen as people who can begin to address this need.

Finally, as one service provider stated, "There's a real need for information—to know what services are available." This need is apparent in Prince George as well as the remote communities. The system is far from being seamless and there is an alarming disconnection between specialized resources in the urban centre and the communities on the periphery.

What Does This Mean for Psychiatric Rehabilitation?

Psychiatric rehabilitation models are based upon integration and normalization. The models rely on key elements such as employment, housing, education, and access to a range of mental health resources that are connected in a network of support. Isolated rural communities like this one in northern Canada experience disconnectedness from service and information, which is the result of barriers like geography and the economy of small isolated populations.

Centralized planning, centralized administration, and lack of research based in isolated rural settings often result in application of practice models that may not be a good fit with the particular environmental context. The concept of psychiatric rehabilitation is important and its application has made a real difference in the lives of many people who require services to address a mental illness. However, the principles and the methods of this approach were formed in an urban environment with accompanying urban assumptions. The reality for northern and remote Canadian First Nations communities is very different. The lack of specialized services, lack of transportation, limited housing options, community prejudice, and lack of employment and education opportunities are important considerations when looking at the development of a model or framework for practice. Direct application of the psychiatric rehabilitation model does not work without major changes and adjustments. It is important to consider some questions as they relate to psychiatric rehabilitation and David's situation as described at the outset of this chapter.

Reflection Questions

1. If David lived in a large city, would he face the same problems identified by the consumers, service providers, and family members from this remote northern community?
2. In adopting an urban-based model for rural or northern practice, what are some of the key considerations or questions that you need to address?
3. How would you deal with questions of cultural superstition to avoid offending or belittling a particular cultural group?
4. Are there other forms of housing that might meet the needs of David and other mentally ill people who live in isolated rural settings?
5. Can you think of some ways to modify the psychiatric rehabilitation model so that it might be more effective for people like David and his family?

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CHAPTER 12

BROKEN HEARTS, SHATTERED SPIRITS:

Social Work, Domestic Violence, and Health Care

Kathleen Mackay and Stan de Mello

Introduction

The violence and abuse in families affects every one of us. As social workers, we believe that the family is a cornerstone of a healthy self and a healthy community. Disturbingly, the family can also be a source of significant difficulty, and, unfortunately, can be a dangerous place for women and children if there is domestic abuse. Most of us know of someone, a friend or family member, who has at one time or another experienced abuse, either by an intimate partner as an adult or teen, or by a family member as a child, adult, or older adult. The reality of abuse at home, in a setting we think of as safe and secure, shakes our sense of what is right in the world. Domestic abuse challenges our ideal of the family as a place where women and children experience healthy emotional and physical development. Violence and abuse in families can create serious dissonance or confusion about the spiritual or religious values attributed to the meaning and purpose of family and family life.

As social workers our understanding of domestic violence situations is reflected in our recognition of the problem, interviewing and assessment skills, and planned interventions. These interventions occur at the micro (individual and family), mezzo (group), and macro (community and policy) levels. It is important to evaluate the effectiveness of social work interventions in this arena, particularly as social work is only one of a wide range of disciplines and professions that provide assistance and support in domestic violence situations. Other professions and organizations include those in health care, law enforcement, child protection, public welfare and offender treatment, and women's, multicultural, gay/lesbian, and seniors' services and faith-based communities.

In this chapter we review the definition, history, and extent of domestic violence; who it affects; the societal response to it; and, specifically, the role of social work in preventing and intervening in domestic violence. The focus of the chapter is on social work implications of domestic abuse, in particular, the way domestic abuse affects health, psychosocial functioning, and family and community health. The dynamics of abuse may pertain to both male and female relationships and to same-sex couples. Abuse in same-sex relationships, child abuse, sibling abuse, elder abuse, and women's abuse of men are beyond the scope of this chapter. Here the focus will be on spousal abuse, particularly woman abuse. The geographical focus is primarily on Canada.

Definition

The *Canadian Oxford Compact Dictionary* (Bisset 2002) defines violence broadly as the often illegal "exercise of physical force to cause injury or damage to a person or property" (p. 1176). The United States Centers for Disease Control define intimate partner violence as an ongoing pattern of coercive control that includes physical and/or sexual assault or similar threats (Saltzman, Fanslow, McMahon, and Shelley 1999). Domestic violence has been called and includes family violence, spouse abuse, woman abuse, intimate partner violence, elder abuse, and child abuse. Although any family member, regardless of gender, sexual orientation, age, or socio-economic status, can be abused, women and children suffer the most obvious consequences of abuse, and most often men are the perpetrators.

Domestic violence includes physical abuse, mental, emotional, and verbal abuse, financial abuse, and sexual abuse, as well as spiritual and cultural abuse. Table 12.1 lists types, examples, and health consequences of abuse.

Women have been subordinate to men and continue to be so in many countries and societies. Traditionally women and children were considered the property of men, even in supposedly democratic countries. The men's responsibility was to control the behaviour of

Image not available

women and children using force if necessary. Justification for this imbalance of power was found in legal codes and religious writings, with women being the "appropriate" victims of family violence (Dobash and Dobash 1979). While violence against women has occurred throughout history, only recently has woman abuse been seen as a serious social and health problem. Violence against women and children generally occurred behind closed doors, a life-threatening reality for those affected, yet it is often unnoticed or denied by society at large.

Violence that occurred in the privacy of the family was invisible and unacknowledged until nearly four decades ago when "the battered child syndrome" was identified (Kempe, Silverman, Steele, Droegemueller, and Silver 1962), moving child abuse out from behind the closed doors of the home and onto the stage of the public and health care community. Wife abuse was the next betrayal within the family to be revealed. It was responded to largely by women themselves who set up a network of safe homes to provide shelter for other women leaving abusive relationships (Gelles 1997). Since that time we have learned that violence perpetrated within the family often has long-lasting adverse effects on those who are abused and those who witness the abuse of others. Societal awareness of woman abuse in the home by their partners has led to considerable social science research and to changes in social work intervention, law enforcement, judicial practices, and, more recently, health care systems.

Prevalence and Incidence

Prevalence refers to how many people are suffering the effects of a problem at any given time. Incidence refers to the number of new cases of a problem in a population. Many social work interventions seek to reduce prevalence through early intervention, while prevention initiatives aim to decrease the incidence of domestic violence cases. Estimates of the prevalence of spousal abuse began with the first national survey on family violence in the U.S. in 1976, in which 28 percent of couples reported some violence in their marriages (Straus and Gelles 1986). In 1993 the federal government in Canada conducted the first national survey of violence against women in the general population (Rogers 1994). The study found that three women in 10 (30 percent) experienced at least one incident of physical or sexual violence by a marital partner. Both the United Nations (1994) and the World Bank (Heise, Pitanguy, and Germain 1994) noted that violence is prevalent around the globe and is not limited to particular countries or cultures.

For many beginning social workers, understanding why and how abuse occurs is often confusing and intimidating. This is particularly so for those who have had some personal history with domestic abuse. To effectively assist others, it is at times necessary to seek counselling or supervision to understand our own reactions to clinical situations. Personal reactions to domestic violence can range from fear and denial to hostility and outrage. Social workers need to identify and deal with their own personal reactions to domestic violence situations if they are to be effective in helping clients who face such situations at home.

Etiology

Social learning theory is one of the more popular frameworks for understanding violence against women. This theory suggests that violence is perpetuated through children's exposure to their father's abuse of their mother, which results in "intergenerational transmission of violence" (Straus 1980). Ironically, those who supposedly love the victim the most are the perpetrators of the violence, reinforcing the role of the family as a training ground for violence.

Family systems theory, fundamental to most social workers, regards abuse as a characteristic of the relationship, usually minimizing the existence of power and control inherent in our gendered society. Marital counselling, in which each partner is held responsible for his or her own contributions to the dysfunctional situation, may be recommended. However, when abuse is present, it is often not safe for a woman to be open and honest with her partner present, as he may inflict more violence once they leave the counselling office.

Psychoanalytic theory holds that intrapersonal pathology caused by a person's early life experiences may lead to abusive relationships (see McLeod 1994). Women may choose abusive men and believe that they deserve to be abused. Men may abuse because they have personality disorders or are otherwise mentally ill. Treatment for both would be long-term psychotherapy and possibly medication. Critics of these psychological explanations assert that social structures and gender inequality are not accounted for in this scheme (Mullaly 1993).

Feminist psychological theory, developed by Lenore Walker (1979), suggests that women who are abused develop coping mechanisms to deal with a cycle of abuse in relationships. The cycle includes a tension-building phase during which the woman tries to appease her partner, but is unable to prevent the escalation of his anger; the explosive phase when violence occurs; and the honeymoon stage. During the honeymoon stage the man is repentant and the woman builds hope that he will change. However, the cycle is repeated with tension buildup, explosion, and calm once more. As a result, the woman may suffer from post-traumatic stress disorder, feel depressed, anxious, and unable to think clearly, thus remaining trapped in the abusive relationship. Interventions include reducing adverse effects of gender role socialization and providing practical help for women (crisis lines, financial aid, legal assistance, and shelters).

A feminist social work perspective views men's power over women in society and its institutions as major factors that support violence against women (Dobash and Dobash 1979). Women are seen to occupy a subordinate position in society that is rooted in traditional families. Many women are still socialized to believe in the privacy of the family; conjugal and parental rights; and the male-headed, two-parent family (Pleck 1987). Some may feel responsible for the success of the marriage and the care of children, and that their children need a father (Hoff 1991). Violence has been a primary means to maintain social control and male power over women. In other words, "oppression is an inevitable result of 'power-over'. In order to end it our challenge is to discover how we can restore the skills, methods and culture of 'power with' [others, not over them]" (Bishop 1994, p. 31).

Interventions require a continuum of services for women, including shelters, support groups, financial aid, safe and affordable long-term housing, and legal assistance. There is also a need for major social transformation in order to achieve real equality for all women, an important pre-condition for healthier relationships between men and women. Criticisms that have been raised against this theory include its inability to explain women's violence in heterosexual and lesbian relationships (Straus and Gelles 1990). Also, if men's domination in society and over women is a primary cause of violence, the question remains as to why violence against women is not more prevalent and perpetrated by all men.

Exchange/social control theory (Gelles and Cornell 1990) suggests that family conflicts are unavoidable and that violence occurs because it works because it helps abusers get what they want. The cost of abusing one's wife was low when it occurred in private, where there were no social sanctions against it, and when women had few options. Increasing sanctions against violence through criminalization, teaching non-violent ways to resolve conflicts, and ensuring that women have access to community resources when they need to leave abusive situations reduces the power of an individual abuser.

It is clear that there are multiple explanations for violence that consider both oppressive social structures and practices and individual characteristics. Understanding multiple risk factors is key to providing effective counselling both for preventing violence and for keeping those at risk safe. As a beginning social worker, being well informed about the multiple and complex theories regarding why violence occurs in families allows practice to proceed in a thoughtful and effective way. Insightful practice requires us as social workers to consider each case (the micro perspective) as unique and within the context (the macro perspective) in which the abuse occurs.

Clinical Interventions

Micro: Recognition of the Problem, Interviewing, and Assessments

Social workers are uniquely placed to both recognize abuse and assess clients for the presence of domestic violence. In addition to the normal protocol for conducting and documenting assessments within the agency, it is important to ask specifically about abuse. Because of the shame associated with domestic abuse, it is unlikely that an abused woman will reveal her situation unless a practitioner asks her about it directly. If a client discloses that she is being abused, the assessment should include the history of the abuse, when it started in the relationship, the nature of the abuse, how it has affected her, and how she has been coping so far. It is important for the social worker to create a safe environment by asking questions in private and ensuring confidentiality. Some initial screening questions about abuse may include the following questions:

- Is anyone hurting you or making you feel afraid?
- Have your injuries been caused by someone?
- Is your life being threatened by someone you know?

It is important to practise asking these questions with colleagues and other students before asking clients. A review of studies on domestic violence screening by Ramsay, Richardson, Carter, Davidson, and Feder (2002) reveals that questions such as these help to identify people who are abused and link them with appropriate services.

It is not uncommon for a victim of domestic violence to assume blame and responsibility for the abuse. Early in the interview, the social worker needs to balance being a good non-judgmental listener and being an advocate for human rights and personal safety. Although a woman may believe initially that the abuse is her fault, the social worker can tell her that assault is a crime and that no one deserves to be abused. During the initial phase the social worker needs to provide empathic responses that encourage the client to talk about her situation, and to reassure her that she is not alone, as domestic violence affects many people. The social worker has an opportunity to educate the client about the dynamics of domestic violence, including the use of power and control. The woman may not have realized that the abuse she is experiencing includes much more than physical assault. Asking her whether her partner controls her behaviour and isolates her from others can help both worker and client better understand the situation. The client is the best person to determine the solutions that will work for her. Listening to the client so that her readiness to engage in further problem solving can be established will suggest how to proceed. She may not be used to making decisions if her partner is very controlling, so both crisis counselling and long-term support may be required. Early in the interview it is necessary to ask about the safety of children in the home to determine if they need protection. In some cases, it may be necessary to involve other organizations to provide help.

Social workers want to know, understand, evaluate, and individualize our approach to helping clients. Kirst-Ashman and Hull (1999) suggest that for assessments to be a sound basis for helping, they need to include: client identification; determination of the social and cultural milieu (i.e., the micro, mezzo, and macro context); description of the client's problems and needs; and identification of the client's, family's, and community's strengths and assets.

Social workers have often found that the use of genograms and ecomaps (Cournoyer 2000) are useful visual additions in enhancing the understanding of family dynamics, strengths, and community resources. Furthermore, these tools are helpful in making effective case presentations in interdisciplinary teams, case conferences, or staff meetings. In health care settings, recording tools particular to domestic abuse that remain as a permanent part of the patient's health record are useful in preserving evidence and in educating other health disciplines about the reality of abuse. Such a tool (the Domestic Violence Record) is in use at the Vancouver General Hospital and includes: details about the client's current relationship with the partner; the forms and history of abuse that her current and any former partners have used against her; the frequency and intensity of the abuse experienced (e.g., use of weapons or other objects and physical injuries); police involvement now and in the past; and a psychosocial assessment that includes the severity of abuse experienced, the risk of danger, current supportive relationships and resources, and the kinds of help used in the past.[1]

Once the assessment has been completed, the social worker can speak to the client about her perception of the personal danger she may be in. Increased danger is indicated when violence has been more frequent or severe during the past year; when a weapon has been used or a gun is available; when there has been a threat to kill; when the abuser is violent outside of the home; when there is a risk of suicide; when sex has been forced; or when children have been abused (Campbell 1986). The social worker might say something like, "I am very concerned about your personal safety." The next part of the intervention is to plan with her so that she has some options for her personal safety in case violence should recur. In this regard family and community resources that might provide a safe haven during episodes of violence could be explored. The safety strategy should include having access to phone numbers of friends and neighbours, shelters, and crisis lines that can be relied upon in an emergency. It is useful for women to have clothing, money, important papers such as copies of passports, birth certificates, health care records, custody agreements, etc., stored within easy access or outside of the home in case of an emergency. Safety planning is best carried out in a calm, clear, and matter-of-fact way without unduly upsetting or alarming your client, who may already be under tremendous stress. A safety checklist providing such information and resources offers a practical, useful, and concrete tool, and can be a focus of social work with the client.

Leaving an abusive situation is a process in which the social worker can assist. There are many barriers to leaving, including fear of retaliation by the abusive partner, financial constraints, limited social support, belief that the abuser will change, commitment to religious vows, responsibility for children and family, and/or community pressure to stay. A woman often leaves and returns many times before leaving permanently. This may be perplexing for social workers and other helpers and difficult to understand and support. As a social worker you will need to draw on your knowledge and critical thinking skills to understand your client's behaviour. It helps to reflect on the privilege and status some of us may have, and the biases held, for example, about individual autonomy and the equality of each person in a marital relationship.

Domestic abuse frequently does not stop once the woman has left her abusive situation permanently, as the abuser may continue to harass her, particularly if there are children involved. Also, the lethality of domestic violence situations increases once the abuser realizes that his partner is intent on leaving the relationship. Some women feel safer within the abusive relationship than outside of it, a reflection of how poorly we are able to control abusive behaviours in our society and therefore keep women safe.

Mezzo: Referral to Community Agencies and Groups

> If you think you are coming here to help us, you're wasting your time. If you see your liberation bound up with mine, then let's work together. (Lila Watson, Australian Aboriginal leader, cited in Napoleon 1992, p. 13)

Beyond identifying and assessing individual situations and safety planning, you will need to connect abused people to community organizations and groups that routinely deal with issues of domestic violence. It is useful to have resources listed on a card that is available for those who choose not to disclose the abuse to you. This type of card may be available in health care settings or social service agencies. If not, such cards are easy to develop and may someday help a woman in a crisis.

The work of Saleebey (1997, p. 12) stresses the importance of both a strengths-based approach and the invaluable assets that lie within communities. Some of the principles underlying the strengths perspective are discussed below.

Every individual, family, group, and community has strengths. While a client may be a victim of domestic violence, she also possesses vital assets, resources, wisdom, and knowledge that can both support her in the moment and help her in the future. Therapeutic, support, and self-help groups and community agencies also have strengths that could be of benefit to her. Within such group settings a client is able to realize that she is not alone. She will also learn that other women have used a variety of effective strategies and approaches in dealing with domestic violence. Through community referrals, social workers can help clients gain access to a collective strength that lies outside their immediate circle of assets and resources. For example, it is likely that they may need assistance with housing, child care, employment, or financial support. Beginning social workers will find it worthwhile to become aware of the community resources that work with abused women so that appropriate referrals can be made.

Trauma and abuse, illness and struggle may be injurious, but may also be a source of challenge and opportunity. Both in individual and group work, the client can be encouraged to move beyond a perception of herself as a victim whose situation is discouraging and hopeless. While it is both normal and natural for the client to feel this way, it is important for the social worker to reinforce that there is dignity and strength in having already overcome adversity and obstacles. The fact that she has been able to tell her story indicates that she has considerable courage and wants her situation to improve. Saleebey (1997, p. 13) writes about this in terms of survivor's pride:

> It is a deep-dwelling sense of accomplishment in having met life's challenges and walked away, not without fear, even terror, and certainly not without wounds. Often this pride is buried under embarrassment, confusion, distraction or self-doubt. But when it exists and is lit, it can ignite the engine of change.

Do not underestimate the capacity to grow and change within individuals, groups, and communities. Individuals have a wealth of possibilities and promise, as do groups and communities. As a beginning social worker, adopting a stance that is positive and hopeful is not only good role modelling for your clients, but also reassures them that you believe in their inherent abilities to solve their own problems. While you may feel overwhelmed by the enormous complexity of the situation, clients, more than anything else, want to know that you believe in them and their capacity to overcome these difficulties and move toward transformation and growth. Groups and communities also need both your professional support and reassurance that they are able to serve women who have been abused and that the service is valued and integral to the healing journey.

Working toward collaboration rather than dependency, social workers may be most useful as collaborators, facilitators, and coaches. As they work with clients, they find it is useful to avoid the expert role, and shift their approach. Collaboration allows a social worker to join with the client to better understand her hopes and fears. This avoids the unpleasant trap of paternalism and victim blaming. In the final analysis a social worker facilitates the client's movement toward the road to recovery and avoids creating an ongoing dependency on the social worker or others.

Macro: Education, Advocacy, and Policy Development

Social workers are in a unique position to educate others about domestic violence. As they work with the police, prosecutors, judges, and other support systems, they will have opportunities to influence how their clients might be treated. Social workers can help create an atmosphere of respect, support, and co-operation. Sometimes other systems have little understanding of the deep psychosocial and emotional impacts that abusive situations have on clients and of the long-term effects on individual women. The role of advocate allows a social worker to both educate and lobby for change. Even among social workers who have only minimal contact with domestic violence survivors, there is a need for more knowledge about the complexities of abusive relationships. Social workers might have the opportunity to provide useful input into the development of policies within their agencies, community organizations, and governments (municipal, provincial, and federal) as they seek to determine how to best serve those who have experienced domestic violence.

It is becoming increasingly important in our multicultural social environment to provide culturally competent services to clients in abusive situations. This sometimes presents challenging contradictions to workers who might want to provide Western-based solutions to women who may have traditional and/or more conservative cultural beliefs. As in all good social work practice, the key is to begin where the client is and to honour the beliefs and traditions the client holds important, to the extent possible. This does not mean endorsing or supporting oppressive anti-woman behaviours, but it does acknowledge that clients are in the best position to decide the direction they wish to take. Our role in social work is to present options and to discuss the consequences of the choices the woman makes. In general, most agencies would agree that there is an acute shortage of professional social work and health care support for all the diverse ethnocultural groups in our society. Advocacy for such services needs to be an integral part of professional social work practice.

New developments in social work theory and practice stress an integration of all three levels of practice (micro, mezzo, and macro) and into a more holistic contextualized model. Contextualized social work practice has the following important elements:

1. Connecting daily practice and the structural features that shape a society's history, policy, economics, politics, social, and cultural dimensions (Mullaly 1993).
2. Weaving individual, family, and community problems into the larger fabric of these structural features (Allen-Meares and Garvin 2000).
3. Directing social action toward a larger goal of social justice through the analysis of power and inequality. Social justice is a central theme in progressive social work practice and endorsed in the Codes of Ethics for social workers in Canada and the United States.

Thus, social workers who provide services for clients in domestic violence situations often engage with the client, the community, and the policy environment simultaneously. Working with the client's immediate problems is useful, but it is just as important to begin to change oppressive and unjust structures that have supported the creation of the problems in the first place.

We are usually shocked to read about difficult social conditions and cruel and unusual events in some parts of the world (for example, stoning to death those women who are accused of committing adultery). It is appropriate to be concerned, but it is also appropriate to recognize that we have pressing, although different, concerns for women's safety and security in our own countries. "Thinking globally and acting locally" by critically reflecting on how the conditions of violence are allowed to prevail within our society can be helpful (Van Soest 1997).

The social work profession has been criticized as having adopted a psychotherapeutic belief system, analyses, and intervention strategies. Dubbing social workers as "unfaithful angels," Specht and Courtney (1994) suggest we have abandoned our mission of helping and argue that social work has lost its direction as a humanistic and community-based profession and drifted into a privatized and individualized view of the world. Those who are beginning in the field of social work can find many opportunities to review how the profession has changed over time and to understand how we can better address the many complex issues addressing women caught in the web of domestic violence.

Health Consequences of Abuse

Living with violence and abuse can result in chronic health conditions, including recurring injuries and medical problems such as headaches, joint pain, abdominal or breast pain, infections, and sexually transmitted diseases (see Table 12.1). The psychological effects of abuse include suicide attempts, drug and alcohol misuse, depression, and other mental health problems (Stark and Flitcraft 1996). Abused people are often frequent users of health care services (Stark and Flitcraft 1996; Tjaden and Thoennes 2000) and a social worker in a health care setting or some other health care provider may be the first person to hear a disclosure of abuse. Unfortunately, the disclosure will usually be made after numerous incidents of abuse have occurred (Schornstein 1997). By the time a woman discloses abuse, she has likely been assaulted many times, and has been living in fear for her safety for an extended period (Shornstein 1997). The long-term nature of abusive relationships means that the problems presented are often chronic. These unhealthy and dysfunctional relationships endure and are often difficult to leave, as noted above, due to shame, self-blame, economic factors, family pressure, and fear.

Jacqueline Campbell (2001) states that for many women, abuse may begin or may escalate during pregnancy. Walsh and Weeks, in this book, describe the many health effects of violence against women during pregnancy. A pregnant or recently pregnant woman is more likely to be murdered than to die of any other cause. Partners are frequently the perpetrators (Cefalo 2001).

Health Care Response to Domestic Abuse

It is clear that health care institutions and health care providers have an important role to play in the care of those who have been abused and in the prevention of domestic abuse. Routine screening can identify abused people who can subsequently be cared for appropriately and referred to community agencies. As Ramsay, Richardson, Carter, Davidson, and Feder (2002) report, women believe that being asked questions about their safety at home is beneficial. Physicians, however, are reluctant to ask questions about abuse, believing that it will "open a Pandora's box" and that they will not be capable of dealing with the issue (Sugg and Innui 1992).

Health care has followed justice, law enforcement, and social services in terms of initiating efforts to help abused women, and to prevent further abuse. Social workers in health care settings can play key roles in articulating the extent of domestic abuse and the proper way to care for abused people. Information on abuse and community agencies that assist abused people, available in waiting rooms and patient washrooms, help patients and visitors to access health facilities that may not disclose abuse to a health professional. When health professionals hear disclosures of abuse and respond empathically, document the situation carefully, talk about safety, and refer appropriately to community agencies, they are being helpful to the people who have experienced abuse.

Summary and Conclusions

Violence against women by their intimate partners, which is only one type of family violence, has occurred throughout history, affecting women regardless of age, culture, socio-economic background, or sexual orientation. Approximately one-quarter of women in their lifetime, worldwide, will experience domestic abuse (Heise, Pitanguy, and Germain 1994). The health impacts of abuse, from injury to exacerbation of chronic health conditions, make domestic violence a health care issue. Social workers, although at times personally challenged by the complexity of the issues, are ideally placed to address violence against women. By asking their clients relevant questions, assessing individual situations, engaging in safety planning, referring women in abusive relationships to community agencies, and educating others about the reality and dynamics of domestic abuse, social workers are part of the community response to prevent violence and care for abused people. Multiple theories have been developed to explain domestic abuse, which help to guide social work interventions. Domestic abuse can be fatal, with women being most at risk after they have left the abusive relationship. The health care response to domestic abuse has lagged behind law enforcement and justice system interventions. By asking routine questions about abuse and providing care that includes documentation and referral to community agencies, health care organizations and their staff can better provide for women who are in abusive relationships.

Reflection Questions

1. In the quotation given earlier in this chapter (and reproduced below), what meaning do you think the statement has for social workers? Give an example.

> If you think you are coming here to help us, you're wasting your time. If you see your liberation bound up with mine, then let's work together. (Lila Watson, Australian Aboriginal leader, cited in Napoleon 1992, p. 13)

2. If a fellow student or new social worker in the health care setting in which you work revealed to you that she had experienced years of abuse in the past and had never disclosed this to anyone before, how would you respond?
3. How do you explain the fact that most of the women you have counselled in social work practice return to abusive partners? How do you cope with your feelings of frustration?

Note

1. In 1992 the Family Violence Prevention Division of Health Canada funded a research project to better understand how to help women who use emergency department services and who are also in abusive relationships. An interdisciplinary group at Vancouver General Hospital in Vancouver, B.C., Canada, developed, implemented, and evaluated an emergency department-based program for abused women. This was the beginning of the Domestic Violence Programme (DVP) at VGH. See www.vanhosp.bc.ca/html/wellness_domestic_violence.html

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CHAPTER 13

SOCIAL WORK AND CONFLICT RESOLUTION:

The Work of a Hospital Patient Ombudsperson

Anna Metteri and Marja Nieminen

Introduction

In Finland, hospitals employ people to receive, investigate, and deal with patient complaints. They are patient ombudspersons. Their recommendations are not binding, nevertheless, hospitals often learn from these incidents and make subsequent changes. The ombudsperson is often required to mediate and resolve conflicts between the patient and hospital.

Conflict resolution is a central task in many fields of social work practice. In this chapter, we describe how conflict resolution between patients and hospital staff is handled by a patient ombudsperson and how patient complaints and written evaluative comments are used to enhance the way the hospital staff treat patients. The ombudsperson's intervention enables the patient's voice to be heard. In Finland, the work of a patient ombudsperson is a separate statutory function, often assigned to a social worker, but sometimes to a head nurse or lawyer. Customarily patient ombudspersons combine their work with another, sometimes full-time, job in the same health facility.

Most conflicts that arise between patients and the Finnish health service system are related to problems in the way individual patients feel they have been treated by hospital staff (Nieminen 2001; Passoja 2001). It is vital to recognize and respect the patient's own expert knowledge about his or her life and to validate his or her account of the illness experience.

The practice descriptions and case example in this chapter are drawn from situations often faced by a patient ombudsperson in a Finnish hospital[1] and an action research project (Reason and Bradbury 2001) conducted by Nieminen (2001). Our case example shows how important human relationship, openness, and reciprocity are as features of good care and how devastating it can be to neglect these fundamentals of care. In order to understand organizational tensions and conflicts and to implement change, the ombudsperson needs to work within the hospital work setting, the administrative structures that govern its activities, and the culture of the facility.

The Patient Ombudsperson System in Finland

In Finland, municipalities are responsible for arranging health care services, receiving government subsidies to perform this activity. The Finnish constitution states that everyone is entitled to receive essential medical and other health care services. In addition, acknowledgment of patients' legal rights was established through the passage in 1992 of the Act on the Status and Rights of Patients. This act governs patients' rights and mandates the work of patient ombudspersons in Finland. The ombudspersons are authorized to respond to the requests of patients, rather than those of the hospital, for services. The patient determines whether the ombudsperson is allowed to discuss his or her affairs with the health care staff or other parties. Further, a patient's file can be consulted only if the patient gives written permission.

For Finland's 5 million inhabitants, there are over 2,000 patient ombudspersons (Etelä-Suomen alueellinen työryhmä 2002, p. 7). Nearly half are social workers. Regardless of educational background, counselling constitutes a major activity for patient ombudspersons. They are employed at the regional level or, as is most common in Finland, they work in health care facilities, where they are are directly involved with patient care.[2] Patients' rights legislation and the patient ombudsperson's mandate provide a means to ensure patient-centred, quality medical care.

The use of ombudspersons has steadily expanded in the Western world, and today there are ombudspersons in many kinds of organizations at different administrative levels (Stieber 2000). The primary tasks of ombudspersons are mediating in conflicts, promoting conflict resolution, and preventing the escalation of conflict. An ombudsperson can be described as follows: "An individual employed by a government or other organizations to investigate possible illegal, unethical activities or harmful unforeseen consequences of that organization's actions" (Barker 1995, p. 262). When a patient ombudsperson responds to a patient request, she simultaneously launches a complaint and investigation process, facilitates and supports conflict mediation, and tries to prevent escalation of conflict.

Working in the hospital setting as an ombudsperson means that, on the one hand, the ombudsperson puts herself in the position of the client and, on the other, in the position of the staff. From the vantage point of a mediator, she examines and helps the parties discuss the issues at hand, reflecting on client-staff relationships and the function of the hospital in the client's experience. An essential part of the patient ombudsperson's work is handling, together with hospital staff, the written complaints that clients submit. A patient ombudsperson participates in a dialogue (Freire 1972, 60–67) with those who have concerns about their hospital experiences and interactions.

Tensions between the Patient and the Health Care System

For the best outcome, it is essential that patients' control over their own affairs is fostered and that client-staff relations contribute to this goal. Patients' views of good care are based on criteria that differ from that of doctors and nurses employed in the health care system (Thorsteinsson 2002). Patients' views of their health care encounters are shaped primarily by their personal experiences (Attree 2001).

Good relations between patients and health care staff are especially important for a satisfactory health care experience. Similarly, among clients receiving counselling services, the reasons for success often point to the therapist-client relationship rather than the type of therapy used (Howe 1993). In a good therapist-client relationship, the client feels that he or she is cared about and respected as a human being.

According to recent Finnish research findings (e.g., Ruusuvuori 2000), doctor-patient communication at health centres is expert-centred. Patient dissatisfaction tends to result from a difference in viewpoint between patients and doctors. Rather than examining the situation from the patient's viewpoint or from different angles, doctors, whose view are shaped by their profession, training, and orientation, may disagree with those of the patient, the receiver of care. Patients with chronic pain, for example, may experience disappointment after seeking and not getting help from the health care system. The patient may feel that he or she is unable to convince the doctor that the pain is authentic and real. In fact, sources of pain cannot be easily measured with current medical technology. Thus, patients may feel that they are not being heard and that the doctor does not believe them. Such an experience can have far-reaching negative consequences for patient coping (Metteri 1999). The patient experiencing pain may fear being labelled a hypochondriac or that the ailment will be seen as a psychological problem to be treated by psychotherapy. Such treatment, however, is not always appropriate nor is it sufficient as the sole treatment for pain. When a doctor examines a patient without finding a physical explanation for his or her pain, the doctor may conclude that the pain is caused by psychological factors and recommend psychiatric care.

Traditionally, hospital staff adopts the orientation of the organization. Patients, however, evaluate what they receive from hospital staff according to the quality of the interpersonal encounters experienced rather than their relationship with the hospital facility (Metteri 2003, 2003a; Pohjola, 1997). Health care legislation, hospital administrative practices, and monitoring systems, including staff time use and economic and performance-based measurements, often guide the staff toward system-centred behaviour (Javetz and Stern 1996). Thus, the staff tends to adopt, maintain, and produce a system-centred orientation in their day-to-day work with patients, contributing to inflexibility and rigidity in practice. For example, schedules filled to capacity can result in favourable productivity statistics, but may not allow for needed discussion with patients, thus adversely affecting the quality of care from the patient's perspective. The same structural inflexibility can also impede the staff's work. The health organization must continually deal with tensions between its subsystems and between its patients and staff. The patients' viewpoint, the care staff's viewpoint, and the viewpoint of the hospital administration (with regard to bureaucratic regulation and practices) create tensions in the environment in which the patient ombudsperson works.

A patient ombudsperson helps patients who have a complaint and want legal recourse. This generally occurs in cases where patients are dissatisfied with the care received in hospital. Ombudspersons advise and inform patients, families, and the staff about patients' rights. To do this, they need to be familiar with hospital complaint and appeal procedures. However, patient ombudspersons do not work as lawyers to assist patients in court, nor do they have an independent right to make a decision. According to Finnish patient law, they must give advice, guide the handling of the situation, and help the patient to file for indemnity in cases of unforeseen bodily injury in connection with treatment or care. The place of patient ombudspersons is at the interface between the patient and the staff, acting as coordinators, mediators, interpreters, negotiators, and conciliators. In helping to resolve conflicts, they require sensitivity toward both patients and staff so they can win the trust needed to be effective.

In their role as conciliators, patient ombudspersons prevent problems from getting worse at the individual level. In conflicts, patient ombudspersons can arrange joint meetings between the parties involved and attend these meetings, supporting the patient. At the organizational level, patient ombudspersons perform preventive work in arranging person-to-person or group information and education sessions for the staff about patients' rights. When conducting staff education sessions, patient ombudspersons utilize data and past experience drawn from their work in conflict situations. In this way, they can contribute to the development of quality in health care, disseminate consumer information to administrators, and initiate change in the structure of the hospital. Finnish social workers who serve as patient ombudspersons hold that social work's professional principles and skills are directly applicable to their work (Nieminen 2001). In the U.S., Arcus (1999) has found similar results.

Social Work and Conflict Resolution

In conflict resolution, it is essential that the professional is able to examine the situation at hand from the viewpoints of different parties in the conflict. A mediator does not take a direct stand in the conflict situation, but may give his or her support to the weaker party, so that any existing imbalance of power does not add unfair advantage in conflict resolution (Maida 2000). As a mediator, a social worker does not determine the solution to the conflict (Kruk 2000; Heinonen and Spearman 2001), but instead helps the parties in conflict find their own solution. The mediator assists as a negotiator and catalyst in the process of problem resolution. In a patient ombudsperson's work, particular conflicts that have arisen between a client and the service system are resolved. A conflict often involves negative aspects that have to be addressed. However, like a crisis, if the conflict is handled well, it can lead to some positive outcomes, such as enhanced learning and growth (Bush and Folger 1994). Whether positive or negative, how conflict resolution is handled tends to affect the outcome (Clement and Schwebel 2000; McFarland 1992).

The diverse needs of patients and rapid, continuing change within health care organizations create new challenges for social work. According to Woodrow and Ginsberg (1997), an emerging role for social work is education of staff in conflict resolution and conflict management to improve both client services and the organization's work environment.

According to Rothman, Rothman, and Schwoebel (2001), the mediator helps to identify the interests of all parties in a mediation process. He or she then attempts to find common interests and uses them to facilitate conflict resolution. Finding a common interest is key in the conflict-resolution process. In the case of the health care setting, it is the patient's well-being.

An established conflict-resolution model in social work and human services is the settlement-oriented model of mediation, a short-term, task-oriented, sequentially structured and future-focused negotiation model (Kruk 2000, pp. 7–8). In recent years, this model has been challenged and conflict-resolution work has developed in several different directions. The most important among the alternative and complementary approaches are: "the therapeutic model, emphasizing the emotional and relational elements of disputes; a feminist-informed approach, focusing on the reality of gender-based power inequities in dispute resolution; and culturally specific models, which build on the traditional dispute resolution processes of diverse cultures" (Kruk 2000, pp. 10–11). Besides facilitating negotiation, the conflict mediator, using a therapeutic approach, also acts as a therapist and an educator at the same time (Kruk 2000, p. 11). The hospital social worker who works as a patient ombudsperson also functions in these roles. According to Kruk, several therapeutic approaches to mediation share following common elements: "The primary focus of mediation is to address underlying emotional issues and relational processes blocking agreement, and the goal of mediation is not only settlement of dispute, but restructured relationships, enhanced communication and problem-solving skills, and increased cooperation and at least reduction of conflict between and among the parties" (Kruk 2000, p. 11).

Mediation as a social work method helps to increase client involvement, thus enabling clients' ownership of their conflict and its resolution. Compared with other methods, it demonstrates respect toward clients and promotes client self-determination, thus remaining connected with the ethical base of social work practice (James 1987).

The three key concepts that are debated in the fields of social work and conflict resolution are self-determination, empowerment, and professional ethics. Emerging approaches in both these fields use elicited rather than prescriptive approaches and increased client or party self-determination. They focus on transformation and empowerment rather than on problem solving alone and take a stance of engagement and advocacy rather than neutrality and impartiality in intervention (Rothman, Rothman, and Schwoebel 2001). Rothman et al. (2001) argue that increased collaboration between those in the field of conflict resolution and those in social work can contribute to innovative approaches that could transform conflicts and promote positive social change. Clement and Schwebel (2000) draw our attention to the fact that people with mental health problems, who sometimes find themselves in conflicts, have benefited from conflict-resolution processes.

In social work, we learn that to appreciate another person's experiences and feelings, we need to put ourselves in his or her position. It is also helpful to use critical reflection about one's practice (Fook 1999; Napier and Fook 2000). This means analyzing one's thoughts, observations, communication, and actions related to the way we practise and apply what we learn. Beginning with Argyris and Schön's work (1974), a great deal has been written on reflection in the development of professional practice and research. When we reflect as a group on our professional actions, we bring out our own thoughts and practice experiences, so that others can collectively consider and respond to them. Usually, dialogue about assumed or invisible practice norms is achieved through group examination of values, dilemmas, beliefs, and assumptions. This makes us question the things about our work that we may have taken for granted. Critical reflection also facilitates the development of inquiry in relation to one's work and fosters collaborative and continuous learning (Metteri 2003). These activities are useful not only to improve the quality of social work, but also for patient ombudspersons who wish to enhance their work with health care staff and patients.

Reflective dialogue (Freire 1972) makes interaction equal between two parties engaged in working together, whether those involved are professionals, clients, or families of clients. Reflection develops one's emotional skills while increasing confidence and courage to reflect on how one's actions affect or are affected by other people. The ability to see how one contributes or is a part of the problem or conflict situation is an indication of emotional skill and maturity.

The following case situation shows how a patient ombudsperson[3] worked to promote conflict resolution, mediation, and critical reflection about actions in a hospital. We analyze the course of events and describe how the ombudsperson helps the staff reflect and talk about the situation that led to a patient's complaint. We describe how the conflict started and how the ombudsperson's work proceeded (see Figure 13.1) in a situation in which the patient, Lea, made a formal complaint about the way the staff had treated her. Figure 13.2 shows the meaning that these actions had for Lea herself.

The Case of Lea: Validation of Client Experience and Promotion of Practice Reflection among Staff

Lea is a 67-year-old, married woman, who came to the hospital for a colonoscopy. The examination was done on an out-patient basis, so Lea required no hospitalization. Lea has had a great deal of prior experience with different medical appointments and hospitalizations because, among other things, she suffers from bronchial asthma.

The colonoscopy did not proceed as expected. During the procedure a diverticulum (section of her colon) ruptured. This kind of complication is rare, but it can sometimes occur during colonoscopy. It is also very serious and may even threaten the patient's life. Immediate surgery is therefore necessary. Luckily, the doctor performing the colonoscopy noticed the rupture straight away and called a surgeon, who immediately repaired her colon. The operation was successful, but Lea had to stay in hospital for a full week and was quite ill for several days after the operation. Because she experienced a lot of discomfort, she was given powerful pain medication.

Lea contacted the patient ombudsperson for the first time when she was recovering from colon surgery. She told the ombudsperson that she had been in and out of consciousness for several days because of the strong pain medication. Lea complained about the conduct of two nurses. One of them had reproached her for not having taken her asthma medication with her to the hospital. Lea had not brought her asthma drugs with her because she had not expected to be in hospital for a week. When she had spoken about the rupture in her colon with another nurse, she was told that because Lea was so old, her intestines could easily rupture during a procedure. Lea felt offended. When she met with the ombudsperson to discuss the nurses' treatment of her, Lea was very angry. She told the ombudsperson about her earlier experiences as a patient, asserting that no one had ever before treated her as badly as these two nurses. The ombudsperson suggested that Lea should talk to the head nurse, so that the distress caused by the nurses could be dealt with right away. The patient ombudsperson told Lea that she could also file a written complaint. First, Lea wanted to talk to the head nurse about the matter. She also gave the patient ombudsperson permission to explain the matter in advance to the head nurse, but she did not want the patient ombudsperson to take part in her discussion with the head nurse.

In this situation, the patient ombudsperson is attempting to prevent the situation from worsening by listening to the patient, helping her to voice her concerns to the head nurse, and providing information about the complaint option. The account also shows how the patient defines the limits of the ombudsperson's work.

Six months after this encounter, the patient ombudsperson heard from Lea again by telephone (see Figure 13.1). This time Lea was even angrier than she had been the first time she met with the ombudsperson. Following the advice given to her, she had filed a written complaint to the head of surgery about the poor treatment she had experienced. The head of surgery responded to her complaint in writing three weeks after it had been received. Lea was upset about this response. The patient ombudsperson agreed to another meeting with her to talk further with Lea about her hospitalization experience six months earlier. The ombudsperson promised that before the meeting, she would review Lea's complaint and the reply received.

Lea's written complaint stated that, besides the conduct of the two nurses, there were also other events that had distressed her. Lea wrote that she shared a room with two other female patients. Suddenly a well-groomed man, clad in a white coat and black trousers, had appeared in the room. The women thought later on that he might have been a doctor, but had not introduced himself. Lea recalled that he was rude to her. He had stopped in the middle of the room, looked at each patient in silence and, upon seeing Lea, pointed his finger at her, saying nothing. After this, the man left the room. Lea felt threatened and very disturbed by what had happened (see Figure 13.2).

When a patient's care in hospital ends, a summary is written about the care and sent to the patient. After receiving the response to her complaint, Lea called the doctor who had treated her in the hospital. When she questioned him about some vague statements in the document, the doctor referred to her as hysterical and hung up the phone. Lea felt that such name-calling was inexcusable from a health

Figure 13.1: Description of Lea's Complaint Process

Lea in hospital, summer 2001

Lea and patient ombudsperson:
- Lea requests meeting with ombudsperson
- Lea complains about the conduct of two nurses
- The ombudsperson informs Lea about the option of complaint
- The ombudsperson suggests a discussion with the head nurse

Patient ombudsperson:
- Explains Lea's complaint to the head nurse in advance

Head nurse:
- The head nurse discusses the matter with Lea
- Lea does not want to give the nurses' names
- Lea asks for a collective reprimand instead

Lea is released from hospital. Six months after Lea's discharge from hospital, Lea:
- Calls the patient ombudsperson
- Has filed a written complaint to the head of department
- Is dissatisfied with the reply
- Agrees on a meeting with the patient ombudsperson

Patient ombudsperson:
- Familiarizes herself with Lea's complaint

Lea:
- Finds fault in doctors' conduct as well
- Wants to meet the doctor who has remained unknown, with no luck

Lea and patient ombudsperson:
- Meet at the hospital
- Lea wants to meet the head of department

Patient ombudsperson:
- Arranges a meeting for Lea and the head of department
- Does not hear from Lea after this

Head of department:
- Meets Lea

Ten months after Lea's hospitalization, the patient ombudsperson and department staff:
- Have a reflective discussion about Lea's complaint and its process

Patient ombudsperson and head nurse:
- Discuss Lea's complaint in retrospect
- No further actions taken

care professional. In her written complaint, Lea had ended her long explanation in the following way: "I am just an ordinary person and I was very ill and heavily sedated while in hospital, but I expected to be treated like a human being."

The quotation above contains the essence of Lea's dissatisfaction. During a week's stay in hospital, she experienced disrespect and vulnerability in encounters with different hospital staff. Lea experienced a feeling of insecurity because while she was seriously ill and sedated

Figure 13.2 Lea's Interpretation of the Complaint Process

Lea is offended by the way the nurses treated her:
- She does not receive feedback about her complaint about the nurses
- She remains offended

Lea experienced distress due to the conduct of an unknown doctor:
- Information in her medical chart shakes Lea's trust in the care she was given
- Lea is offended by the attending doctor's name-calling
- Lea's feelings and experiences are not validated
- Lea feels insecure
- Lea feels her human dignity is denied

Lea wants amends for her experience:
- She gets it by having a talk with the chief physician
- Lea gets an apology and her experience is validated
- Lea forgives and calms down
- Lea ends the complaint process

after an unexpected complication, she was frightened by a strange doctor who singled her out. Subsequent interactions with the staff had only increased her feelings of insecurity. What she remembered of her stay in hospital were the distressing encounters with nurses and doctors. The most disturbing part was that the staff did not seem to care about or regard her feelings and experiences as valid.

In her complaint, Lea said that she wanted to meet the strange doctor who had entered her room. As for the nurses, she felt that a collective reminder to nursing staff about how patients want to be treated would be sufficient. In his reply to Lea's comments, the head of the unit said he was sorry for the patient's negative experiences. He then explained the medical progress of her illness and the procedures that were performed, stressing that the doctor performing the colonoscopy had noticed the rupture in the colon, and it had been repaired immediately. He also wrote that he saw no cause for complaint in how the doctors had done their work. The head of the department also apologized for the doctors' conduct, but at the same time, emphasized the role of professional expertise in her treatment. He said that he had discussed the complaint with the doctors in question and reminded them of the importance of good conduct in patient care. Nothing was said about the identity of the unknown doctor.

Finally the head of the department thanked the patient for the information about her hospital experience, which he said would be used to improve the quality of care in the organization. The reply did not dispute the staff's conduct, but remind Lea about the significance of professional intervention in her care. The patient, however, had not found fault nor complained about this aspect of her care.

According to our experience, it is common for the staff to perceive that a reproach concerning their interpersonal communication also applied to their professional expertise. The head of the department, in his letter to Lea, also referred to this. Patients, however, generally view professional practice, expertise, and respectful treatment (i.e., in interpersonal communications with staff) as separate issues. In one Finnish municipality, Passoja (2001) found that health care clients who had filed a complaint often reported that doctors who responded to their complaints did not sufficiently focus on the cause of the complaints, which were usually related to interaction with hospital staff. Instead, doctors explained the medical treatment given and defended their expert practice.

Lea thought that the chief physician's reply invalidated her experiences because he told her that the unknown doctor Lea had seen was likely one of the two who had treated her. Lea remembered well both of these doctors. The patient ombudsperson asked Lea what she intended to do next. Lea replied that she wanted to talk in person with the chief physician. The patient ombudsperson immediately contacted the chief physician and arranged a meeting for Lea for the following week.

We do not know for sure why Lea did not want the matter to be discussed openly with the nurses, but she did want her concern about the doctors to be addressed. The doctors' comments had been more distressing to Lea than what the nurses had said.

How can we make amends for maltreatment of a patient? It may be difficult for doctors and nurses to understand that successful performance of difficult emergency surgery on a patient does not automatically dispel a patient's negative feelings about treatment during hospitalization. In this case the operation was successful, but the interaction was not. The way in which this patient's dissatisfaction was addressed did not satisfy her. The written reply from the chief physician only angered her because it did not adequately consider her experiences nor respond to her concerns.

The role of the patient ombudsperson in a patient complaint process is primarily advisory. He or she takes part in the face-to-face handling of disagreements between the patient and the health care staff only with the patient's permission. The ombudsperson does not make decisions for the patient, but helps the patient when necessary and provides information about patients' rights and the process of complaint. It would be more accurate to say that conciliatory action rather than conflict resolution is often involved. In Lea's situation, the patient ombudsperson did not talk with any staff members about the issues Lea presented in her complaint, except collectively in an informational meeting arranged for the Department of Surgery staff. This is described in the next part of Lea's story below. In order to carry on person-to-person discussions with the individuals that the complaint implicated, the ombudsperson would have needed Lea's permission, which she did not give. That is why we do not know exactly what kind of conversation Lea had with the chief physician. The ombudsperson simply arranged a meeting for them both at Lea's request.

When patients file written complaints to the hospital administration about the way they have been treated as individuals, they want explanations and a response from the people whose conduct or actions offended them. Often patients are not able to take up these issues while hospitalized. Through filing a complaint, some patients hope that they help other patients, so that they do not have to experience the same distress. In other words, they expect the staff to improve their conduct. Lea seemed to have lost confidence in the staff who took care of her, even though the operation was successful and she recovered.

Nearly a year after these incidents occurred, the patient ombudsperson took up Lea's complaint in a reflective discussion session in the department where Lea had been hospitalized (see Figure 13.1). The head nurse and a number of other nurses were present. Toward the end of the discussion, the doctor who had referred to Lea as hysterical joined the group. It was his conduct that had led to Lea filing the complaint. At first the doctor regarded the complaint with an air of humour and made fun of the "black trousers." The nurses asked him to refrain from joking and the doctor did not participate in the discussion after this. However, he stayed until the end of the meeting. The fact that the complaint concerned him was not disclosed to the other participants during the discussion.

The nurses took the patient's complaint seriously. They wanted to know who the culprits were. They were sorry that they had not had a chance to respond to the matter themselves. At this point the head nurse told them that she had discussed the matter with the patient during her hospitalization. She had asked Lea to give the names of the nurses she was complaining about, so that the matter could be dealt with. However, Lea was not willing to give their names, and therefore the matter had not been discussed further. Understandably, the nurses found this unfortunate. As the matter had not been taken up, the complaint was targeted at all of them. It was evident that the head nurse had not spoken with the other nurses about Lea's comments; they appeared surprised when the matter was brought up.

The discussion with the nurses then became more difficult. The young nurses stood their ground and defended their expertise. The discussion started after someone suggested that patients complain mostly about trifling matters. The nurses also wondered whether the same patients also had difficulties in interactions with staff in other departments or hospitals. The patient ombudsperson took part in the discussion by answering questions and by presenting examples of difficult encounters she had experienced with patients. To generate a fruitful dialogue, the ombudsperson gave examples of situations in which she had found it difficult to be completely professional. After this, the tense atmosphere dissipated. Finally, the nurses stated that they wanted patients to complain about issues that the staff could act upon. They said that patients' complaints currently referred to issues that the nurses also found distressing and about which they could do little.

It is interesting to consider how the health care staff felt about the public presentation of a patient complaint concerning their own department. The head nurse told the patient ombudsperson later that the nurses liked "direct talk" in the department. Reflective discussion was experienced as constructive. The head nurse said she wanted to plan an educational session and promised to invite the patient ombudsperson to participate.

The patient ombudsperson in the example above consciously sought to initiate reflection to encourage shared learning and awareness. She also expressed her need to understand hospital activities through the staff's day-to-day work. By using an actual case, she provided concrete examples that could be discussed collaboratively and, through sharing her own challenging practice experiences with the staff, the ombudsperson was able to break through the culture of expertise (needing to be correct), which tends to block reflection.

It is justified to ask whether a patient, on the basis of an individual experience, has the right to make a general accusation that hospital staff has mistreated him or her. Should the patient be required to provide specific details about the accusation so that the matter can be investigated? We believe that these kinds of questions will become much more common in the future, as staff members in Finnish hospitals have begun to inquire about their own rights. For all actors to be on an equal footing, negotiation and reciprocity in the complaint process are essential. In the case of Lea, we sought to show how collective reflection helped the health care staff to study and learn from complaint situations from the perspective of a patient's needs. Joint reflection facilitated by a patient ombudsperson can give hospital staff an opportunity to collaboratively discuss the nature of conflicts and problems in patient care. This collaborative learning experience enables sharing of ideas and building of staff co-operation, which in turn foster the development of quality in health care.

A good response to a patient complaint is one that is carefully worded so that a patient's account of negative experiences in the health care facility is not disputed, but is validated. Health professionals who respond need not fix on a defence of their own or others' professional practice knowledge when it is not appropriate or necessary. Instead they might extend their apologies for the distress the patient has experienced and convey the necessary response to each one of the patient's questions.

Even though it is not possible to undo a bad experience, it is important to deal with the consequences. When the complaint is discussed and handled respectfully and with care, most patients feel better about their health care system. The patient's account of his or her negative experience is acknowledged, validated, and valued. If the matter is left unaddressed and the patient's experience in the health care system remains unvalidated, a negative impact on the person's coping may result (Metteri 1999, 2003b). A change for the better in the handling of patient complaints is directly related to a patient ombudsman's straightforward and open approach in staff discussions related to patient complaints. Through these discussions, staff members can view their own actions through the eyes of patients and recognize aspects of their practice that can be further developed or improved.

Discussion

In the example above, it has been shown that, in encounters involving health care professionals providing care to patients, it is important that patients be treated respectfully. Patient ombudspersons, in accordance with their legislated mandate, advise and assist patients in filing complaints when problems arise in their health care. For a patient ombudsperson, there are two dimensions to conflict resolution. On one hand, ombudspersons guide the patient who wishes to initiate an official complaint, support the patient in this process, and promote conflict resolution using the authority given to them by the patient. On the other hand, ombudspersons help health care staff to examine conflicts that arise in interactions between patients and staff, making use of case examples to promote reflection. Thus, conflict promotes what Argyris and Schön (1978) have called "good dialectic." That means a kind of organizational learning in which "error is continually interpreted and corrected, incompatibility and incongruity are continually engaged, and conflict is continually confronted and resolved" (Argyris and Schön 1978, p. 146). Patient-staff relations within and across health care departments can improve as a result of reflection, inquiry, and new insights about practice, which can prevent serious conflict and benefit the whole organization.

The quality of interaction between a patient and the health care staff and the way in which an individual patient is treated increases or decreases the patient's confidence in the care provided. A key feature in health care encounters is trust. The patient needs to be able to trust the care process in all of its phases. Patients' complaints and other negative feedback are often about the faltering of trust. A collegial, reflective approach to examining patient accounts of health care experiences can create a partnership between staff members. It can also enhance collaboration between patients and staff members to improve communication and care. Such collaboration will augment the patient's participation in and responsibility for his or her own care.

Reflection is an excellent technique for social workers who often encounter and cross professional boundaries in their work. At the same time, they learn how to develop their own practice. The reflective discussion activities developed by hospital ombudspersons can be seen as a continuing action research project (Reason and Bradbury 2001), where reflection leads to change. As more patient ombudspersons understand that in their role as facilitators of conflict resolution, they work in partnership with both patients and staff, they will be able to add to collective learning and job satisfaction in their facility.

A collective, reflective discussion about patient complaints moderated by the patient ombudsperson can help to open boundaries between different professionals in a hospital setting, assisting members of different professional groups to understand better the nature of one another's work with patients. It is useful for health care staff to see themselves as patient care providers in the hospital organization in the way that their patients perceive it. To enhance their practice, the health care staff needs to be sensitized to patient accounts of care experiences and their meanings. When one loses this sensitivity, and performs care tasks without empathy, patient dissatisfaction rises. That is why the psychosocial needs of the staff have to be considered when reflective discussion and related activities are initiated or further developed. Leadership skills are particularly important when patient complaints are being handled, since heads of staff must examine and discuss these together with other staff members. Skilfully conducted, collaborative reflective discussions in the workplace about patient concerns enable the sharing of experiences and lessen an individual staff member's feelings of failure. Reflection can also help in dealing with negative feedback from clients.

The Act on the Status and Rights of Patients has created a structure in health care that attends to patients' rights and helps the patient's voice to be heard. However, legislation and its formal processes are alone not sufficient for patients in the health care system to be heard. An open reciprocal process is needed to discuss problems and ways to solve them. Lea continued to seek a satisfactory response to her complaints, but was unable to shake the feeling that she had been emotionally injured. It was not until the head of the health care unit arranged for a face-to-face discussion with her that Lea's experience of distress was validated.

Patient dissatisfaction and the lack of the staff's well-being are two sides of the same coin. Unacknowledged tension in a workplace reduces employees' individual and collective resources, and lessens capacity to communicate with empathy. The person who suffers from these problems is usually the patient. Attending to patients' rights and seeking to understand patients' experiences can help us make connections between patient satisfaction and workplace well-being in health care.

Reflection Questions

1. Why do you think it is important to develop patients' rights in health care?
2. How can a social worker promote conflict resolution in situations in which patient and staff disagree?
3. What factors are important to consider when a patient's maltreatment in hospital is being discussed with staff members who cared for the patient?
4. A patient's dissatisfaction may reflect weaknesses in a workplace, including staff functioning. How can a social worker's intervention be a catalyst in improving such a workplace?

5. The chapter describes a patient ombudsperson who engages in a dialogue with staff in a health care setting. As a social worker, in what way do you think you could contribute to better communication with other staff members in your organization?

Notes

1. The hospital is one of Finland's largest. It is located in a major city and, although linked to a wider system of hospitals, it constitutes an independent administrative unit.
2. According to law, a written complaint is always handled by the organization named in a patient's complaint. It is the responsibility of the management of that organization to respond and address the complaint.
3. The patient ombudsperson is Marja Nieminen, co-author of this chapter.

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CHAPTER 14

SOCIAL WORK SUPERVISION IN THE NEW MILLENNIUM:

Tapping the Power of the Social Work Group[1]

Joanne Sulman, Diane Savage,
Paul Vrooman, and Maureen McGillivray

Any Hospital, Anywhere …

Nurse to social worker who is new on the obstetrical service: "Sali, the doctor is discharging Mrs. Wapella tomorrow, but I am worried about her. She delivered yesterday, a healthy baby boy, but something just isn't right. I can't put my finger on it. Mom is quiet, doesn't complain, but she looked anxious when the doctor told her she could go home tomorrow … I think mom has a two-year-old being looked after by a friend. Haven't seen or heard from the husband. You know, she has some funny marks on her legs, like bruises ... I asked her about it, and she said she banged herself on the kitchen drawers, but it didn't look like it to me …"

Introduction

Social workers in health care settings deal with tough situations on a daily basis. The pace is fast, especially in acute care hospitals where we don't have any client waiting lists. Our roles include risk assessment, counselling, referral to community agencies, and discharge planning, and in addition, we advocate on behalf of patients and families. As advocates, we identify gaps in patient care and community services that we address by designing interventions and by spearheading action plans. In teaching hospitals, social workers anchor the constantly changing staff on multidisciplinary patient care teams. We are the group and community workers whose roles and responsibilities go beyond the walls of the hospital. Research and teaching are done "in our spare time." But where and how do social workers in hospitals find the support and counsel needed to perform this daunting array of tasks?

In this chapter, we will examine the process that has traditionally been known as supervision. In the health care field, social work supervision has been the route to consultation, support, and accountability. Is it necessary? Is it even possible, given the drastic changes to management structures in hospitals? To answer these questions, we will explore several key concepts:

- Why does social work place such emphasis on supervision? What purpose does it have in social work?
- Does supervision have a special role in health settings?
- How is the altered state of health care delivery transforming the position of the social worker?
- Can we adapt the helpful features of supervision for all types of settings in order to foster support, autonomy, learning, and creativity while, at the same time, fully address the needs of the profession and the hospital for accountability?

What Is the Purpose of Supervision in Social Work?

The term "supervision" has a long history in the profession of social work and even longer in the field of social welfare. It dates back to the 1700s in England and later in the United States. There are roots in the English Poor Law, the early reform of mental health laws, and the growth of public concern with the regulation and supervision of services in institutions and local communities (Jones 1972; see also Roberts, n.d. at www.mdx.ac.uk/www/study/mhhtim.htm for discussion of legislation). A more contemporary concept of supervision of social work professionals has been incorporated into the practice of social work since the early 1900s in family service agencies and in the delivery of social casework to individuals and families (Hartman and Laird 1983; O'Donoghue 2002). It has also been a part of group work (Konopka 1963; Middleman 1968) and community work (National Association of Social Workers [NASW] 1962; Ross and Lappin 1967). Tsui and Ho (1997), in their comprehensive review of supervision and the role that culture plays, state that supervision "has been identified as one of the most important factors in determining job satisfaction levels of social workers" (p. 181).

Today's social workers also place a high value on independence, autonomous practice, and a commitment to a professionally determined code of ethics and standards of practice. However, the majority of social workers still provide their skills as employees in public and private sector agencies and institutions. These organizations, as well as legislated regulatory bodies or colleges of social work, expect social workers to be accountable for the quality of their practice. Accountability is an important aspect of supervision. Education and support are the other two main functions of social work supervision (Kadushin 1992). In the rest of this section, we will explore the general function, roles, and elements of supervision in social work. This will be followed by a discussion of social work supervision in changing hospital settings, focused primarily on Canada.

In their book *The Social Work Supervisor*, Allan Brown and Iain Bourne (1996) provide a general but management-centred definition of supervision as "the primary means by which an agency-designated supervisor enables staff, individually and collectively; and ensures standards of practice" (p. 9). Brown and Bourne note that the aim of the supervisory process is to have the supervisee carry out work "as stated in their job specification, as effectively as possible" (p. 9). In this view, the method of supervision is described as interactional participation in regularly scheduled meetings. From their perspective, individual supervision is the norm. They characterize group supervision as "largely uncharted territory looking for pioneers" (p. 144).

Freda Brashears (1995) provides a rich overview of the literature on social work supervision. She views supervision as a kind of direct social work practice. Supervisors have been identified as managers, teachers, enablers, and consultants. When the supervisor is a social worker, sometimes there has been a relationship framed that perceives a need to both socialize and train the supervisee in the practice and values of the profession. This type of supervision has been referred to as "task therapy."

Anthony Forder (1974) views social work as operating within a broad definition of social services that include health, welfare or social assistance, education, and housing. He states that one of the objectives of management is to structure social and health service organizations in ways that deliver services in accordance with hierarchically defined goals and initiatives. In this context, supervision is a management strategy to ensure communication, coordination, collaboration, and co-operation among employees. Without management supervision, professional employees who value autonomy might otherwise "fail to recognize the limits of their own knowledge in meeting the needs of their clients; fail to appreciate the importance of the values held by others; and fail to respect the knowledge and skills of those with different backgrounds" (Forder 1974, p. 137). Management supervision, however, is not just a socialization tool of the organization. It also provides an opportunity for professionals to have reciprocal impact on the organization's behaviour. As noted previously, part of social work's advocacy role is to gain access to and to influence the management hierarchy to improve patient care.

Dr. Alfred Kadushin conceptualized social work supervision as a middle management function. He clearly places the role in an organizational hierarchy. In his book *Supervision in Social Work* (1992), he defines a social work supervisor as "an agency administrative staff member to whom authority is delegated to direct, coordinate, enhance, and evaluate the on-the-job performance of the supervisees" (p. 22). In this paradigm, the supervisor is accountable for the work of the supervisee.

For Kadushin there are three basic categories of social work supervision: administrative, educational, and supportive. His framework is not only relevant to the occupational life of most social workers but is also clear and elegant. For these reasons his three types are described in some detail.

Firstly, administrative supervision includes specific tasks: staff recruitment and selection; induction and placement of the worker in a job assignment; work planning, scheduling, and prioritizing the work flow; monitoring, reviewing, and evaluating the work so that it meets agency procedures and expected skill level; coordinating work by organizing co-operation and collaboration across workers and ensuring that human and technological supports are available; disseminating information up and down the agency hierarchy and into the community; providing conflict resolution and interpersonal stability within the agency, between clients and the agency, and between other community organizations and the agency; and helping staff to accept both needed change and maintenance of the status quo (pp. 46–77).

Secondly, Kadushin discusses educational supervision as being "concerned with teaching the worker" the knowledge that is needed to do the job and providing the help to learn it (p. 135). Kadushin lists a number of activities, including teaching, facilitation of learning, training, sharing of experience and knowledge, providing information, clarifying, guiding, helping social workers develop solutions, enhancing professional growth, giving advice and suggestions, and providing assistance in problem solving (p. 135).

Thirdly, for Kadushin, supportive supervision addresses motivation, job satisfaction, and staff morale, and is meant to help staff cope with the stress of performing their jobs. It has to do with contentment and keeping workers "comfortable, satisfied, happy in their work [so that they] have a sense of psychological well-being" (p. 226). These are "people-centered, expressive considerations" that, in Kadushin's metaphor, keep the mechanics of a physical system oiled and cooled "to reduce abrasion and the possibility of overheating" (p. 226). Supportive supervision can help staff feel positive and empowered, and also help them to deal with critical co-workers and aggressive clients. These measures are essential in order to prevent burnout or work conditions that can reduce performance, produce high rates of time off for illness and staff turnover (see pp. 233–274).

Until recently, the type of supervision described by Kadushin has been taken for granted as a core element of social work practice. However, a recent cross-Canada study has identified challenges to the profession that affect supervision and support in many social work settings (Stephenson, Rondeau, Michaud, and Fidler 2000). In the health sector, the impact has been profound: "This is a watershed moment for the survival of social work in hospitals" (Levin and Herbert 1999, p. 37). In the next section we will trace the path of supervision in hospitals over the past decade.

Social Work Supervision in Hospitals: Past and Present

Hospital organizations have been changing dramatically. The special role of supervision in these settings, and the impact of restructuring on the design and delivery of supervision for the future needs to be examined.

Traditionally, hospitals have been, and continue to be, hierarchical power structures that have been highly influenced by medical practice. In these organizations, services are centralized and organized by functions. Social work is one of the many professions under the same roof, brought together to work in teams (Hunter 1996). In these professional departments, decisions typically come from the top down. Social work departments have also been organized in this way, with a director, supervisors, and front-line staff (Globerman 1999). Berger and

Mizrahi (2001) refer to both clinical supervision for skill development, and administrative supervision that provides organizational accountability. These traditional structures have utilized the supervision function to ration clinical resources, to comply with standards and hospital expectations, and to support professional development needs. Until recently, social work supervision took place under the auspices of professional departments, and was most often delivered in a one-to-one model (individual supervision) incorporating many of the tasks and functions noted in the previous section. The radical shifts in health care management have had a major effect on social work supervision in hospitals, and we will look more closely at this phenomenon later in the chapter. But first, we need to understand what is at stake.

Does Supervision Have a Special Role in Health Settings?

In their first hospital field placement, students are quickly confronted with the complexity and weight of social work roles and tasks. Support in the form of a field supervisor is crucial at this stage of learning. However, the need for professional support and consultation does not end at graduation. It continues throughout our social work careers, and is needed in every type of management structure. The administrative, educational, and supportive supervision functions described by Kadushin have particular meaning in hospitals because of the complexity inherent in the work and the multidisciplinary nature of practice.

In the acute care hospital, with its high patient volume and rapid turnover, social work has focused on episodes of illness. "Social workers have assumed primary responsibility for moving patients through the system to help them attain optimum levels of functioning while using the least possible amount of system resources" (Volland 1996, p. 44). This doesn't sound so difficult, but the intricacies of hospital funding and care delivery can make it challenging. In the next section, we explore the reasons why even the most experienced worker has trouble going it alone.

Challenges and Needs

Practice in secondary or host settings has special challenges, as noted elsewhere in this textbook. Today, most hospital social workers deal with high caseloads and high social risk while, at the same time, they face shrinking resources and shorter lengths of stay for patients (Sulman, Savage, and Way 2001). New staff need orientation to the setting and to the formal and informal structures within the organization. Levin and Page (1991) describe the need for workers to have "reinforcement on the connections between various forms of practice (individual, family, group, community, and organizational), as well as the links between practice and policy" (p. 152). In order for new staff to develop strong practice skills that transcend the constant changes in health care, they also need to learn systems thinking and be able to observe it within a social work framework. The "daily importing [of] distress, disturbance and dis-ease [*sic*] through the process of empathically identifying with their clients," as noted by Hawkins and Shohet (1996, p. x), requires ongoing support at all stages of practice.

How Is the Altered State of Health Care Delivery Transforming the Position of the Social Worker?

Given the unique demands of social work practice in hospitals, how have the new management structures affected the nature of the work and the methods of supervision? Over the past 10 years, social workers have lost vital underpinnings for social work practice in hospitals as a result of the changes in health care. Around the world, health care reform is being driven by market influences on cost and quality of care. "Restructuring, resizing, and rightsizing are organizational strategies to achieve systemic change. A by-product has been the elimination of many management and supervisory positions within hospitals" (Berger and Mizrahi 2001, p. 2).

Munson (1996) describes the negative impact that "managed care" is having on social work practice in the United States, and identifies how "the role of supervision has changed as the locus of control has shifted from practitioners to managed care companies" (p. 248). He adds, "supervision is replaced by licensing exams as the primary method of establishing competency" (p. 248).

In Canada, the most significant change has been the move to program management. The intention of program management is to place the patient rather than the provider at the centre of care. The hope is that by dissolving professional departments and by moving administrative and decision-making functions to programs and teams, both efficiency and quality of care will improve (Globerman 1999;

Globerman, Davies, and Walsh 1996). However, the deconstruction of departments has left social workers and social work students with scant professional backing. Unlike nursing and medicine, which have a critical mass of colleagues to provide day-to-day contact, health care social workers find themselves in a secondary professional setting. Our numbers are small in comparison to doctors and nurses, and we simply do not have the same informal opportunities to support one another.

In two Canadian surveys of hospitals that moved to new management forms, social workers reported serious concerns about the consequences of the new structures (Globerman, Davies, and Walsh 1996; Michalski, Creighton, and Jackson 1999). Although Globerman, Davies, and Walsh urge social workers to accommodate to the changes, in both studies workers cited problems with decreased leadership roles, professional identity, and the loss of control over decision making. The studies also noted that workers felt isolated from their social work colleagues and were worried about maintaining professional practice standards.

How has the profession responded? Despite these major alterations to health care delivery, new models for social work supervision have been slow to evolve. In a survey of 750 hospitals between 1992 and 1996, Berger and Mizrahi (2001) found that in the first two years, over 80 percent of the respondents indicated the use of traditional supervision. By 1996, a significant drop was seen in this model of supervision. What has replaced it? We know that more social workers are now reporting to non-social work professionals and that management positions will likely decrease further. Writing about the U.S. hospital environment, Munson wrote, "supervision by a seasoned clinician has been replaced by telephone and written contacts with managed care case managers, many of whom have no clinical background" (1996, pp. 249–250). Levin and Herbert (1999) reflect a similar experience in Canada. They describe the disbanding of departments and the reassignment of social workers to program-based teams that are led by members of other disciplines. They also comment on the effect that this is having on social work staff:

> Hospital social workers have lost much of the mentoring, supervision, education, and support traditionally available from supervisors, managers, and peers. In settings where social work departments no longer exist, individual social workers are being challenged to justify the usefulness of their role. (Levin and Herbert 1999, p. 30)

What are we going to do about this situation? What social workers always do: facilitate change. In a report on Canadian social work (Stephenson, Rondeau, Michaud, and Fidler 2000) the authors recommend rebuilding support in the workplace by using low-cost measures like the development of supportive networks of occupational groups at work. Like Levin and Herbert (1999) and Michalski and his associates (1999), we conclude that groups of social workers need to make "opportunities to create a professional social work community within their work environment" (Michalski et al. 1999, p. 23).

A Social Group Work Model of Peer Supervision

According to Steinberg (2000), mutual aid always needs to be a part of social work practice. In this section, we will describe a model of supervision based on mutual aid and social group work theory that strengthens professional practice while transcending management forms. At its heart are the elements of professional accountability, support, autonomy, and collective decision making within democratic peer group structures.

The professional social work group has its roots in the radical democracy of settlement houses and the labour movement (Breton 1990; Coyle 1930/1979; Ephross and Vassil 1988; Konopka 1963; Lang 1979; Lee 1984; Middleman 1968). The skills developed by social group workers involved with early immigrant communities were later translated into the delivery of clinical services such as patient and family support groups. Social work groups possess a unique feature that makes them effective vehicles for management and peer supervision. Glassman (1991) describes it as the purposeful "development of a democratic mutual aid system" (p. 203). Within the context of mutual aid, social work groups are empowering (Lee 1996; Steinberg 1997). As with client groups, peer group supervision is a strengths-based model that begins with a proactive assumption that people already possess the capacity to modify their own situations (Fagan and Stevenson 1995). Parsons (1991) states that social work groups "provide the opportunity for dialogue necessary for the development of critical thinking, knowledge and skill building, validation and support" (p. 13). They do this by giving members the opportunity to create a network for support, motivation, and practical help. Moreover, membership in a social work group, whatever the purpose, carries responsibilities as well as rights (Falck 1979, 1988). Members of mutual aid groups engage in authentic discussion and collective decision making, experience their own expertise in helping each other deal with issues, and allow members to take leadership on issues of importance to them (Lang 1972, 1979).

Can Any Social Worker Form a Supervisory Group in Any Setting?

No matter whom you report to formally in your facility, any social worker in any setting can form a peer group with other social workers in order to obtain professional social work consultation and support. In some instances, until workers demonstrate the benefits of this format for learning and organization to their administrators, meetings may have to be held after work hours. What are the benefits? Two that top the list are increased practice effectiveness and arrangements for mutual coverage during absences. If there are other social workers in your setting, there are likely to be natural groupings that occur, such as medicine/surgery, out-patients, or a combination of complementary services. If you are the sole worker in your setting, you will need to establish a network with social workers in other settings who have similar roles.

What the Social Group Work Model of Supervision Looks Like

The model that we present in this chapter evolved in a traditional, hierarchical department, but now is self-sustaining. The significant feature is that the social work group is the key in a management system that runs itself and has the capacity to generate moment-to-moment solutions for all practice issues. The model addresses the need for a strong professional reference group that can foster "best practice" while transcending management forms. Features central to the model are professional accountability, support, autonomy, and collective decision making within democratic peer group structures. These features create a safety net (see Figure 14.1), woven from the interactions of social workers who are members in a web of intersecting peer management and total staff groups. (In our setting the term "total staff group" generally refers to all social workers, clerical/administrative staff, and students in the department. The total staff meets for a variety of purposes that will be described later in the chapter.) The indelible values of social work and social group work infuse group process. Together the members of these groups create an available community of expertise, accountability, support, creativity, motivation, and practical help for each other.

Image not available

Case Illustration of a Safety Net for Supervision and Consultation

Group Members

Sali, the social worker introduced in our opening vignette is employed in a 300-bed community hospital. The hospital has six social workers, including the team leader. The workers meet weekly. Sali, not sure of her next steps with a difficult case, has a peer group meeting that afternoon and decides to bring the case for consultation. The other group members work in a variety of service areas. They include:

Mary: 15 years' experience in the perinatal program; now works in ambulatory setting
Lin: Two years' experience in surgery
Jon: Seven years' experience; works in a community outreach program

Janis: Three years' experience on a medical service ward
Gita: 10 years' experience; team leader; works in perinatology

Group Discussion

Sali: I have a case I could use some help with. A nurse referred a 26-year-old woman, Mrs. Wapella, who delivered yesterday—a baby boy. He's healthy. The nurse says they're supposed to be discharged tomorrow, but she's concerned about this mom. She told me the mom has some funny marks on her legs—bruises. When asked about them, Mrs. Wapella said she had banged her legs on a drawer, but the nurse is skeptical, so I spoke with Mrs. Wapella. She seems nervous and says that everything at home is fine, except she needs a crib and a car seat, and she's not sure how she'll get home. When I commented that she seems worried, she said that she doesn't feel well, she has headaches and is tired. She's also a bit concerned about how she'll manage with her two-year-old son, Jay, at home. She says a friend is looking after him while she's in hospital.

Lin: Did you speak to the doctor?

Sali: Yes, I spoke to her obstetrician, Dr. N., who says the baby's fine and that dad is a hard-working guy who works long hours. She says that Jay is cute, a little slow talking, but fine. Mrs. Wapella comes in sometimes with headaches, but any new mother is stressed. Dr. N. needs the bed because Labour and Delivery is really backed up.

Mary: Sounds like the nurse is concerned about this mom. Did the nurse mention anything about her other son being brought in by the friend to visit? Do you know if mom had any prenatal care? Is she planning to breastfeed?

Sali: The nurse didn't really say …

Jon: Was she connected to Public Health or any community-support programs?

Sali: There is nothing in the chart about it.

Janis: Practices around childbirth are so varied. Do we know anything about her cultural background? Is English her first language? It helps to know what people's traditions are ...

Gita [team leader]: It seems like everyone is asking important questions, but what would be most helpful at this point to you, Sali?

Sali: I know I need to think about any risks to the children and mom, but I'm not sure where to go from here …

Jon: In these situations, because of the potential for domestic violence and possible child-protection concerns, I'd find a place to speak to the woman confidentially and ask about the relationship with her partner and how things are for her at home.

Sali: So let's say mom begins to talk about a lot of stress at home and admits that she is sometimes afraid her husband will hurt her. I'm guessing she doesn't have many supports either because no one has come to visit her …

Janis: In this type of situation, don't we need to do a safety assessment for mom and Jay?

Sali: You're right, I should do that—where? When do fights take place? What happens? Where is Jay when this occurs? Does anyone ever hit Jay? How is he disciplined, etc.? But I am worried that she'll be discharged tomorrow morning before we're sure that it's safe for her, before we know that she has the supports she needs. I also feel bad about having to call the child welfare agency to consult. This mom just came here to have her baby, it's not like she's asking for anything from us.

Mary: Yes, it's really tough to know how to handle this. What I try to do is get a good assessment of the whole situation from the mom, her friend, and her partner if possible. Then I discuss it with the nurse to gain her perspective. If at that point I still have safety concerns, I will see if the nurse can speak to the doctor with me about the safety issues in the family. This usually helps the doctor to focus on the concerns related to the discharge of the patient.

Sali: Sounds reasonable, but I heard that Dr. N. is very busy and sometimes doesn't listen. I also hear that she can be touchy. I'm new here and I'm trying to get along with everybody!

Jon: I remember how hard it was to be new in the hospital. And we all like to get along without tension, but I think you'll find that part of our work is to alert the team to problems. It's also part of our professional responsibility to advocate on behalf of the patient. The team may not always agree, but they realize it's one of our roles. They really rely on us to make sure that all discharges are safe for the family, and they'll be more likely to accept our advice when they realize the serious safety concerns here. Dr. N. will let the patient stay until it's safe for her and her new baby to go home.

Sali: I suppose you are right. It's not very comfortable for me, though.

Gita: No, it's not easy, but it's a very important part of our work. We need to talk about this with each other to figure out the best ways to help our patients while, at the same time, keeping alert to the needs of the team. Very often we're the interface between the patient and family on the one hand, and the health care system on the other.

Janis: Remember a couple of weeks ago I had that awful domestic violence case? And I felt so disloyal to the mom when I had to call the child-protection agency. Sali, you were the one who helped me see that I wasn't doing the family any favours by not pursuing help for them.

Sali: (Smiling) You're right, but it's a lot easier to know what to do when it's someone else's case!

Lin: Is there anything else about this case you'd like to discuss, Sali?

Sali: What if I need to contact Child Welfare? Do I talk to the team and Dr. N.?

Mary: If you need to contact Child Welfare, it's best to alert the team, including Dr. N., and you need to chart it on the patient record, as well.

Sali: What if she disagrees with me, and says it's not necessary?

Gita: She may, but if you gain support for this plan from Nursing and other team members, Dr. N. usually accepts it. Even if she doesn't agree, if we see a child at risk, we need to consult the child welfare organization.

Sali: I sure hope she agrees with me. And I guess I can start connecting Mrs. Wapella to some of the community agencies people were mentioning earlier. If she gives permission, I can call Public Health and agencies that people were mentioning earlier. If she gives permission, I can call Public Health to arrange a visit.

Janis: Maybe you could see if she is eligible for help from the Home Help support services, and see if she is interested in parent-child programs in her community.

Sali: It's hard, you know. I feel like I should know all this …

Gita: Sali, the collective experience in this room provides a safety net for all of us, no matter how long we've been in practice …

Lin: Let us know how this works out and don't hesitate to call any of us if you want to talk some more about it. I certainly don't wait for group time to consult.

Sali: Okay. Thanks. That's helpful.

Summary of Group Process

The group meeting above is a typical example of consultation in a peer supervision social work group. Members have designated a group leader role, but also rely on mutual aid and shared responsibility to accomplish the triple tasks of accountability, education, and support. When Sali is hesitant to confront the doctor because of her anxiety, the group suggests strategies to address the physician. When Sali expresses discomfort and guilt about the possible referral to Child Welfare, group members help her focus on the supportive aspects of connecting the mother with the correct community supports, one of which could be Child Welfare. When Sali talks about not wanting to cause problems with her team because she is new, the members help her learn to integrate professional practice standards with team and group skills.

An implication of mutual aid is that members will process problems constructively rather than sidestep issues with false-positive support. Social group work methodology values reciprocity, and carries an expectation that members will move toward each other in a genuine, helpful manner.

Review

In secondary settings like hospitals, professional social work supervision has played a key role in supporting authentic, value-based social work practice. Given the pervasiveness of restructuring in health care, supervision for social workers is moving toward new reporting lines that favour administrative accountability to program or unit managers, and leave responsibility for professional accountability and consultation to the individual worker. To counter this trend, we suggest that, as social workers, we need to make our own paradigm shift back to social work.

The fact that social group work skills are uniquely the province of social work gives us good reason to use them in our social work collectives and in our organizations. In order to position the profession in any organizational form—whether it be traditional hospitals and clinics, health maintenance organizations, or reformed primary health care centres—we need to capitalize on our professional strengths while retaining social work's patient-focused roles and values. How we can do this is through the use of regularly scheduled meetings of social work peer-consultation groups that process the broadest range of issues. The integrity of the model rests on social work's mandate to deal with conflict and to assume shared responsibility for problem resolution. There is a collective accountability, delivering continuous quality improvement that each member owns and accepts. This combination of high accountability, autonomy, and collegial support provides staff with power that can be harnessed on behalf of patients, families, communities, and the profession.

The social group work model of supervision discussed in this paper keeps the critical functions of support, consultation, learning, and accountability centralized within groups. It provides a home base whether this is in a professional department or a unit-based program. It is difficult to adhere to social work values in market-driven, bottom-line climates, but when we nourish a social work community in our health care settings, it can be done.

Reflection Questions

1. What are the main features of a social group work model of peer consultation and supervision?
2. How would you organize the composition of groups in your setting?
3. What criteria would you use to select a group facilitator?
4. How would you use your group to deal constructively with conflict between members?
5. What are the elements of supervision that promote lifelong learning?

Exercise

Invite a group of your fellow students to a “potluck group consultation” meeting. Everyone brings a snack and a real-life social work problem to share with the group. The problem can be a micro-, mezzo-, or macro-level practice issue. Make sure everyone gets 10 minutes to talk. During the last 10 minutes, evaluate the process.

Note

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CHAPTER 15

MANAGING SCARCITY:
Joint Decision Making in Interprofessional Meetings

Pirjo Nikander

Introduction

Making concrete decisions about clients' well-being and care lies at the core of social work. The day-to-day practice of social work—the efforts made toward ensuring and supporting the health and well-being of individuals, families, and whole communities—requires professional education and skill. Increasingly, decision making occurs in co-operation between people from different professions. For individual professionals to work as a team, qualifications and proficiency related to one's profession are not sufficient. In addition to the individual professional expertise of each person, skills in interprofessional negotiation, co-operation, and communication are also crucial. The ever-growing centrality of participation and decision making in interprofessional teams thus brings with it the requirement of flexibility and negotiability of professional roles and boundaries (e.g., Biggs 1999).

In this chapter, the actual day-to-day practices of professionals meeting in groups as part of routine activity in the health and social service sectors are discussed. This "interprofessional practice" is both a central element of skilled social work practice and central to the function of current and future social work. The chapter has two other starting points. The first is the notion that the provision of care and social support is about managing scarcity. That is, doing the business of social work is often permeated with questions of scarcity either in terms of finances or availability of professional resources. Financial restrictions, eligibility criteria, and prioritization of services to clients thus form a part of the practical reality in which concrete action is carried out. Intervention is shaped by all these things.

My second starting point is that collaboration and coordination between various professional groups is increasingly seen as a means of ensuring better decision making and more economic support systems. Given that the proportion of older people (over age 60) is rising in most countries, it simply means that support needs to be organized, often with less money and other resources. Interprofessional co-operation is not a novelty in the field of social work. One can say, however, that cross-professional skills and the application and appreciation of multiple roles and identities have gained importance. Good professional practice needs to include the adoption of a strong and clear professional identity, on the one hand, while simultaneously challenging and testing rigid distinctions or boundaries between professions, on the other.

The aim in this chapter is to provide detailed insight into the everyday practices of interprofessional co-operation. The particular area of focus is the nature of interactions in professional group meetings. It is during such occasions that different values, orientations, and proposed solutions arise. What can social work contribute in this environment and what kinds of input do social workers and other professionals have in the care plans for people?

The chapter draws on videotaped material and examples from my study (Nikander 2001, 2003) of interprofessional meetings[1] to examine how "well-informed" and "rational" professional decisions about client cases are reached, and how being well-informed, rational, and looking out for clients' best interests are negotiated in institutional talk (Gunnarsson, Linell, and Nordberg 1997; Hall 1997; Jokinen, Juhila, and Pösö 1999). The chapter does not offer simple lists of do's and don'ts, but instead shows how professional groups from the health and social services sectors, by working together, manage scarcity, and move between and handle the often-conflicting demands that characterize their work. The aim is to provide readers with examples to help them to reflect on day-to-day social work practices in general and offer tools to enhance skill development for work in cross-professional groups.

The chapter begins with an introduction to the promises and problems of interprofessional collaboration in the health and social work fields. Second, after briefly reviewing some of the existing literature on interdisciplinary collaboration, a set of concrete grassroots-level examples are given. The specific site of these examples consists of meetings where professionals from both the health and social service sectors meet to make joint decisions about elderly clients' life situations. Meetings naturally represent only one social site where decision making and interprofessional co-operation take place. Such group meetings are time-limited and occur in a specific place in sites where concrete and binding decisions are made. As such, they offer a practical and effective way to view and understand everyday interprofessional interaction. Looking at specific everyday activities and the detail of professional-to-professional, face-to-face interaction provides a window to see the concrete ways in which social workers and other professionals adopt and act out their professional role(s). The examples in this chapter also show how conflicting interests and professional boundaries are set up and dissolved, and how professionals, by working together, discuss and reach decisions about their clients. The chapter concludes with a discussion and some practical reflection questions.

Interprofessional Co-operation and Social Work Practice

Health and social services increasingly face the need to justify their practice in terms of efficiency and effectiveness. At the same time, co-operation across professional boundaries has entered workplace policy documents and mission statements, and is also found in professional education and professional literature. It is depicted as a means of combining different kinds of expertise, and as quality assurance for making balanced, well-informed, and grounded decisions (Nikander 2003; c.f. White 2002). Such tight co-operation and coordination between various professional groups:

1. cuts unnecessary costs
2. guarantees less fragmentation in the service and/or treatment chain
3. promotes sensitive and appropriate institutional practices

Interprofessional collaboration is, in other words, clearly seen as a safeguard that fosters sound organizational rationality. Despite these ideas, there is a lack of detailed information on how interprofessional collaboration as a mode of decision making actually works, and on how and whether the outcomes of such collaboration are actually reflected in the form of more holistic, integrated, and rational decisions. The interprofessional collaborative mode is, in other words, widely used, but how it operates and whether it is efficient remains unclear.

Social work practice is permeated with different levels of interprofessional co-operation and decision making. Teamwork, consultation, and discussion across professional boundaries take place in various social sites, from informal chats in the corridor, in the coffee room, and over the phone, to the more formal settings in team meetings and committees. The manner of interprofessional decision making in health-related settings also varies. Client cases, questions about discharge, rehabilitation, or about the need for an intervention are sometimes discussed only between professionals, but may also occur in case conferences and meetings, where the client and some of his or her relatives are present. This variability in sites and situations of interprofessional collaboration requires a multitude of communication and social skills from the participants.

Every professional brings in his or her special point of view and knowledge base. Consequently these encounters may also include a display of professional knowledge and an outlining of professional boundaries (Beattie 1995; Griffiths 2001). We can also think of cross-professional encounters as, first, windows into the power structures, routines, and morality of health and social work practice, and, second, into the detail and everyday functioning of professional practice in organizations (c.f. Boden 1994, 1995; Drew and Heritage 1992; Pithouse and Anderson 1988; Sarangi 1998). Such professional exchanges are also sites where new members, for instance students, are socialized into the ways, routines, and practices of their profession.

Interprofessional encounters are not merely about combining the various types of expertise that different professional groups bring into them. They are also arenas where the wishes, experience, hopes, and opinions of clients need to be voiced and heard. Ideally, understanding and communicating in these situations calls for a space that includes and invites both the expertise of different professional groups, and one that supports the voice, well-being, and healing of the client (Metteri 1999; Nash and Steward 2002). In practice, however, encounters like these may be restricted by time, resources, and different levels of skill in communication. In addition, the scope of possible decisions is dictated largely by policy and economic considerations (Nikander 2001). Pressures brought in by clients and/or their families, by colleagues, by time frames and financial scarcity are all part of the decision-making equation. Conflicting medical, moral, social, psychological, and economic arguments for and against a specific decision or route of action are often used, rejected, and developed further in the course of the discussion. Interprofessional encounters represent both a practical resource used in work with clients, and a potential site for trouble, where conflicting interests and arguments, practical dilemmas, and moral issues surface (Biggs 1997; Griffiths 2001; Hall, Sarangi, and Slembrouck 1997; Housley 2000; White 2002).

The existing literature on interdisciplinary collaboration between professionals gives a good picture about the experiences professionals themselves have about interdisciplinary co-operation and the potential difficulties in embracing and implementing interdisciplinary work and decision making (Leathard 1994). The problems and the benefits of cross-professional collaboration and interdisciplinary projects that draw on the perspectives of professionals and their clients have been highlighted in research studies (Forbes and Sashidharan 1997). Such studies summarize and describe the experiences and views that either clients or professionals have on interdisciplinary collaboration.

Others have characterized interprofessional co-operation as continually developing. Some of this work, also called "managerialist" (Biggs 1999, p. 189), is quite technical in nature. That is, it seeks to identify specific features of successful versus unsuccessful interprofessional teams and to distinguish characteristics of good leadership and successful team management (Gorman 1998; cf. Dockrell and Wilson 1995; Øvretveit 1993).

In contrast to some of the literature briefly outlined above, this chapter adopts a different perspective on interdisciplinary collaboration. It examines interprofessional co-operation and decision making in action, and gives examples of the actual day-to-day practices where interprofessional collaboration is achieved in the routine practices of health and social work settings. The chapter zooms in, offering a real-life close-up of team discussions.

Red Tape, Scarcity, Conflicting Interests, and Moral Dilemmas: Some Examples

Several examples taken from a large body of videotaped interprofessional meetings show the nature of interaction between participants. During these meetings, representatives employed in social and health services in a Finnish town came together to decide about elderly clients' placements in nursing homes. The participants include staff from home care teams. In Finland such teams consist of professionals both from the social and health care services. One of the goals of these teams is to support elderly clients to continue living in their homes for as long as they wish. Other participants in the meetings include representatives of a community-run nursing home, a doctor, hospital and nursing home social workers, and a secretary. At times social work students also attend the meetings as part of their education and training.

In many ways, these meetings and the content of discussion reflect those in other social service and health care settings in other Western countries. It is interesting to note that the issues of financial constraints, limited services, and prioritization of care are common talk among health and social service professionals in many nations.

The team meetings were videotaped and tapes transcribed into text for examination.[2] The key activity during the meetings was to go through a set of client cases and decide which elderly clients could no longer cope at home and needed long-term nursing home placement. The professionals met to describe and discuss client cases, and to provide criteria and arguments either for or against a specific decision. These meetings included only professional staff. Those clients whose life situations were discussed were, in these cases, present only through their client files, and through the descriptions and narratives provided by the professionals at the meetings (Nikander 2003).

Due to the continuing scarcity of nursing home beds, local home help teams, hospital social workers, and other staff come to the meetings with prioritized lists of clients recommended for placement. Everyone in the meeting knows that not all client candidates on their lists for placement will be accepted. The talk at the meeting also includes explicit reference to scarcity and to the poor availability of nursing home beds. The excerpt below, Case Situation One, is derived from the early part of a meeting and illustrates how the discussion proceeds. In the excerpt, the meeting secretary reminds the participants about the current situation concerning acceptance rates and bed availability.

Case Situation One: Scarcity as a Fact and a Starting Point for Decision Making

Speakers		*Institutions (pseudonyms)*
S:	Secretary	Pine Woods and Greyfield nursing homes
DN:	District nurse	

S: I think we should agree upon and think about how many cases we're going to accept beforehand. I had a look at the client list in the Western District and there were **14** names accepted in previous meetings who are all waiting for a placement. So 14 names who … and I went through them all, and it looks like **two** had already been placed in a nursing home, so that leaves **12**. One of the people accepted is on a short-term place in Pine Woods and may get a long-term place from **there**, so that leaves 11. [pause]

S: And if the approximate monthly turnover in Greyfield is **20** a month and the quota for the Western District in Greyfield is scarcely half of that, then that would come up to 10 places a **month**. So, in other words, this means that we **already** have the turnover of a month here. [pause]

DN: Well in that case this is an easy meeting.

All: He he heh, Ha Ha Ha ha hah [laughter]

S: No, I didn't mean, I guess this is [laughing] a cruel reminder of the reality.

Here, the secretary has given specific facts and numbers concerning clients who, in a previous meeting, were accepted to the waiting list for Greyfield, a large regional nursing home. The secretary reminds the people at the meeting that almost all of the clients who have been accepted from the district in question are at that point still waiting for a bed or a room to become available. She presents the meeting participants with what seems like an impossible equation, that in light of the numbers, the monthly quota of nursing home placements have already been used up. Paradoxically, those attending the meeting to make decisions really have no way to make new decisions at all. Their hands are tied even before the meeting begins. The dilemma created by the scarcity and non-availability of beds is also made explicit by the district nurse's comment, "Well, in that case, this is an easy meeting," and by the group's laughter at the nurse's comment.

In Case Situation One, professionals are aware of the paradoxes in their work. Dealing with issues of scarcity does not bring the meeting to a halt, however. It is interesting to see how the professionals dealt with, managed, and solved moral dilemmas that arose due to conflicting demands between their roles as responsible professionals and the codes dictated by economic and bureaucratic rationality, on the one hand, and notions of the clients' rights and best interests, on the other.

The shared knowledge about the lack of latitude in the number of clients accepted often results in various forms of advocacy for specific client cases. An example of a different conversation in the same meeting illustrates such a situation. In it, an elderly client who is currently in hospital care is being described by a hospital social worker. The question here is whether the client should be given a nursing home placement or whether discharge from hospital and provision of home care is still an option.

Case Situation Two: Claiming Professional Knowledge

Speakers
SW: Hospital social worker
CN: Charge nurse (nursing home)
S: Secretary

SW: Yes, well, then the **next** one there is, I think [the client] who's, I think … from May 17th onwards **comes** to the hospital. Decline in general condition has been the **reason** for hospitalization and **she's** been …. This, of course, has nothing to do wi- [laughing] mitigating circumstances at all, but she has already been offered **several times** to the meeting, so I mean the situation has been completely … clear to **us**. But then … **she's demented** and … **needs some** assistance, but so anyway, a person who **tends** to **leave** the ward and therefore is now in ward 3B Dementia ward with **closed doors**. But, I mean, **the meeting** did at some point support the idea that she **might** still cope at **home** and that, from **our perspective**, is **quite** an impossible idea …. I mean, **exactly** because of this tendency **to escape**. She will **leave** then. [pause]
SW: So a calm, **demented** patient in need of **some** assistance [pause] **can't** cope at home, to **put** it briefly. Lacks initiative. Middle-stage dementia at this moment; the dementia has developed, however, I mean **now** compared to last spring. [pause]
CN: Is this perhaps then a case for the nursing home's ward for the **demented**?
S: Mmm, sounds like it.
SW: **Yes**.

What we have above is an example of a client description. The social worker, who is best acquainted with the client's present situation, delivers the description by listing specific details and characteristics regarding the client. These include the client's prior history and current health status that are routinely used as criteria for the decision-making process. If you read the excerpt carefully, you will notice, however, that the social worker also does something in addition to this. That is, while describing the client's medical history, diagnosis, level of assistance needed, and length of hospitalization, she also makes repeated reference to earlier meeting discussions about this particular client. By doing this, she simultaneously makes a distinction between "us" and "our perspective" as opposed to the ideas and opinions voiced earlier in "the meeting."

While conducting the routine business of client case description, the social worker simultaneously underlines the specific institutional perspective and interest of the hospital that she represents. Her argument underscores the first-hand information she has on the patient so as to block any alternative routes of action, such as discharge, and to secure the freeing of a hospital bed. This excerpt in Case Situation Two is thus an example of how conflicting interests surface and are aired in meeting talk. Note that this time the social worker does manage to convince meeting participants, when, after a pause, the nursing home charge nurse concludes that this client should not be sent home, but, instead, be placed in long-term care.

■ Acknowledging and Appreciating Others' Expertise

Case Situation Two showed an example of how first-hand professional knowledge and the institutional setting can be used to emphatically argue for a specific course of action. Below are two examples where the opposite occurs. In Case Situations Three and Four, client case description proceeds in a way that invites and supports the opinions of others at the meeting. In Case Situation Three, a hospital social worker starts a client description by explicitly displaying a lack of knowledge.

Case Situation Three, Part One: "A Person I Don't Know"

Speakers	*Institutions (pseudonyms)*	
HSW:	Hospital social worker	Sunnybrook Hospital
HHH:	Head of Home Help Services	Greyfield Nursing Home

HSW: Then there's **a person I don't know; this** one is on a colleague's ward [client's name] who has a long … history of hospitalization, I mean … really long periods of care. The first of March gone to **Sunnybrook** D Seven and from then on hospitalized now with us on ward 4B starting from the fourth of October. [pause]

HSW: **I mean, this one, I think, is known to the district**. [pause]
HHH: Yes
HSW: **Is this?** [pause]
HHH: There was the information that … this one no longer has a **flat** any more. Right. Here, heh [laughing]
HSW: Yes.
HHH: In the district that the flat has been given away and …
HSW: Yeah.
HHH: … then there are at least a couple of attempts at …
HSW: Yeah.
HHH: … discharge, but they have completely failed and in that way it seems that …
HSW: Yeah. Right. [pause]
HHH: The possibilities of home are quite at **zero**.

This time, after beginning the case description by a reference to her individual lack of professional knowledge about the client, the social worker proceeds to offer some basic information about the length of hospitalization. Very soon after this, however, she passes the case over to the professionals representing the district, in effect renouncing again her knowledge claims about the case. This passing over is done by asking about knowledge that representatives of the town district and the home help team may possess on the client, and via a direct but incomplete question ("I mean, this one, I think, is known to the district? and "Is this?").

Such relatively simple signposting seems to open up the discussion and to shift the task of client case description. From the first "yes" onwards, the head of home help takes over and fleshes out the client presentation with further detail. Note that the social worker keeps herself in the picture as a recipient of the description and by offering some minimal feedback. Despite her initial display of lack of knowledge, she, in other words, does not hand over the responsibility for case description entirely. In Case Situation Three, Part Two below, the discussion continues as others join in.

Case Situation Three, Part Two: "A Person I Don't Know"

Speakers
HSW: Hospital social worker
CN: Charge nurse (nursing home)

NHSW: Nursing home social worker
S: Secretary

NHSW: Is Greyfield her **own** wish? [in a challenging tone] I have **met** with her and she **under no circumstances** wanted to come to Greyfield then.
HSW: **Ahaa**
NHSW: **When she** was with us.
HSW: [reading a colleague's notes from the case file] By her request seeking a place in a nursing home, writes _________ [says colleague's name].
NHSW: Right.
HSW: Yes. [pause] This sort of a situation. [long pause]
CN: Are there any other **options**? [pause]
S: Probably not.

Here we have something of a confrontational exchange between two social workers. The nursing home social worker joins in the discussion with a challenging question that takes up the issue of the client's perspective. By this she also clearly indicates that the client description thus far is lacking in some respect: it does not include the client's own wishes and opinions. Referring to an earlier discussion she has had with the client, she points out that in the past, the client has been strictly against long-term residence in Greyfield. The confrontation is rapidly resolved, however, this time with the hospital social worker consulting her case files and the written report of a colleague. Reading directly from the case file, and quoting the name of her colleague removes any doubt that the client's opinion has not been taken into account. After a considerable pause and silence, discussion of the case ends with a suggestion for action.

Case Situation Four (below) shows another example of explicit and emphatic acknowledgment of other colleagues' expertise and knowledge in meeting talk. Here, a district head nurse, who leads the local home help team, describes the pre-meeting consultation she has had with her local team. She starts by saying that the team ended up not placing elderly clients in order of urgent need for a nursing home placement. She also explicitly downplays the centrality of her team's knowledge, deferring instead to that of the hospital social worker. Despite its brevity, the excerpt indicates that declining knowledge again results in co-operative client description and decision making.

Case Situation Four: Demarcating Areas of Expertise

Speakers	*Institutions (pseudonyms)*
DHN: District Head Nurse	Roundhill, Sunnybrook, and Central hospitals
HSW: Hospital Social Worker	Green Grass Private Nursing Home

DHN: Shall we begin then? We have in our service team, and … this went so that all the people we ended up **accepting** there are currently hospitalized and therefore we didn't make any sort of prioritizing, 'cause, I mean, **we** [the home help team] don't know. You know best. These are in Roundhill and in Sunnybrook. Only one is living at home who's going into Green Grass so …. [pause] I'm not going to give a priority list of any sort, so first there is [client's name] who's in Roundhill. And so what's the situation here, do you know? This is on D6.

HSW: This [one] is on six D, that I do not know personally, but has been however on six D from the seventeenth of April and … ah … [continues with the case description]

In Case Situation Four, explicit signposting and reference to a lack of professional knowledge is again made, this time by the district head nurse who is part of the home help team. Note how, in the beginning of the extract, she makes specific and clear reference to areas and boundaries of professional expertise. She refers to institutional collectives and parties in the care and decision-making process by using pronouns such as "we" and "you." She also demarcates the limits and areas of knowledge relevant to the case. Given that the participants at the meeting are at this point talking about clients who are currently hospitalized, the head nurse downplays the home help team's expertise ("we don't know") and subsequently hands this expertise over to the hospital social worker ("You know best"). Note also how after this direct deferring of expertise, the hospital social worker takes over and continues the case description.

In Case Situations Three and Four, we can see how explicit renouncement of professional knowledge elicits views from others, and thus also helps to loosen the restrictions that normally characterize the description of case situations in these meetings. Tentatively then, it could be said that explicit displays of a lack in personal or professional knowledge may work either as interactional signposts indicating that certain cases are open for joint description from the start, or as shorthand to show no particular investment in the client case. Referring to clients as cases that "I don't know personally," or as ones in which "you" have the first say, may enhance the development of a collective body of knowledge and views on the client and provides a basis for orderly local decision making. Acknowledging someone's special area of expertise also highlights the speaker's or his or her professional group's special area of knowledge and skill. Appreciating and acknowledging others' professional expertise is therefore a part of everyday give-and-take in interdisciplinary meetings, where one's own expertise can become further defined and acknowledged.

Multiple Voices, Client Rights, and the Timing of Outside Support

From the discussion and case situations above, it is apparent that meeting interactions involve displays of individual professional opinions and expertise, on the one hand, and clear evidence of the collective nature of the decision-making process, on the other.

It is helpful not only to focus on professionals' individual or shared expertise, but also on the analysis of client rights and obligations. In practice, the rights and obligations of clients and of professionals often become intertwined, as needed professional intervention starts where the coping of clients, their relatives, and significant others stops. The timing of specific supportive interventions and care also typically involves reflection over the moral rights and obligations of both parties.

Decision making in the health and social service sectors requires that the strengths, coping, and abilities of individual clients must be appreciated and supported fully. At the same time, professional skill in making well-informed decisions about the timing, form, and level of outside support is also important. In interprofessional encounters joint deliberation to deal with these issues is commonplace. Below in Case Situation Five, the team is discussing an elderly client's case. This time, the case description also includes detail about the rights and obligations of the client and his relatives.

Case Situation Five: Negotiating Client and Relative Rights and Obligations

Speakers
DHN1: District Head Nurse
DHN2: District Head Nurse
HHH: Head of Home Help Services
S: Secretary

DHN1: This one has help home help **nine times** a **week** and … [pause] **the daughter's quite involved in the network of care. Now feels that she cannot participate as much as earlier.** Confused day rhythm, sleeps a lot, tired. Mmm, burners left on, **food** left uneaten, leaves home, gets lost, cannot find his way **home**, age. The relative also hopes for a secure place of care and for good quality of life for his final years. We from home care recommend institutionalization … home care personnel …
HHH: Yes.
DHN1: … and home visitor so …
S: Ninety-two years.
DHN2: Yeah.
HHH: Yeah.
DHN2: Exactly. Yeah.
DHN1: So I guess that …
DHN2: Or 93.
DHN1: So the **grounds are quite** sufficient in this case.

Here, the group is discussing an elderly male client who is currently living at home. The district head nurse's brisk list of facts suggests that she is reading out descriptions presented in the written case file in front of her. She lists some details about the client, such as the number of home help visits provided per week, his existing family ties, and his medical status. Also included are details about the client's inability to take care of daily living needs such as eating, and his tendency to wander off, and the client's advanced age. A careful reading of the excerpt shows that there is more, however, than a routine listing of facts. For example, it is mentioned that the daughter's involvement in the care of her father changed over time. The district head nurse starts off by describing the daughter as "quite involved in the network of care." This reference to longer term or, perhaps, "devoted" involvement is marked by the district head nurse's self-correction when she describes a change having taken place in the caring relation between the father and the daughter ("Now feels that she cannot participate as much as earlier"). This particular wording suggests that an appropriate time for a professional intervention has been reached.

Case Situation Five illustrates how professionals' description of clients and decision making about them often evoke more general ideals and moral notions about the responsibilities of "us" as the professional caregivers *vis-à-vis* the responsibilities of the relatives or the clients themselves. In this case, the discussion seems to move from the particulars of the case to more general ideas about the right for a secure and good old age and the professionals' responsibility to help provide exactly that. Thus, in the course of client description, more generic questions concerning both the client's and his or her relative's rights and the professional care providers' obligations and responsibilities are reinforced.[3]

The final case situation is taken from a much longer discussion about the care of a male client with dementia who is currently living at home and being cared for by his wife. The discussion again raises issues about rights and obligations, and about the rational route and timing of professional action. This time, however, the rights of the client's primary caretaker, and the consistency and suitability of long-term professional support are taken up. The excerpt begins at a point where the nursing home charge nurse asks the social worker's opinion on whether shorter term periods of care can still be of assistance to the elderly couple, or whether the husband should be placed in long term institutional care.

Case Situation Six: Rights and Obligations Intertwined

Speakers
CN: Charge nurse (nursing home)
SW: Social worker (nursing home)

CN: But is it so that in this case short-term periods of care are not helpful? I mean, if the situation really is that this one is so demented that … if [pause] … So what do you think? Is this in the end, however, a case that would be wiser to … [pause]

SW: I think it is 'cause I think we went through the whole process during the time on One [ward number] with the wife and … [at] that point she didn't want to accept outside help at home 'cause, as she stated, that no help will ease the **tiredness**, what with the husband staying up all night. [pause]

SW: I mean, no one's gonna take care of the husband at night to allow the wife to get some sleep. I think those processes had in this case been dealt with. But the wife didn't at **that** point, she didn't want to submit him to long-term care. So, if she **now** has given her consent, approval then she, the wife, has travelled a long way to get to the point that she, like, gives up. [pause]

SW: And it would be like we started again to support her and to convince her otherwise.

Here the crucial question is the consistency of the client's relationship with his wife and the appreciation of the decisions that she has slowly reached about the care of her husband. The social worker points to earlier contacts that she has had with this elderly couple (on Ward One). She makes direct reference to first-hand information and to the wife's previous reluctance to give up caring for her husband at home. The responsibilities and obligations of the interprofessional group involved here expand to include the well-being and coping ability of both the elderly client and his wife.

Again a timeline or normal trajectory is inferred and the rational course and timing of professional intervention is measured against this. Referring to distinct "processes," and to the "long way" the wife has travelled to get to her decision, the social worker recommends that no advice or support is given that might contradict with the view now taken by the client's wife. The active choices and wishes of the client are thus voiced, appreciated, and taken as a guide for future action to be taken.

Discussion and Summary

It is impossible for any social worker doing his or her job in health care and social services to avoid co-operation and work with clients in interprofessional settings. The aim of this chapter was to provide concrete examples of how such co-operation functions in one particular institutional site. Looking at excerpts of talk between social workers and other professional groups in elderly care, the chapter set out to provide a glimpse of what happens behind closed doors when professionals meet, and to shed light on the dynamics of interprofessional meeting talk and joint decision making.

In discussing these excerpts from interprofessional meetings, the aim was not to give direct advice in the form of do's and don'ts, but rather, to identify some characteristics of meeting interaction as it occurs in the institutional context and everyday working environment of social workers and other professionals. A key theme in the chapter is that working interprofessionally is complex. Scarcity of time and resources, conflicting demands and professional interests, the need to secure the rights of clients and to fulfill the obligations of professional agents all contribute to the complexity of joint decision making.

Ongoing negotiation of professional boundaries and expertise, different ways of rationalizing and citing criteria for or against a decision, the practices of description and shifts in professionals' viewpoints characterize the process whereby any organization or a professional group talks itself into being. The task of any skilled professional is, therefore, to reflect on, and to continuously seek to understand his or her contribution and role in these processes. Doing this also helps ensure that the well-being of clients and their families and significant others remains central.

Reflection Questions

1. What kinds of skills in working with other professionals do you have and how can you actively develop them so you can be more effective in interdisciplinary/interprofessional teams?
2. How can you become more aware of your role and contribution in interdisciplinary group situations? How is your particular expertise respected? How do you respect the professional expertise of others?
3. What kinds of strategies can be used to make your area of professional expertise, or your specific point of view accessible and understandable to people coming from other disciplines?
4. How have you in the past dealt with conflict in groups you participated in or led? As a social worker, what skills have you acquired that could help you in dealing with conflict in interdisciplinary group meetings?
5. Drawing on the examples provided in this chapter, what would be the most effective way (in an interprofessional meeting setting you have experienced) to argue on behalf of a client for a needed service? What kind of communication style would work best?

A Practical Tip for the Development of Interprofessional and Other Communicative Skills

As a part of your studies, start collecting your ideas, thoughts, and observations about successes and failures from the various interprofessional situations in which you participate. You can also observe and note down other people's and colleagues' communication styles, instances of skilful argumentation, and problem solving. You may want to develop these notes and observations into your own personal portfolio that can function as a practical tool for analyzing the ways in which you participate in being a social worker in interprofessional team meetings and as a means of identifying strong points and weaknesses.

Notes

1. The data was collected in the course of 2001–2002, as part of the Academy of Finland funded research project (SA170002) titled: Constructing Age, Health, and Competence: Argumentation and Rhetoric in Institutional and Personal Discourse. The data consist of a 42-hour videotaped corpus of meeting interactions from two types of meetings: (1) those held to determine elderly or disabled clients' home care benefits, and (2) those used to decide on long-term nursing home placements. Only the second type is discussed here.
2. The transcript is a translation from the original Finnish (for questions of translation, see Nikander 2002). For the sake of clarity, the transcription has been kept simple. Bold indicates emphasis. All names of places are pseudonyms.
3. For a closer analysis of this same area of talk, but from a different angle, see Nikander (2003).

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PART D

RESPONSES TO SERIOUS THREATS TO HEALTH AND EXPERIENCES OF LOSS

INDIVIDUALS CAN DIFFER MARKEDLY IN THEIR UNDERSTANDING OF WHAT constitutes a health threat or problem for them, what it means in their lives, and what can be done about it. Listening to the accounts or narratives of patients who are ill or injured can tell us a great deal about human suffering and resilience. We can also learn much about how people make sense of events and trauma, how they prioritize and reprioritize what is most important to them and what changes they would like to make in their lives. The next seven chapters shed light on meaning and action in the lives of people who have experienced deep feelings of grief and loss, anticipate death, and try to reconstruct their lives anew in the face of multiple obstacles and continuing challenges. The strength and hope that endures in the human spirit and the importance of kindling and nurturing these is an important theme throughout this section.

CHAPTER 16

THE ROLE OF MEANING CONSTRUCTION IN LIVING WITH GRIEF[1]

June Allan

Introduction

Experiences of loss and grief are part of everyday life and living. As we traverse our paths through life, certain events or circumstances inevitably leave us with a sense of significant or profound loss. This sense of loss can result from a myriad of factors: the death of somebody close to us; the breaking up of a significant relationship; the loss of innocence through experiencing or witnessing violence, trauma, or assault; changes to our physical and mental health or our self-image through illness or accident; the loss of an ideal or a sense of freedom through social or political upheaval; or the physical severance of relationships with people and land through flight from a war-torn, drought-, or flood-affected region, to name a few. We respond to these significant losses with grief, the experience and expression of which is shaped and influenced by both personal and social factors, including the dominant discourses of the culture within which we live or have been raised.

The circumstances of people who come into contact with social workers in health care or other settings are frequently complicated by losses such as these, which have had a profound and enduring impact on their own lives and the lives of others. It is therefore imperative that social workers have a sound understanding of issues concerning loss and grief, and of the ways in which individuals struggle at a personal level to live with their grief. I believe it is important to consider grief within its broad structural location, acknowledging that there are many points of intervention, and I have written elsewhere on this issue (Allan 2003a). However, for the purposes of this particular chapter, the focus will be on individual experience and implications for work at the individual level.

This chapter therefore focuses on the grieving process, and the theories that have shaped Western understanding of this process and the means by which social workers assist people who are grieving. Recently emerging social work practice theories and theories about grieving have been shaped by postmodern thought, which de-emphasizes modernity's focus on reason, rationality, and universal truth in favour of a view that reality is socially constructed, with many "truths" possible, according to the different times and places in which they develop (Best and Kellner 1991; Parton and O'Byrne 2000a). These recently emerging theories suggest the value for people who have suffered major losses of having as options the possibility of engaging in meaning making, and of fostering a continuing relationship with the deceased person. In particular, the chapter focuses on the reconstruction of meaning in the event of significant or profound loss. Meaning reconstruction is one of the most significant factors that will influence the potential for growth following a major loss (Janoff-Bulman and Berg 1998; Neimeyer 2000). If social workers can assist people who are grieving in their struggle to reconnect to the world of meaning—a social world—then this is an important contribution.

Following an outline of the central issue in the chapter concerning different understandings of grief and my own growing interest in related theory and practice issues, I explore relevant theories and popular beliefs concerning the grieving process. Some ideas from recent social work theories are discussed in terms of their usefulness for helping a person live with grief. I then reflect on my recent work with Teresa—a woman whose two sons died from a progressive genetic condition—over an extended period in my role as grief counsellor, and discuss key points arising from our work together. A summary of the issues raised is followed by questions to reflect on in practice with people who have suffered a major loss.

Competing Understandings of the Grieving Process

The practice of social workers and other practitioners in the field of loss and grief has typically been dominated by psychological theories, including psychoanalytic and attachment theories (Walter 1999). The experiences of people who are grieving have also been shaped markedly—not always positively—by these theories as they have influenced dominant discourses. However, newly emerging theories for understanding grief, shaped by postmodern social constructionist perspectives (for example, Klass, Silverman, and Nickman 1996; Neimeyer 2001; Small 2001; Walter 1999), are resulting in richer understandings of loss and grief at the personal and social levels.

Drawn from a number of developments in Western intellectual thought, including sociology, anthropology, and psychology in recent years, the notion of social constructionism emphasizes human action, choice, and creativity. It gives emphasis to the construction of social realities in people's everyday lives and relationships through the creation of some language and discourses as more legitimate or credible than others. Language and discourse are seen as having the capacity to not only constitute reality but also to change it, and reality is viewed as being socially constructed. Key features of social constructionist approaches are, first, a critical stance toward our taken-for-granted ways of understanding the world. Second, the categories we use to interpret the world are historically and culturally specific, varying over time and place. Thus, we cannot assume that our ways of understanding are the same as those of others. Third, understandings between people are negotiated in different ways, with a variety of possible actions as a result (Parton and O'Byrne 2000a).These new theoretical understandings reject universal solutions to personal and social issues. They offer the potential for more flexible responses to be made by social workers and others to people who are grieving.

These shifts in thinking have led to divergent points of view in practice, to be detailed in the next section. In summary, there is a strengthening discourse that highlights the importance of assisting individuals to make meaning of their loss through the notion that they can have a continuing bond with the deceased or lost object without having to sever the attachment. This strengthening discourse contradicts and challenges earlier dominant discourses that have focused on the importance of bereaved individuals progressing through a series of stages to resolve or "complete" their grief by severing their relationship or attachment to the deceased person or object of loss. The newer discourse does not assume that grief necessarily has an end-point—that it is something to be completed or resolved (Klass, Silverman, and Nickman 1996; Neimeyer 2000; Walter 1999).

I personally became interested in these theoretical trends for two main reasons. Firstly, the concepts are consistent with critical social work theory from a postmodern perspective (see, for example, Allan, Pease, and Briskman 2003; Pease and Fook 1999), a framework for practice that I find to be particularly useful and, above all, relevant to people's lives. Postmodern critical social work affirms difference and locates people in their historical and cultural contexts, seeking to bring about change through locating possibilities for resisting and challenging dominant discourses at local sites (Allan 2003a). The second main reason for my interest in these ideas is that the notion of a continuing bond seems to fit with the personal narratives of many people who have experienced significant loss. In particular, the concepts of meaning making, meaning reconstruction, and continuing bonds were particularly useful when I was working with Teresa, whose story I will return to later in the chapter.

■ Understanding the Grieving Process

Understanding the grieving process has been dominated by several key theoretical discourses over the last 100 years, influenced by modernist approaches emphasizing reason, observation, and "a faith in continuous progress" (Stroebe, Gergen, Gergen, and Stroebe 1996, p. 32). It seems that only now, early in the twenty-first century, is there firm acknowledgment and validation of the continuing bond that bereaved people may feel with the deceased (Walter 1999). Here I briefly trace the development of these ideas. Detailed overviews and critiques of this development can be found elsewhere, for example, in Klass, Silverman, and Nickman (1996) and Small (2001).

Grief as a process

Freud (1917/1984) and later psychoanalytic theorists developed the notion that it was necessary for grieving people to work through the memories and expectations that linked them to the lost figure in order to loosen their investment in the lost figure, to become emotionally detached and disengaged from the object of loss. This generated the notion of grief as a process to be worked through and also separated grief as a process from depression (Silverman and Klass 1996). Freud's views helped establish the notion of grief as an expected event in people's lives, but it is based on a particularly Western view of the world that values autonomy and individuation, emphasizing the separateness of people from each other, and the goal of independence rather than interdependence (Silverman and Klass 1996, p. 14).

Stage Theory

Building on Freud's ideas, many theorists promoted the notion that people who are grieving progress through a common and linear series of stages or phases in order to work through their loss. Lindemann (1944) pioneered the notion of grief work facilitated by therapeutic intervention. This had the effect, however, of medicalizing and pathologizing grief. Implicit in Lindemann's work was the notion that individuals could be assisted through a series of stages to resolve or complete their grief. The work of Elizabeth Kubler-Ross (1973) was germane in popularizing the notion of grief and grieving as a series of stages to be moved through by her development of a five-stage model for processing reactions to learning that one has a terminal illness.

Attachment Theory

The attachment theory of grief developed out of John Bowlby's work (for example, 1979, 1980). Similarities were noted between separation distress in children and grief in adults, with the understanding that a person strives to regain the lost figure with whom they have a relationship of emotional attachment, and experiences a sense of vulnerability in the figure's absence. Explicit in Bowlby's theory was a notion of four phases that individuals moved through as a result of separation. The first phase incorporated a brief period of shock and denial. The second phase featured searching and protest, an acute phase of agitation, tears, and preoccupation with the image of the deceased or lost object. The third phase involved reaction, a persisting, chronic phase in which hopelessness of the loss is recognized and searching is replaced by sad withdrawal. In the final phase, the individual moved to gradual recovery, experiencing increasing well-being and acceptance of the loss.

■ The Phases and Tasks of Grieving

In the early 1970s the work of Colin Murray Parkes (1996) solidified this dominant model of the grieving process as a series of phases that people moved through to resolve their grief and break their attachment with what had been lost. Of note is the fact that in research conducted by Parkes and his colleagues, they ignored their significant observation that the widows in their study maintained a continuing bond with their husbands in their ongoing lives, and the comfort this provided to them (Silverman and Klass 1996). Parkes also introduced the notion that some losses require us to change the assumptions we hold about the world and the meaning we make of it—our "assumptive world."

William Worden (1991) developed the idea of sequential tasks of grief to be achieved during each phase of the grieving process if grief is to be resolved or completed. Interestingly, Worden shifted to seeing the final task as emotionally relocating the deceased rather than reinvesting in new relationships (Silverman and Klass 1996, p. 14).

The "old" narratives, or dominant modernist discourses, on "normal" grieving in the Western world that have been shaped by these theorists' ideas have emphasized the severing of bonds with the deceased person or lost object and letting go of the past to free the survivor to make new attachments (Silverman and Klass 1996). Even though the ideas were put forward as tentative theories that were not meant to be prescriptive, they nevertheless have become embedded in Western clinical lore and systems of intervention as fixed sequences applicable to all (Small 2001). Grief from a modernist perspective came to be seen as something that would be resolved over time, with the expectation that a person who had experienced a significant loss would progress through a series of identifiable stages and tasks in order to arrive at resolution of the grief and move on in life. These modernist views that have dominated among Western health professionals provide people with some idea of what to expect when people are grieving, but are being challenged. As Napier (2000) points out in questioning this modernist perception of grieving, the stages and tasks seem to provide a sense of certainty and order for people dealing with major loss and death, and this dominant model of the grieving process has been remarkably persistent.

These popularized discourses have resulted in the regulation of grief and a set of prescriptive ideas in relation to grief and bereavement in Western societies:

1. Grief is short term, following a linear trajectory to completion or resolution.
2. The bereaved are expected to restrain displays of grief to appropriate times and places.

3. Time is expected to heal grief.
4. The expression of grief cannot be too short, too long, delayed, too demonstrable, or not demonstrable enough.
5. Maintaining an ongoing attachment to the deceased is regarded as pathological (Silverman and Klass 1996), and strong views about people who hold onto the deceased person (e.g., see Rando 1992 in Silverman and Klass 1996, p. 14) have persisted.

Continuing Bonds

The above perspective is a 20th century model of grief, as only in the last 100 years has a continuing bond been seen as abnormal (Silverman and Klass 1996). But new ways of thinking about grief, influenced by postmodern thought and social constructionist and narrative theory, have questioned this dominant discourse. There is recognition that the notion of bereavement as something that ends does not apply for everyone. An alternative view is the idea that the meaning of a loss is negotiated and renegotiated over time. Bereavement is recognized as affecting us for the rest of our lives and as we change, we experience a changed but continuing relationship or bond with the deceased person (Silverman and Klass 1996).

We remain connected to the deceased through the use of active processes such as memorials, remembering the person who has died, and allowing the deceased to influence the present. Other active means of maintaining a connection include dreams and talking to the deceased. This perspective looks at how the bonds we have formed in the past can inform our present and our future. It gives a message that it is appropriate to stay connected with the deceased person and that the way in which this is done changes over time as individuals change and develop. It recognizes that a process of adaptation and change occurs after the death, and that new connections are constructed and reconstructed as the meaning of the loss is negotiated and renegotiated.

Meaning Making and Meaning Reconstruction

To make meaning of our losses, it is suggested that we need to listen to and understand both personal and public narratives (Weber 2001). Two powerful and competing discourses or public narratives, for example, are moulding attitudes to death in contemporary Australia. The first is shaped by a set of values that privileges youth, vigour, and flexibility, and where death has no place. However, a competing discourse is shaped by an ecological consciousness that acknowledges death as a natural part of life and advocates openness to death (Griffin 2000). These dominant narratives influence and shape the set of core assumptions that we hold about life and the world we live in.

Our personal narratives depend on our assumptive world, the world of meaning we construct based on our assumptions, our taken-for-granted beliefs, and our ways of living. By adulthood, our fundamental assumptions are entrenched in our psyches, shaped by our culture and our spiritual beliefs (Janoff-Bulman and Berg 1998). Janoff-Bulman and Berg (1998) suggest that people influenced by a Western perspective hold three assumptions at the very deepest levels of their psyche. The first is that we are worthy as individuals. The second assumption is that the world, its people, and events are basically benevolent. The third assumption is that what happens to us makes sense, as life is assumed to be rational and the world meaningful. This final belief is based on an assumption of the operation of justice, that we are rewarded for our effort. It is also underpinned by an assumption that we can behaviourally control our outcomes and that by taking proper precautions (for example, eating properly or driving carefully), we will have a good life.

An experience of profound loss or trauma shatters these assumptions and our assumptive world is challenged to the core. Neimeyer (2000) suggests that with such an occurrence, we seek to make meaning within the narrative of our lives and the core assumptions that we hold. We do this not in isolation but by negotiating with others—family and broader society—and in the process, we are influenced by norms and expectations about how to grieve. However, when an individual experiences loss or trauma, the world can again be perceived as good, but this is not absolute (Janoff-Bulman and Berg 1998). For the individual who has experienced major loss, the world can never again seem the same and it would be naïve to pretend so. Individuals now make meaning of life in a different way, not through belief in a benevolent and meaningful world, but by finding or creating value in their own lives. The realization that tragedy can strike can prompt a person to re-evaluate what is important in his or her own life, and to develop a greater appreciation or valuing of life itself (Janoff-Bulman and Berg 1998).

Ideas from recent social work theories will now be explored in terms of their relevance for assisting a person to live with grief.

Social Work Theories

Constructive Social Work

Parton and O'Byrne (2000a, 2000b) have developed a model of social work practice strongly influenced by postmodern thought and social constructionism. They have developed the concept of "constructive social work" as a way of acknowledging the importance of language and narrative, and in particular of providing concrete ways of working with people that respect difference.

Parton and O'Byrne favour a client-centred approach that acknowledges that "clients seek to control the meaning of their own experience and the meanings that others give to that experience" (Howe, cited in Parton and O'Byrne 2000a, p. 5). Concerned with aspects such as the importance of process, deconstruction, and reconstruction, Parton and O'Byrne's approach to practice prioritizes receptivity, dialogue, listening to and talking with the other. It "reveals paradox, myth and story, and persuades by questions, hints, metaphors, and invitations to the possible …" (2000a, p. 14). The social constructionist approach requires a critical stance to our taken-for-granted ways of understanding the world and ourselves, and is thus particularly useful for helping people to explore their assumptive world after experiencing major loss. The approach has opened the way for the acceptance of strengths (Saleebey 1997) and narrative interventions (White and Epston 1990) in social work practice.

Narrative and Strengths Approaches

Narrative and strengths approaches value the uniqueness of the individual experience and focus on the individual making meaning of that experience (Saleebey 1997; White 1992; White and Epston 1990). Helping individuals to identify the influence of dominant discourses on their individual perceptions and experiences achieves this. White's (1992) narrative approach externalizes difficulties experienced by individuals, and focuses on developing different stories from the ones they have constructed. The exceptions to the initial story allow for a different conceptualization of and response to the difficulties (White, in Jessup and Rogerson 1999, p. 169). A narrative approach provides a means of including people in challenging the status quo or dominant discourse through the exploration of alternative discourses. Saleebey's (1997) strengths perspective focuses on the development of potential "rather than the magnifying of limitations produced by concentrating on deficits …" (Jessup and Rogerson 1999, p. 170). It opens up ways of building on existing strengths and personal change strategies with action informed by alternative ideas.

Critical Questioning

Critical questioning, a strategy derived from the thinking of both Freire (for example, Freire and Faundez 1990) and Foucault (Jessup and Rogerson 1999, pp. 164–165), is especially relevant to the process of meaning making. Used in critical social work practices to reveal the role of external factors in determining life experience, it is needed because people continue to hold cultural meanings about the ways their lives ought to be. Critical questioning has the effect of opening up ways of perceiving a given situation other than in taken-for-granted or stereotypical terms, and is used as a way of deconstructing unhelpful ideas and beliefs. Deconstruction can be understood as the pulling apart of a phenomenon "to understand its meaning within a particular context or discourse, for a particular person or group, at a particular time" (Ife 1997, pp. 87–88).

The use of critical questioning provides the opportunity for people to explore their expectations and how they feel they have to act (Fook 1993). It allows for the exploration of alternative ways of perceiving a situation. As a form of deconstruction, critical questioning acts as an invitation to another person to engage in a dialogue about reconstruction of new ideas and beliefs. This is particularly useful for a person endeavouring to make meaning of significant or profound loss.

Teresa's story is used to illustrate how she engaged with the process of making meaning of her experiences.

The Experience of Meaning Making

I worked with Teresa in my role as a grief counsellor over a period of 14 meetings. Our first meeting occurred just over one year after the death, at the age of 18, of her second son, Nathan, from Duchenne muscular dystrophy. This is a progressive genetic condition leading to disability and death. Teresa's first son, Jeremy, had already died of the condition two years earlier when he was 19 years old. Teresa had cared for her sons for over 14 years, from the time they were diagnosed when they were preschoolers until their deaths. She has a husband and a teenage daughter and, like myself, is from an Anglo-Celtic background. The public narrative that privileges youth and where death has no place was not a "reality" for Teresa and, as we shall see, left her with a strong sense of injustice.

Through reflecting on Teresa's experience, I consider how she has endeavoured to give meaning to her life and live with her grief. The story is offered as an illustration of one person's experience. It is not a truth, yet it clearly demonstrates the changing core assumptions that Teresa holds about herself and the world she lives in.

How does Teresa view life now? What is she learning from her experiences? What is her philosophy of life now? And how does she make meaning of the isolation and desolation she has experienced? Teresa has felt isolated due to limited understanding in the community, with people lacking the ability or skills to communicate with a mother who has experienced the death of two of her children. Through the use of a narrative approach, incorporating critical questioning and deconstruction of beliefs that were unhelpful to Teresa, together we were able to work at exploring the meaning her experiences have given her in her life to date, both socially (looking outwards) and personally (looking inwards). For example, Teresa believes she is developing a more humanitarian outlook on life, is more appreciative of other people's struggles, and values qualities she sees in herself: She recognizes that she now "appreciates humankind," is "more selfless," and is more accepting of herself—"I feel pretty humble—I accept that's the way I am … I like that."

Talking with Teresa about what her experience had given her, she reflected on how her sons inspired her by how they both dealt with their shortened lives and faced death. In exploring further what she took from this inspiration, Teresa said "I'm tolerant of people who are not privileged," "I've learnt tolerance, I'm more sensitive to people. I'm a 'good person' and material comforts are not so important." Teresa spoke in rich terms of what this period—this "chapter of her life," as she calls it—means to her. Her words illustrate the continuing pain, the isolation, the uncertainty, as well as the internal contradictions: "I'm working through a lot of pain"; "I don't see it as growing or developing;

that may come"; "I still feel shut off from the world—by choice I need this, I deserve this." Yet, "It's a time to sort myself out, individually and within my family"; "It's like an awakening"; "It's a time to reflect on all those years" and "It's a time for finding my place and to give to my daughter."

In exploring the meaning of the isolation she feels, Teresa stated that her experiences have "hardened" her, making her more cynical. "I don't expect life to be perfect. I've learnt" and "I won't take any rubbish … Why should I have to put up with all the trivia?" (That is, the rudeness, whingeing, the perceived trivial concerns of people around her.) Teresa recognized that her place in the world had changed because of her experience and was grappling with how she fitted in a world she did not feel part of. "I belong to a world for the disabled, not the usual world," and "When thrust back in that other world [a world where it is "normal"], it's very hard to deal with not having all that hard work [that I used to have to do to care for my sons]. Without it, I have time on my hands. How others have been living their lives. It feels so different." Here, we explored the differences for her between the two worlds and how she connected with each.

We explored Teresa's "assumptive world" and her altered sense of justice (Janoff-Bulman and Berg 1998), experienced as feelings of anger and injustice about the unfairness of what her sons had to go through, sadness and tears over the realization that her sons will never come back, "scariness" about the future, and a feeling of being "crushed" and "cheated" (a sense of unfairness to herself and her sons).

Teresa has also become aware of feeling a greater vulnerability because she can no longer assume she is in control (Janoff-Bulman and Berg 1998). She spoke about the "good" and the "bad," the "darkness" she has felt in herself since her sons' deaths. For example, a feeling of lack of control when, for example, she is in an airplane or a passenger in a car: "death is not in your control … their deaths made me realize I'm not in control"; "when I'm not in control I feel quite insecure"; "life is fragile." Teresa now values each day because life is so short, something of which she had not previously consciously been aware.

Teresa has recognized that she now feels vulnerable and uneasy, but that she has come to value life more. Through my use of critical questioning, we were able to explore how her view of herself had developed within the narrative of her family and the broader community, and how this had changed through the experience of her sons' illness and deaths. She has also been able to identify aspects of herself that she believed she "lost" with the death of her sons, perceived by her as extensions of herself. When each died, parts of herself that she saw in them and shared with them were lost. She named these as her spirit, her passion, and her orientation to family (both sons were family-oriented). She was able to draw on this understanding to begin to reconstruct what her sons' lives and deaths might mean for her own life: "Their short experience can't be for nothing. At this point, [I] don't know. Their coming to me, me bearing them, there must have been a reason, and maybe I'm still to discover … maybe it was to shape my life. This is the next chapter in my life."

Teresa has been grappling with very difficult existential questions about what her sons' experiences have meant for her and how these experiences have shaped her. She talked about her continuing relationship with her two sons, and how they are constantly "with her." She still feels the pain, acknowledging she always will, but experiences it less intensely. She is caring for herself through music, watching comedy, and participating in an informal support group, and has acknowledged an "inner strength" and resilience she possesses. As somebody who is grieving as a result of death from a progressive genetic condition, Teresa shares the following words that illustrate the significance of an alternative discourse that "allows" people to have a continuing relationship with their loved ones: "Mothers like us, we've grieved for a long time, and when our children die, there is some sort of peace, a release. But I don't want to let my children go. I want to continue to have them in my life."

Discussion

This example concerns just one person's story, yet it illustrates the significance of making meaning of the major losses in our lives through meaning deconstruction and reconstruction. It also reveals the complexity of the issues, and the importance of practitioners not making assumptions about the meanings that people attach to the losses they have experienced. To dogmatically follow the popular beliefs derived from stage theories, where dominant discourses about how we should grieve might impact negatively, can mean that we miss helping people deal with their real issues. Focus on the meaning that Teresa was struggling to make of her experience revealed the anger, injustice, and uncertainty she was feeling. Alan Kellehear, professor of palliative care at La Trobe University in Melbourne, Australia, reminds us that "in social science, we rehabilitate uncertainty … professional literature privileges certainty" (2001). Uncertainty in the work of practitioners and in the lives of those we work with means that we have to rethink our quest for certainty and order.

Foote and Frank suggest that traditionally, the object of grief work has been to discipline grief to keep life safe from "the chaos of the uncontrollable," brought about when death threatens a rational controlled world (2000, p. 180). They propose that as practitioners we need to accept that chaos is legitimate and marks the "necessary beginning of allowing oneself to experience the full magnitude of the loss that the person has suffered" (Foote and Frank 2000, p. 180). Instead, "the 'quest' is … acceptance of lifelong processes of seeking to find the meaning of the deceased person in one's life while resisting the demand to relegate that death to the past and 'get on with' a life that excludes the presence of the deceased" (Foote and Frank 2000, p. 180). Such an approach, combined with ideas from a constructive social work approach, helps to create an atmosphere in which a diversity of beliefs and behaviours are accepted and acceptable.

I had to learn to sit with the uncertainty, the feelings of injustice and lack of control, and my own feelings at times of uselessness. What could I do to assist a woman who has cared for her children over a number of years and watched them die? My learning came in the realization that it was important to witness Teresa's pain and through dialogue, critical questioning, listening, and affirmation, to create space for her to begin to search for meanings. This involved assisting her to deconstruct the messages she was receiving from people around her that made her feel different and isolated, and to start to accept "the chaos of the uncontrollable" (Foote and Frank 2000, p. 180).

Summary

Traditional ways of understanding grief have attempted to discipline people's experiences of grief by categorizing these experiences into stages and tasks to be achieved. Such discourses have emphasized the need for people to sever the bonds with deceased people and to let go of the past in order to "move on" with life. Other possibilities for practice need to be considered that account for the chaos and lack of control that people typically feel after experiencing a major loss. While to seek certainty is one way, acceptance of the uncertainty and lack of control that people often feel creates other possibilities. Ideas from social constructionism and critical, narrative, and strengths approaches in social work provide alternative strategies.

The use of meaning making and meaning reconstruction can free up social workers and clients from focusing on what stage people are at in the grieving process, and on whether grief is complicated or pathological. Instead, it allows them to focus their energies on assisting people to make sense of their experience, accounting for the uniqueness of the experience, the diversity of possible responses, the uncertainty in the process, and the open-endedness. More important, it encourages reflexive practice on the part of the practitioner who is not locked into a quest for certainty.

Reflection Questions

1. What are some of the advantages and problems that might be associated with the traditional and popularly accepted Western theories and understandings of grieving?
2. How can postmodern constructionist ideas be useful for practitioners who are working with people who have suffered a major loss?
3. What does the term “assumptive world” mean? What are some ways you could assist people to explore their assumptive world? Why might you want to encourage them do this?
4. What do you understand by the terms “meaning making,” “meaning reconstruction,” and “continuing bond”? How might you draw on these concepts when working with someone who has suffered a major loss?

Note

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CHAPTER 17

TRANSFORMATION INTERVENTION:
Facilitating Growth After Loss and Grief Due to Cancer or Bereavement[1]

Cecilia Lai-Wan Chan, Amy Yin-Man Chow, and Rainbow Tin-Hung Ho

Introduction

Social work interventions in health care settings are geared toward adaptation and resumption of normal functioning. For families with members facing life-threatening illnesses or even death, returning to pre-illness or pre-death circumstances is not often realistic. It has been well documented that experiences of loss, grief, and bereavement may have negative impacts on one's health and mental health. Patients and their family members are often shocked and frightened by the diagnosis of cancer, frustrated by the side effects of treatment, and depressed by the possibilities of death (Holland and Rowland 1989; Leung 1997; Mak 1996). Loss of a loved one is also associated with higher physical and psychiatric morbidity and elevated mortality (Stroebe, Hansson, Stroebe, and Schut 2001).

What are the possible social work interventions for families facing loss, grief, and bereavement? As practitioners and researchers, we have observed a range of reactions in our daily encounters with cancer patients and bereaved people. At the same time, we also witness their resilience and strengths in facing great adversities in their lives. Nevertheless, the experience of cancer and death may also bring some positive growth. For example, Elizabeth Kübler-Ross (1975) took death as the final stage of growth in life. Death can be a fulfilling completion of life (Spiegel and Classen 2000; Yalom and Greaves 1977). Sometimes, death can be a great teacher. Levine (1997) found through his work with dying patients that some actually experienced "secondary spiritual growth" when they knew that they would die soon. He designed and promoted a model of practice for the dying that uses meditation. The model can be applied to all people facing death, even if it is not expected until much later. Albom (1997) developed his weekly conversations with his professor, who was facing death, into the bestseller, *Tuesdays with Morrie*. These books about death are, paradoxically, about the meaning of life. In facing the death of significant others or even one's own impending death, there is an opportunity for retrospection, reexamination of the meaning of life, and rediscovery of the laws of nature.

In helping clients cope with grief and loss, it is essential to assist them in recognizing that there can be gains realized through experiencing losses in life (Tedeschi and Calhoun 1995). Experiencing cancer or losing a loved one may open new horizons, broaden perspectives, and even transform the meaning of one's life. If people can maximize learning from living through grief, a life-threatening illness, or bereavement, they may be rewarded by increased enlightenment (Schaefer and Moos 1998, 2001).

This chapter highlights a new perspective for social work with people facing cancer and the death of someone close to them. Instead of focusing on reduction of distress, our intervention goal is meaningful growth. We first review some of the literature on the positive consequences of traumatic experiences and then build a tentative framework for intervention. A discussion about social work intervention and strategies to facilitate growth in people who experience cancer or bereavement then follows. The intervention described applies Eastern philosophies for working with Chinese cancer patients and bereaved people in Hong Kong.

Role of Social Work in Health Care Settings

The major role of a social worker in a health care setting is helping patients and their families in dealing with the social and emotional problems that arise from illness and disability (Germain 1984). In Hong Kong, the stated objectives of medical social services [social work in health care settings] are: (1) to assist patients and their families with the social and emotional problems involved in illness; (2) to enable them to make the best use of medical/rehabilitative services in the community; (3) to contribute to the total rehabilitation (physical, mental, and social) of the individuals and their reintegration into society; and (4) to strive for the promotion of health of patients, their families, and the community (Social Welfare Department, Government of Hong Kong 1987). The main focus is usually on dealing with stress, promotion of coping, rehabilitation, and crisis intervention. If patients and their families are helped to function more effectively, the intervention is considered successful.

Negative Consequences of Loss, Grief, and Bereavement

Facing cancer can be a stressful experience. The stressors encountered by cancer patients change from phase to phase, ranging from practical difficulties in the diagnostic phase, uncertainties and side effects during the treatment phase, to increased vulnerability in the post-treatment phase (Ma 1996). In facing all these stressors, cancer patients experience reactive psychological reactions such as depression and anxiety (Holland 1989). In Holland's research (1989) family dysfunction, non-participation in treatment regimens, and suicide were linked with a lack of relief from the emotional suffering associated with cancer.

Bereaved family members may face negative physical and psychosocial consequences, including higher physical or psychiatric morbidity, higher mortality, and lowered self-esteem (Chow, Koo, Koo, and Lam 2000). Being confronted with inevitable trauma in life, cancer patients and bereaved people may be fully absorbed in feelings of loss and may thus become preoccupied by their suffering. Such a focus on one's own pain can, in some cases, turn into general bitterness and the individuals concerned may live in chronic resentment and remorse. Some people may refuse help from others or even remain stuck in a state of fear and blame. This is illustrated in the following situation.

Case Situation: Mrs. A.

Mrs. A., now 64, experienced the death of her husband due to lung cancer two years ago. They have no children. She joined a bereavement group in which she often expressed herself by crying plaintively in a song-like manner: "My life is full of suffering and pain" and "My life is cursed." Singing out one's sorrow and suffering is a traditional Chinese ritual of older people. Mrs. A. continually reminisced about the past, taking up much of the group's time at sessions. Other group members found it difficult to listen to her because of her bitterness.

Some Chinese cancer patients and bereaved people connect their experience with bad luck and evil spirits (Chan and Fielding 2000). They may externalize their problems and blame them on ghosts and fate; they may become depressed and suffer low energy, sometimes leading them to lose their jobs and income even if they are physically able to work. With a self-definition of being cursed, everything seems to go wrong for such people. Their preoccupation with loss may sound to others like a broken record, repeatedly playing feelings of their sadness, despair, and bitterness. Those affected may hate themselves and engage in blaming, complaining, and expressing anger at other people around them. These negative emotions can erode hard-earned trust and love from others and adversely affect business and personal relationships, further isolating these clients from others and alienating potential sources of support.

Case Situation: Mr. B.

Mr. B. was a cook in a five-star hotel in Hong Kong. He was diagnosed with nasopharyngeal carcinoma three years ago. As Mr. B.'s cancer advanced, the side effects of radiotherapy affected his cognitive ability and he was unable to continue working. He became depressed and resentful. The loss of income and work activity affected his self-esteem enormously. He complained about discrimination by his employer and was very bitter about having to live with cancer.

A New Perspective: Growth through Trauma or Life Crises

In our experience in working with cancer patients and bereaved people, we have often been amazed at people's resilience in facing adversity. Those we worked with have reported gains in life due to their cancer experiences and some have even considered cancer as a kind of gift in their lives.

Case Situation: Ms. C.

Ms. C., 45, developed nasopharyngeal carcinoma. She was a secondary school teacher and loved singing. Unfortunately, after radiotherapy, her mouth was continually dry and her jaws became tighter and tighter. She could no longer sing the way she had in the past. Ms. C. became depressed and angry about her situation. With the help of *qi-gong* exercises (traditional Chinese breathing and physical exercises for health enhancement), the side effects of treatment were reduced. Ms. C. also joined some support groups and her attitude toward having cancer changed. She began to view the experience of living with cancer as a personal growth challenge and focused on writing instead of singing. She wrote about her experience of cancer in books and short poems and shared her experience with newly diagnosed cancer patients.

Case Situation: Mrs. D.

Mrs. D., 31, developed cancer of the colon when her son was only two years old. Her cancer was quite advanced upon diagnosis. Both Mr. and Mrs. D. were upset and afraid that their family would break up if Mrs. D. died. They discussed this a lot and reassured one another about their mutual love and appreciation. There were tears and goodbyes. Mr. D. read a lot about options in palliative care such as alternative healing, herbal medicine, acupressure, massage, and home care. They learned *qi-gong* together and also learned ways to communicate with their son about his mother's enduring love as she faced imminent death. Cancer and death were seen as inevitable losses, but they accepted these with peace of mind and love in their hearts. When Mrs. D. died, Mr. D. found that he now felt more compassionate toward people who suffered, and volunteered his time to help other cancer patients.

Through hardship and suffering, individuals learn to persevere through difficulty and may become more patient, compassionate, considerate, wise, kind, and generous as well as stronger and more resilient. Their emotional and spiritual capacities may also be enhanced.

Research findings in Western populations (Cordova, Cunningham, Carlson, and Andrykowski 2001) also reflect themes of growth through emotional pain. A study on breast cancer patients found post-traumatic growth, which included improvement in relationships with others, more appreciation of life, and positive spiritual change. Petrie, Buick, Weinman, and Booth (1999) asked breast cancer patients undergoing radiotherapy about any positive effects their illness had on them. Seven themes of improvement were identified: healthy lifestyle change; improved close relationships; greater appreciation of life and health; a change in personal priorities; greater knowledge of health; gratitude at being given a second chance; and improved empathy toward others. Similarly, Taylor (1983) found that over half of a research sample of breast cancer patients experienced some positive outcomes following development of their illness, including a reordering of life priorities, a greater appreciation of daily life, and more positive views of themselves.

Positive changes can also occur in those who have experienced bereavement (Schwartzberg and Janoff-Bulman, 1991; Thomas, Digiulio, and Sheenan 1988). Nerken (1993) found that increased empathy, self-awareness, and self-confidence after the bereavement experience, but the prerequisite condition was that the individual had to grieve actively, confront his loss, and engage in self-reflection. Similarly, research by Lund (1989) on bereavement among older widowers and widows showed that they used positive coping skills and were proud that they could draw on these as they faced the loss of their spouses.

Growth through life crises is not restricted only to cancer and bereavement experiences. Research studies have found that those who survive a wide range of traumatic experience such as divorce, loss of a job, or severe illness in oneself or one's family members, a severe accident, fire, natural disaster, childhood sexual abuse, rape, heart attack, serious chronic illness, stroke, HIV infection, and even infertility may experience growth (Cordova et al. 2001; McMillen and Fisher 1998). Of course we do not deny the presence of pain and distress in people's experiences. Rather, we believe that distress and growth are not mutually exclusive, as reflected in the phrase, "No pain, no gain." As there is very little research on this area, it is premature to reach a firm conclusion.

Concepts of Post-Traumatic Growth, Thriving, and Transformation

Conventional social work literature dealing with identifying and solving problems (Northen 1995; Perlman 1958; Siporin 1975) has tended to focus on how loss and grief in life can hamper one's health and mental health. However, a strengths-focused orientation of positive growth in situations characterized by pain or trauma has more recently become prominent (Saleebey 2002). The earlier focus on coping and post-traumatic stress disorder (PTSD) has shifted to one of transformation and post-traumatic growth (PTG). Post-traumatic growth, a term introduced by Tedeschi and Calhoun (1995), is defined as the gains that result from struggling with the losses incurred due to traumatic events or life crises (Calhoun and Tedeschi 2001; Tedeschi and Calhoun 1995, 1996, 1998). Their framework of post-traumatic growth includes three features:

1. changes in one's sense of self, involving increased self-reliance and personal strength, and a recognition and appreciation of human vulnerability
2. modified relationships with others, including greater self-disclosure and emotional expressiveness, and increased compassion and empathy, and more effort focused on improving relationships
3. a revised philosophy of life, including enhanced appreciation for one's own existence, a new awareness, and enjoyment of life and simple everyday pleasures (Calhoun and Tedeschi 2001; Tedeschi and Calhoun 1995)

In addition to model building, Tedeschi and Calhoun (1996) studied ways to measure growth after trauma. From research on perceived benefits after trauma they constructed the Post-Traumatic Growth Inventory (PTGI). This scale, made up of 21 items with five subscales, has become a useful measurement of post-traumatic growth. It represents a balanced approach to understanding people's experiences of trauma. In social work practice, we have often seen that clients tend to view problems differently when they recognize that there are some positive aspects.

"Thriving" is another term to describe positive consequences that can occur as a result of experiencing an adverse event. O'Leary and Ickovics (1995) suggested that there are at least four possible consequences of a traumatic or stressful event on an individual:

1. a downward slide in functioning and eventual succumbing
2. survival in an impaired condition
3. resilience and recovery to the prior level of functioning
4. thriving and the attainment of a level of functioning superior to one previously reached

In O'Leary and Ickovics's classification, resilience is not the same as thriving. The former refers to homeostatic recovery to a prior level and the latter refers to recovery that is at a higher level or with some gains experienced. As Carver (1998) suggested, thriving can be grouped into two categories, namely, physical and psychological. Thriving might be seen as decreased reactivity to subsequent stressors, quicker recovery from them, or a consistently higher level of functioning.

Transformation refers to the positive consequences of trauma (Tedeschi and Calhoun 1995). It literally means a change in form, appearance, structure, condition, nature, or character. It is also used in the field of science, for example, to describe a change in a form of energy (physics) or a change in a condition, such as that observed in the transformation of a caterpillar to a butterfly (biology).

These concepts can help us to understand the positive consequences of trauma or life crises. First, a person who experiences such a situation is not merely coping with the trauma, but may be doing so at a level that is superior to his or her prior level of functioning. Second, growth or gains do not appear naturally, but are products of the person's inner struggle in facing the trauma or crisis. Third, the process of struggle involves reorganization and rebuilding. The shattered beliefs or assumptions are transformed into a new structure. Fourth, the concept of positive consequence does not exclude distress or pain. These concepts are independent and occur simultaneously. Therefore, the presence of positive consequences does not mean that there is no distress or pain.

Chinese Beliefs about Post-traumatic Growth and Transformation

The concept of post-traumatic growth fits well with Chinese beliefs. The Chinese word for crisis consists of two components, threat (*wei*) and opportunity (*ji*). The coexistence of threat and opportunity implies that there is a relationship between them. It also suggests for people that a challenge can become an opportunity. We can make use of a difficult situation and experience transformation, emerging with deeper personal insights and emotional capacities. The Chinese word for trauma also consists of two different components, creation (*chuang*) and hurt (*shang*). Although traumatic experiences often involve painful and distressing emotions, they may also open up new opportunities to enhance one's life.

A classic Chinese legend reflects the meaning of gains and losses:

> One day, Mr. Choy's servants found a beautiful white horse on Mr. Choy's lawn. They were very excited and congratulated Mr. Choy for this gift from heaven. Mr. Choy, however, said "Who knows if it is a blessing or a curse?"
>
> A few months later, the horse threw Mr. Choy's son off its back and the boy broke his leg. The servants went to tell Mr. Choy the bad news, and Mr. Choy again said, "Who knows if it is a blessing or a curse?"

> Two years later, war broke out between two states in China and all the adult males were summoned to join the army. Mr. Choy's eldest son did not need to join because of his disability. The war was sure to end the lives of many young men. After some reflection, it became clear to Mr. Choy that the accident that caused the disability might have saved his son's life. The horse had, in fact, been both a curse and a gift.

This old Chinese legend encourages people to accept life and fate as they occur and not struggle against them. This let-it-be attitude is part of Taoist teaching: people cannot fight nature; we can only respect the rule of nature (Tao), and accept what comes our way. In addition to Taoism, other Eastern philosophies, such as those in Confucian and Buddhist teachings, show people how they need to remain calm and restrained, exhibiting little emotion even in a crisis or traumatic situation. Perseverance in the face of hardship and tolerance, even when a situation becomes unbearable, is a very important life virtue in Eastern philosophy.

In Chinese populations, patients with cancer can be helped to develop insight so they can begin to perceive the crisis of their illness more positively. If there is a shift in focus to positive aspects, the crisis or trauma experience can be seen very differently. The knowledge that cancer or bereavement can lead to positive gains in life can be consoling to the people affected. These ideas are integrated into an approach that has been developed for use with Chinese cancer patients and their families (Chan 2001).

Process of Transformation

As suggested by Tedeschi and Calhoun (1998), a prerequisite condition for post-traumatic growth is the presence of trauma or significant life crisis. Further, the event should be sufficiently significant so as to shake the individual's previous assumptions, those that give a sense of reality, meaning, or purpose to life, or force one's assumptive world (Kauffman 2002) into new assumptions. The transformed self can usually function more effectively and at a more superior level than the prior self.

Carver (1998) used an analogy of muscle development to illustrate human resilience and thriving. Muscle develops steadily only if it is worked beyond its ability through increased use. Similarly, thriving takes place when one's limited cognitive skills, pushed to handle the current situation, achieve success. The disequilibrium between existing skills and knowledge and what is required to successfully deal with a challenging situation forces growth to occur in the person.

Calhoun and Tedeschi (2001) warn clinicians that the early stage of trauma is not a suitable time for reinforcing post-traumatic growth. To face losses associated with trauma, people need to experience safety and security. As well, those who experience traumatic events might have occurrences of flashbacks and intrusive thoughts. Growth and transformation can occur only when a person is not overwhelmed by intrusive images or thoughts.

Growth depends on the person's perception of existing distress, but if no distress is perceived, there will be no need for reorganization. Further, those who are numbed by trauma might not be able to cognitively process the situation because they remain in a state of disorganized thinking. In such a state, it is difficult to experience transformation.

Determinants of Transformation

In order to design an appropriate intervention that encourages transformation, it is helpful to know about the factors that are related to it as these can offer significant guideposts. Research in this area is still in its infancy, although some authors have pointed to key factors that may be important in promoting transformation resulting from trauma and loss experiences (Calhoun and Tedeschi 2001; Carver 1998; Schaefer and Moos 2001). Carver (1998), drawing from social psychology, holds that there are two types of factors related to transformation: those related to the person and those related to the situation. The first type of factor, the person, includes his or her sense of mastery, hope, hardiness, self-efficacy, security of attachment, and coping ability. Coping that involves positive reframing (identifying a different, more positive perspective on the problem) can foster a better outcome. Avoidance coping, characterized by a strategy that avoids dealing with the problem, can lead to poorer outcomes. The second type of factor, the situation, includes the existence of social support resources, circumstances that promote self-determination, and positive views on the trauma as an opportunity.

Through their work with bereaved people, Schaefer and Moos (2001) suggested that growth results from the interactions of a few factors, including environmental resources (social support and positive family functioning), personal resources (maturity and religiosity), event-related factors (severity of the loss, the threat to life, proximity and amount of exposure to the event, and its scope), cognitive appraisal and coping responses (viewing of new tasks as a challenge, searching for meaning, and approaching rather than avoiding trauma effects or problems).

Similarly, Calhoun and Tedeschi's (2001) three domains of suggested factors for transformation through trauma include: the trauma itself (minimal threshold for growth, but not so large that it immobilizes the person); the person (outgoing personality open to learning from one's own experiences); and the process (need for cognitive processing of loss and trauma in order to finding meaning).

The factors that seem most important for transformation through trauma and loss to occur can be summarized as: (1) a sense of mastery; (2) a sense of self-efficacy; (3) an ability to approach rather than avoid the trauma experience; (4) social support that facilitates growth; and (5) use of a cognitive appraisal process that promotes growth.

Strategies That Facilitate Transformation

Some implications for social work practice can be inferred from these five factors.

Fostering a sense of mastery in clients: Social workers observe the principles of respect for and self-determination of their clients. At the same time, they can explore with their clients different ways to master difficult emotions and flashbacks and identify external factors that foster a client's sense of mastery.

Facilitating the development of self-efficacy: Strengths-focused intervention is preferred over methods that are primarily problem-focused. Instead of viewing solely the loss brought on by crisis and trauma, people's personal resources and strengths are explored. By offering a nurturing environment, a caring attitude, and instrumental forms of support that draw on a client's knowledge and skills, the client is helped to handle his or her situation autonomously.

Facilitating approach rather than avoidance in response to trauma: Avoidance of response to trauma is often rooted in a fear of being overwhelmed and an inability to visualize positive outcomes. Through encountering people who have successfully survived similar trauma and who might be seen as positive examples or role models, a sense of hope can be encouraged. The coping strategies used by those who have successfully dealt with trauma and loss can serve as useful resources for those facing similar issues. In addition, a supportive and nurturing environment can help develop psychological strength in clients who face trauma.

Enhancing social support of the client: Social support can be provided by close family members, friends, or others. If the social worker can extend services and care to the client's family members, and even facilitate them to help, they can be good sources of support to the person dealing with trauma. Moreover, expanding a client's social network to include those who have had similar experiences and who are willing and capable of helping can increase potential social support.

Encouraging the cognitive appraisal process of clients: Individually or in groups, clients can be helped to share their own accounts of trauma. Such narratives can take the form of verbal expression (through dialogue), written expression (through journaling, poetry, or e-mail communication), or even artistic expression (through music, dance, or visual art). New perspectives or understandings may be developed in reflective discussion and feedback from a social worker. By recalling significant life events, clients can be reminded about their previous life dreams, resilience in facing other crises, and past successes. Calhoun and Tedeschi (2001) remind clinicians to use respectful language with clients, draw from clients' world views, listen actively and fully, and be sensitive to the timing of intervention.

Teaching and using meditation with clients can be useful in fostering a greater sense of mastery. The control and cognitive discipline that meditation involves can help to bring out clients' inner wisdom. Meditation has been used in cancer and bereavement groups in Hong Kong, where participants are helped to focus on the body and mind and enter into a more peaceful and quiet world (Chan 2001).

Intervention Model: Facilitating Transformation in Cancer Patients and Bereaved People in Hong Kong

Based on the ideas discussed above, a tentative model for facilitating transformation has been formulated and summarized in Figure 17.1. This model has been applied to cancer patients and bereaved persons in Hong Kong. Figure 17.2 illustrates three phases experienced by clients who are dealing with cancer or those who are bereaved. Each phase is associated with tasks for the social worker and/or for the client.

Image not available

Supportive Phase

In facing life crises, the presence of a safe and peaceful environment is an important requirement for nurturing clients' courage. With this firm foundation, growth is possible. Psychological, instrumental, and social forms of support are needed during such crises. The worker's care, demeanour, warmth, and respect for clients are essential and can invite clients to become more open and reduce their feelings of fear and apprehension.

Bereaved people may be reluctant to go to an unfamiliar place and to meet new people. Even if they agreed to receive bereavement counselling in a community bereavement centre, they may have difficulty in following through. In our experience, about a third of first appointments in the bereavement centre are missed. Thus, we need to

Image not available

find ways to convey our concern for clients. We may initiate telephone calls and write special cards, letters, and e-mail messages to invite them to sessions in our counselling centre and remind them a day before the appointment. Sometimes, a home visit may be preferred. When they come to the centre, clients are usually met personally by the social worker and are offered a cup of hot tea as a welcome ritual. These actions will help to break the ice and relax clients. A calm and sensitive approach is important in preparation for the work with clients.

Clients might feel plagued by unwanted and intrusive flashblacks of memories and traumatic scenes. Sometimes, they are overwhelmed by the necessary tasks to be completed when they experience life crises. Provision of information and referral to a helpful resource can free their energy so they can meet their own psychological needs. A large number of cancer patients actively learn about alternative healing techniques, meditation, expressive art, songs, prayers, yoga, and dance to foster their recovery. They may regain a sense of control through learning. Some patients develop skills in *tai-chi* or *qi-gong* (Chinese marital arts and exercise). Aside from the potential benefits of using these alternative methods, the sense that they have options and are able to make their own choices is vital for clients in crisis.

Although much of the literature on intervention in trauma is aimed at individual casework, there is also much potential for group work in helping clients. The opportunity for clients to learn that they are not alone in facing serious life crises can reduce their sense of isolation and promote their well-being.

Reorganization Phase

Offering clients a chance to meet others who face or have faced similar crises not only serves the purpose of social support, but can also have other benefits. Once clients are emotionally stable and psychologically prepared to work on their shattered lives, other group members who have successfully survived similar trauma can act as role models, offering support for coping and transformation. This experience can provide for clients the hope and motivation needed to move forward.

Cancer patients and their family members can use the group experience to contemplate their pain and suffering. There can be new insight and enlightenment generated through active reflection on life and suffering. Individuals may embrace spirituality in their lives in the face of their own mortality. Most patients make important decisions about what they will do in their lives if they survive their life-threatening illness. Some may commit themselves to helping other people in need or develop new interests, new projects, and activities (Spiegel and Classen 2000). Through addressing death and dying, life may be appreciated in new ways and the love received from others may become more meaningful.

The experience of living with cancer or bereavement can create opportunities to rediscover meaning in one's life (Neimeyer 2001). Learning and growth accrue through the painful and disabling effects of treatment, experiences of social isolation and stigma, stress and worry about family members, and financial concerns related to the illness and one's own dying and death. The suffering experienced by individuals facing these issues can be turned into positive energy that enables more effective coping and pain management.

Consolidation Phase

Social workers in Hong Kong hospitals and other health care settings can organize survivors who have faced adversity successfully into a kind of crusade. These "exceptional patients," as Bernie Siegel (1986) calls them, can become volunteer crusaders who promote transformation after traumatic experiences. Crusaders can make personal visits to patients in hospitals, document patients' individual stories (with permission) and share their own personal experiences. It may be feasible to produce and loan videotapes or other resource material, as appropriate, for hospitalized patients to view.

In Hong Kong, we have produced audio and videotapes of the stories of former cancer patients and bereaved people. The information on the tapes reflects the trajectory of the illness and bereavement experience and the coping strategies used. The social worker later watches the tapes together with clients, stressing that each individual has his or her own unique experience. Those who share their stories also benefit. By declaring and describing in front of an audience the positive changes experienced and the coping strategies used, a patient's own belief in his or her resilience is reinforced.

In approaching individuals who are suffering, social workers and survivors adopt a positive, strengths-focused orientation to bring out the strengths in those they work with. Social workers can help to encourage people who can act as role models and who share a common background or experience with particular patients or clients. The role models can help those who are suffering to focus on their growth and personal learning through the cancer experience. Individuals who contribute by helping other people can themselves grow and develop through the "helper-therapy principle" (Riessman 1965). This principle refers to the fact that helping others can be therapeutic for the person who helps. The more that people reflect on and talk about their own change and growth, the closer they move toward transformation. Effective documentation of their transformation experience helps role models in consolidating and articulating their experience further. The growth of a selfless compassion toward those who suffer can be the key to free a person from continuing absorption in personal pain. Compassion and commitment to collective well-being through caring about others can be liberating.

Conclusion

With a commitment to transformation through pain, social workers can help clients grow from their experiences of loss and grief to share their knowledge with others and focus on the needs of those who are suffering. People who persevere through difficulties and trauma in life (survivors) often become stronger and more compassionate. They may want to find ways to relieve other people's suffering. They may also have greater motivation and strength for creative and innovative ways to cope and thrive, and have gained knowledge that can be used to support people in similar circumstances.

Physical, emotional, social, and spiritual transformation can be enhanced and promoted by both social workers and role models who have effectively transformed themselves through dealing with anger or bereavement. When clients adopt a new purpose and help others, they may become willing to refocus their lives, turning attention away from their own pain while helping themselves and others to move forward in life.

Meaning reconstruction of trauma and loss situations can offer a shortcut to transformation. Many people experiencing pain can find meaning and personal growth during times of difficulty. Social workers adopting this approach will need to have faith in the process, which can assist both clients and practitioners. Social workers cannot, nor do they aim to, do everything for clients, but they can facilitate the transformation process. With transformation in mind, we can take the classical principle in medicine—"To cure rarely; to relieve suffering often; to comfort always"—and adapt it for social work with clients dealing with trauma and loss: "To accept, appreciate, learn from, and transform suffering always." Suffering and pain can be seen as welcome insofar as they offer a path to personal transformation.

This chapter has discussed initial experiences in integrating a new conceptual approach into our intervention with bereaved clients and cancer patients. There is a need for systematic analysis of the outcomes of this approach in practice and for identifying and differentiating the key determinants in effective intervention with client populations. We are now working in this direction.

> A little boy found a butterfly struggling out of its cocoon; it was struggling so hard that the boy felt that he should do something to help. He found a pair of scissors and cut open the cocoon. The butterfly

> was freed, but it could not fly. The boy then realized that the butterfly needed to generate energy from its body fluid to expand the wings. Without the struggle, the wings of the butterfly could not become strong enough to perform this function.

The story of the boy's effort to free the butterfly from its cocoon offers a lesson: There is necessary pain in growth that needs to be experienced to learn needed lessons in life and to appreciate the beauty of nature.

This story illustrates how transformation is realized through struggle and pain. It is hoped that through the promotion of this approach, we can all become witnesses to our clients' transformation: from caterpillars to energetic and colourful butterflies that fly freely.

Reflection Questions

1. In this chapter, how does the concept of "letting go" of emotional distress help those with cancer?
2. How has the experience of pain or suffering marked a turning point in anyone you know? How would you, as a social worker in a health care setting, support a client's struggles to find meaning in painful experiences?
3. What is the significance of spiritual or cultural beliefs in the case situations discussed in this chapter? How have cultural or spiritual beliefs been a factor that guided those you have known in dealing with serious illness or a traumatic event?
4. The Eastern approaches described in this chapter may be different from your own way of practising social work. Name some key differences and give examples.

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CHAPTER 18

USE OF NARRATIVES IN PSYCHOSOCIAL WORK WITH CANCER PATIENTS[1]

Pirkko Ollikainen

Introduction

There is always a big change in life when a person is told that he or she has cancer. This change is not a positive one. These people become patients of the health care system. They face not only physical illness but often also challenges to their mental well-being. Their appearance changes and they may experience less connection with friends and previous interests. The disease may make them feel helpless, as if they are losing control over their lives. Besides medical help, people with cancer often turn to other health care staff to seek help for the mental, social, emotional, and economic problems brought by the disease. A social worker is often the person patients turn to for most of these concerns. A social worker has knowledge about how living in a hospital transforms one's usual everyday life and he or she can help build a link back to that everyday life with the patient.

In a narrative approach to work with patients, a patient's narrative constitutes the starting point for his or her care and rehabilitation.[2] The practitioner does not analyze the narrative or change it to make it more positive. When telling his or her story to the social worker, the patient already "hears" new coping strategies in his or her own narrative.

The use of a narrative, the patient's own story, as the starting point for care and rehabilitation is a natural approach for a social worker, one that considers each patient's unique situation. A patient often tells a social worker, rather than a doctor, much more about his or her life, for example. The story told to the doctor focuses on the disease and symptoms because patients are seeking relief for these. To the social worker, on the other hand, a patient opens up his or her world outside the hospital setting and struggles to fit the illness experience into his or her everyday life. The social worker can consciously utilize this aspect by developing his or her narrative approach to practice. In this chapter, narrative as a social work method in health care with cancer patients is discussed.

A narrative or life history is a patient's interpretation of his or her life. Different people who live with cancer can interpret the same disease very differently, and even the same person can, in varying situations, give different interpretations to his or her illness experience. The narrative changes over time, as plans for the future change and the interpretations of the past shift at different stages of the disease (Hänninen and Valkonen 1998, p. 4). Hänninen (1996) maintains that by using narratives, people create order in the chaos of their experiences. A narrative always has a beginning, middle, and end. In other words, it has a plot. The events are not unconnected, but form a chain of causes and their consequences. Once an individual event turns into a written or spoken story that can be heard, we can experience the story as we hear it. Storytelling has many levels. The teller gives to an individual incident a subjective meaning on the basis of his or her own stock of stories (what they have come to understand about such events through their own and others' experiences). The listener, the social worker, adds his or her own professional interpretation to the story. Thus, the patient's narrative emerges from his or her interpretation of past experience, but the listener reinterprets it in the light of other experiences and understandings.

In my 15 years as a social worker in the oncology department of a large hospital, I have observed that every cancer patient's narrative contains messages. These offer clues to skilled social workers that help them judge whether the patient is able to continue life on his or her own after falling ill, or if outside help is necessary. Among other things, narratives reveal how patients have been able to continue along their life paths after earlier crises, what sort of support networks they have used, and how they feel about securing professional support. My experience is that hearing a patient's story never depends solely on the length of time spent with a social worker. A competent social worker will be able to ask appropriate questions even in a short period of time and pick out from the story what is meaningful in the care of the patient.

We can use illness narratives to glean information about individuals' interaction with those close to them and about relevant features in their environment. According to Lars-Christer Hyden (1997), illness narratives generally offer:

1. a narrative construction of the world of illness
2. a narrative reconstruction of life history
3. a narrative explanation and understanding of illness
4. a narrative for use as a strategic device, whereby a social worker advances the helping process
5. a means to transform individual experience into collective experience by sharing the narrative with others, which can help both health care professionals and other cancer patients to understand how one lives with cancer

Narratives are often used in therapeutic work. However, social work in health care often requires immediate intervention due to rapid changes in the patient's situation. There is little opportunity to engage in the long therapy process needed to hear a patient's detailed life history. An adapted narrative approach provides the basis for an intervention that makes it possible for the patient to write at least a short continuation to his or her future life. The story does not always lead to follow-up work by the social worker, since the story may point out that the patient is able to continue his or her life without such intervention. In such a case, the social worker encourages and supports the choices the patient makes.

Narrative, Story, and Told Narrative

Social scientists have written a great deal about narratives (Bruner 1987, 1991; Hänninen 2000; Saleebey 1994; White 1981). The word "narrative" derives from the Latin word *narrare*. The words "narrative," "told narrative," and "story" are often used synonymously. Vilma Hänninen makes a distinction between "story" and "told narrative" (one that is recounted to another). Hänninen defines a story as a meaningful whole made up of words, comprising a plot and characters. A spoken narrative, she holds, is the presentation of a story by means of different codes, generally spoken words (Hänninen 2000, pp. 19–21). The spoken narrative is the unique part of a narrative that a person wants to tell to another person or persons in a particular situation. A patient often tells one story about the cancer experience, for example, to a social worker, but a different story to a doctor, or tells it one way at one point in time and in another way at some other time. Hänninen herself often uses "narrative" synonymously with "spoken narrative," but she defines narrative as a time-bound whole delimited by a specific meaning. Here I use the words "narrative," "told narrative," and "story" in the way Hänninen has defined them.

According to Hänninen (2000, p. 20) an inner narrative refers to a process in the human mind in which a person interprets his or her own experiences through narrative meanings. She maintains that the meaning of "narrativity" and an inner narrative is closely related to how people generate an understanding of their lives to themselves and find their existence meaningful. For example, in a crisis, people need to make sense of the events that have occurred so that life can continue. Much of this sense making occurs in the person's own mind as he or she sifts through and attaches meaning to the events, feelings, images, and words experienced during an event. The concept of social stock of stories refers to all the cultural stories that people can encounter (Hänninen 2000, p. 21). This means that even social workers can utilize this stock of stories when making their professional interpretations of patients' stories.

The patient's narrative (spoken narrative), the disease (lived narrative), his or her conditions of life, and stock of stories all have an impact on the patient's inner narrative. A change in one of these components influences the content of the other factors. For example, the cultural stock of stories (collective) and personal stock of stories (individual) influences individual interpretation of an event, such as radiation therapy in cancer. Those experiencing the therapy will have a lived narrative that they can speak about (spoken narrative) in a partial way to others. They will also have their own inner narrative, which helps in making sense of the radiation therapy and its significance. When a serious disease threatens the continuation of one's life history (lived narrative), a break in one's life history can result (Bury 1982). An unexpected change in life actively blocks a person's life plan from the past to the future, one that he or she has anticipated and strived for.

According to Maria Cheung (1998), a narrative is a history of a person's past, present, and anticipated future. She states that the way in which people tell their stories reflects how they perceive their experiences. Through their stories, people remember their own experiences and turn remembering into knowing. In his examination of narratives, Dennis Saleebey (1994), writing from the viewpoint of social work practice, says that social workers ought to remember that people construct meanings from their own world by creating them, and that they use words to define these meanings. In social work practice, our methods and theories, a client's narratives, and the culture-bound myths and rituals we are exposed to in our society shape our work. The more familiar a social worker is with a client's cultural and personal meanings (stock of stories), the more effectively he or she can be of help.

Psychosocial Work

A narrative method is appropriate in psychosocial work and rehabilitation because it provides professionals with case history material that is based on the patient's own narrative, and offers information useful in intervention planning. The concept "psychosocial" was first used in social science research as early as 1941 by Hamilton. Since then the concept has been further developed, defined, and evaluated (Meyer and Mark 1995; Morén 1994).

Jorma Sipilä (1989) defines psychosocial work as an orientation to social work in which therapeutic discussion is the most central feature and the significance of the material environment is also stressed. This view places the work in the intermediate zone between psychotherapy and social work practice that focuses on material needs of clients. Timo Toikko (1997) sees the psychosocial approach as helping work that is based on face-to-face interaction. He emphasizes the unique situation of a client and the client-social worker's encounter in it. Toikko's view does not, however, draw from any clearly defined therapy method.

Professional Use of Narratives in Helping

Not until this decade has the narrative approach become part of the professional practice and a subject of study in the social sciences (see Mattila, Brandt-Pihlström, and Katajainen 1997; Valkonen 1994, 1998). In social work practice, the starting point for the narrative approach is the narrator, meaning that the intervention is based on the person's narrative. In a health care facility, a patient may tell a range of narrative to different listeners; a doctor or a friend gets a different story from the one told to the social worker. Each story is, however, equally genuine. Michael White (1988) maintains that it is not possible to know objective reality, so it is through systems of interpretation that we give meaning to experience. In their stories to the social worker, patients consciously or semi-consciously underline the concerns they want help with.

Stories are the most authentic way of describing life experiences and meanings. This applies both to stories that are historical narratives and individual accounts. The narrative approach is a patient-centred approach. In their stories, tellers visualize themselves and others on their own terms. The encounters between storyteller and story-listener are understood as story sharing. Use of a narrative method also guards against the trap of explaining and analyzing in detail since every story is more than the sum total of all the explanations given to it. Generalizations, hypotheses, and diagnoses cannot substitute for the story, but are instead only partial sketches drawn for a specific and often quite narrow viewpoint (Lindqvist 2002).

People do not always speak about narrative therapy when doing therapy work, but a story is often the starting point for the helping process. Michael White (1988) uses the concept of externalization about the therapeutic approach in which a person is encouraged to distance himself or herself from distressing experiences by objectifying and depersonalizing them. The base for externalization are people's stories. Everyone has a dominating story that shapes his or her life and influences decision making and problem solving. It is difficult to detach oneself from this story and some experiences remain hidden. When narrators leave out parts of a narrative from the dominant story, examining these hidden parts of the story with them can help create new ways to cope with illness, to solve problems, and to change the course of their life narrative.

According to Dennis Saleebey (1994), narrative therapy has been criticized because emphasis is on the subjective narrative of a patient or the family as a basis for intervention. Such an emphasis means, for example, that the socio-economic circumstances in which the narrators live are ignored. However, Saleebey (1994) maintains that stories always generate information about the surrounding society and the circumstances in which the narrators live. This information must not be ignored or minimized in social work practice.

Cancer and Health Care

Health has been estimated to be one of the most important dimensions of a person's well-being. Becoming ill with cancer changes one's life so that well-being is threatened and normal roles, such as that of worker, shift at least temporarily. Cancer also affects the lives of the family and significant others, and often economic concerns arise.

Cancer is a common disease globally. Approximately 2.6 million people had been projected to become ill with cancer in 1995. This figure, a significant underestimation, represented only 25 percent of the new cancer cases in the world in that year (Bray, Sankila, Ferlay, and Parkin 2002). In Finland, for example, the number of diagnosed cancer cases was 5,941 from 1967 to 1971, and in 1992 to 1996, it was 9,619 (Finnish Cancer Registry 2003), representing a sharp growth over time. The main reasons for the increase in cancer incidence are the aging of the population, changes in lifestyle, and the improvement of diagnostic methods. On the other hand, the development of treatment methods and options has also increased the chances of lengthening the lives of cancer patients or allowing them to fully recover. Seventy percent of all newly diagnosed cancer patients are alive one year after the diagnosis; over 50 percent are alive five years after diagnosis; and approximately 45 percent are still living 10 years after being diagnosed. In Finland, the most common cancers are breast cancer among women and prostate cancer among men, both of which have relatively better prognoses than other types of cancers (Rautalahti 1999).

Because of modern communication methods, current research data about cancer treatment is available anytime, almost everywhere in the world. However, there are differences in treatment, depending on factors such as the economic and human resources. Also, there are differences in the content and degree of psychosocial and psychological support offered in different health care environments and national contexts.

The role of the patient as a client of health care has changed in many European countries during the past few decades. Patients, who have generally been passive recipients of treatment, can now make choices about services used. There are many reasons for this change in the patients' position. More public information on diseases and their treatments is now widely available because of increased access to electronic communication channels where health information is accessible. Patients' organizations have also become more active, forming groups and networks to share information. The general attitude toward illness has also become freer, in that people speak more openly about diseases and about suffering from illness. In 1993 Finland was the first country to enact a law focused on patients' rights. Similar laws also exist in 11 other European nations. In many other countries patients' rights are addressed though various regulations and policies (Exter and Hermans 1999).

Health care professionals have responded to the new, more active role of the patient by changing their approaches to patient care. They understand that they should listen to patients more closely and make use of their spoken narratives when planning and implementing treatment. Relying on the patient's own story as the starting point in the interaction is the service system's means of responding to the new situation.

Recently, the interaction between the patient and the professional has been emphasized in the education of health care professionals in Finland. This trend in education is influential in preparing health care professionals who will be more disposed to listening to their patients. This more egalitarian approach does not, however, always work in practice. This can occur, for example, when the context of health care provision shifts. In the 1990s, health care professionals' time available for patient treatment was halved (Lehto and Blomster 2000) and the pressure of work has increased among staff. As a consequence, the opportunities for the patient's voice to be heard may also have diminished.

Meaning of a Cancer Diagnosis

There is one common denominator in the narratives of those who been diagnosed with cancer: they acutely realize the impermanence of life. The disease causes patients and their family members to think about the past and future. Cancer causes a disruption in their life histories. In day-to-day life changes, there is an interruption or cessation of work, one's physical condition deteriorates, social interaction is reduced, and thoughts of death emerge. For some patients, these changes represent the first serious crisis in their lives. Others may have experienced stressful life transitions such as divorce, the death of someone close to them, or unemployment. The narrative of a cancer patient tells the listener not only what it means in everyday life to be ill, but also how, in past life crises, the patient has found a continuation to his or her story.

In narrative, a rupture in a person's life history resembles the shock stage in crisis theory (Cullberg 1991). The narrative is a continuation of one's life history after the disruption, but is based on a current reflection and interpretation of earlier life history. Crisis theory holds that after that initial shock stage, a person goes through a reaction and processing stage, seeking a new direction or, in other words, a continuation to his or her life story. Thus, narrative theory adds new concepts and a different view of existing survival and crisis theories. It underlines the individual's active role as a builder of a new life story.

The impact of cancer on a person's body image is significant (Hughes 2001). A serious illness poses a threat to one's self-image. If there are visible signs of the disease, it may affect the patient's life a great deal. In my work with cancer patients, it has become evident to me that personal interests diminish, connections with friends become weaker, changes in marital relationships occur, and life generally becomes more constricted than before the cancer diagnosis. Helping cancer patients to improve their self-image is an important part of psychosocial work in health care. If this is done successfully, patients can experience more satisfaction as they continue living each day, often through a prolonged and sometimes chronic course of illness and treatment.

The image that cancer brings to mind and the fears connected with it are similar all over the world. Pain, death, and uncertainty are some of the most common words that people use to describe cancer. Slowly, this image is changing, along with an increasing number of patients who, in many economically developed nations, have recovered from cancer. Drugge (1988) states that Swedish cancer patients, at the point when they became ill, referred to cancer as "horrifying" and "a death sentence." At the initial stage of the disease, patients reported that it was difficult even to say the word "cancer." The word was replaced by terms such as "polyp," "lump," or simply referred to as "it." My own observations are similar. In addition to these words, cancer patients use words such as, "disease," "growth," or "bump" instead of cancer, yet using the correct name of the disease is a first step in the adjustment process.

People who are diagnosed with cancer draw on their stock of stories in order to establish what kind of threat they see in cancer and what chance they have of recovery. In order to explore this idea, a case situation is presented below. In the case of Mari, a woman diagnosed with cancer, the impact of her stock of stories is substantial. Mari had a positive experience in the past because a family member recovered from cancer. This made it easier for her to patch the rupture in her life history when she was diagnosed with cancer.

Uncertainty is an undeniable feature associated with cancer. Even if the advance of the disease is stopped or the disease is "beaten," the doctor, who provides treatment, cannot guarantee that the person will remain disease-free in the future. People who have recovered from cancer often fear that cancer may recur even 10 years after recovery. The patient may become hypersensitive to various and often minor symptoms as evidence of the recurrence of cancer.

The experience of suffering from cancer and treatments during the course of disease includes several stages. During these stages patients consistently need psychosocial support to reconstruct a meaningful life history. Drugge (1988, pp. 239–243) lists four stages in an illness career that represent periods of crisis when the person's uncertainty is greatest. I have added a fifth phase, the stage of cancer recurrence. At this stage, in particular, patients need to be heard and supported.

1. Cancer is suspected and the patient awaits the final diagnosis. At this stage, people may feel chaotic and quite alone. They do not yet have the support of a community or network of care providers.
2. The person has received a diagnosis of cancer. Plans for treatment are made. There has been no relief yet of anxiety. At this stage, the patient is best referred to a hospital social worker to discuss his or her feelings and the problems brought about by the illness and other concerns.
3. The treatment has begun. The patient's uncertainty eases now that measures are underway to treat the disease. At this stage, the treatment and its side effects are common fears for patients.
4. The patient completes treatment and will begin to receive follow-up care. His or her connections to the treatment facility are reduced. The patient starts to think of changes in his or her body and its functioning. A normal rhythm to daily life is sought. The short-term plan made at the point the person became ill is no longer sufficient and long-term planning is needed.
5. There is a diagnosis of cancer recurrence. This news is often a greater shock than hearing the diagnosis of cancer for the first time. There is another serious rupture to the person's life story as, once again, the foundation one has built his or her future on is shaken. Finding hope is much more difficult now than it was with the first cancer diagnosis.

In Mari's story, these five stages and their effects on Mari's narrative are described. The case situation illustrates the impact of cancer on

Mari's life and describes the process of social work intervention. The example shows how Mari was able to find new survival strategies as her situation changed with the progress of the disease. The social worker, besides offering information, provided emotional and instrumental support.

Case Situation: Mari's Story

Mari was born in 1971 in a large Finnish city. She was the youngest of two children. Her father worked at a paper mill and her mother was a homemaker. Mari's childhood was overshadowed by her father's alcoholism. His bouts of drinking sometimes lasted several weeks. During these periods he was often violent, especially toward Mari's mother. The family's income was inadequate to meet all their needs.

When Mari was 17, her parents divorced, and soon after her father died. For nearly 20 years, Mari's mother had suffered as a result of her husband's alcoholism and violent behaviour, but had never talked about her suffering to anyone outside of the family. Mari had a small circle of friends as she was growing up. She also had few interests and low self-esteem. In school she was an average student. She completed secondary school in 1990, studied at a commercial college, and graduated in 1992. Until 1999 she worked as an office clerk.

In 1995 Mari fell in love with Matti and married him in the following year. Mari stated that she has a good marriage because when she married Matti, she felt for the first time that her life was proceeding as she wanted it to. Mari became pregnant in 1999. In the sixth month of pregnancy, she went to see a doctor because she had a fever and felt a lump on her neck. The doctor diagnosed melanoma, a malignant cancer. Mari's labour was induced in the 32nd week of pregnancy because cancer treatment was urgent and could be harmful to her baby. Mari gave birth to a healthy baby boy and within two weeks of the delivery, she had her first chemotherapy treatment. The course of treatment lasted six months.

In March 2000, a few months after the first treatment phase ended, the cancer recurred; metastases were found in her lungs. A new kind of chemotherapy treatment was started, combined with radiotherapy to the lungs. In June 2001, metastases were found in her brain, and again a new round of treatment was begun.

The first chemotherapy treatments were relatively easy for Mari. There were hardly any side effects. Her hair fell out, but Mari did not view this a major problem. The subsequent periods of treatment were more difficult. Mari's general condition worsened as the treatments sensitized her to various infections. Some medication also caused significant swelling on her face. There was a marked change in her appearance and in her physical capacity to function. Still, Mari continued to be very hopeful about the treatment. She even joked about how she looked.

I heard three stories from Mari. The first one was told at the point when the cancer was initially diagnosed. We met for the first time at the Department of Oncology when treatment was being planned. Mari was pregnant then. She was happy about the baby and this had a strong effect on her and on her future plans. The crisis caused by the disease was not her only concern in life. This serious disease did not cause a rupture in her life history. On the contrary, the future seemed to her like a long continuum. When she came to see me, we spoke mostly about practical concerns such as social security and child care.

The second story was told less than a year after the first. Mari's disease had recurred. It was the most difficult crisis of Mari's life so far. This time the disease crisis that she had not experienced the first time hit with all its force. The recurrence of cancer made it extremely difficult to find hope for recovery. Mari became severely depressed. There was a gap in her life story. Her narrative needed reassessment and reconstruction.

Mari's father's alcoholism was a family secret, a topic that had not been mentioned outside the family. The model of her childhood home guided Mari's conduct and her way of resolving crises. She was not able to recognize her depression when the cancer recurred. She experienced it as part of her declining health and thought that nothing could be done to improve the situation. Together we reflected upon her everyday life and thought of forms of support that could be arranged for her and her family. In addition, everyday coping and matters related to income and child care were also dealt with during our meetings together. We mapped Mari's strengths and those of her other family members and tried to find ways to strengthen the limitations and weaknesses she identified. We discussed how she could talk about difficult topics with other family members and the fact that all who participated in the discussion could draw energy and support from them.

In addition to meetings with a social worker, Mari and her husband were given an opportunity to visit a psychiatrist at the hospital psychiatry clinic. Mari's husband was urged to contact the clinic whenever his anxiety became overwhelming. Home help services were arranged for times when household chores or caring for the baby become too exhausting for them.

Mari did not experience any terrible images of cancer prior to becoming ill. Her older sister had been ill with cancer a few years previously and had totally recovered. Mari's stock of stories about cancer helped her continue her life history when the cancer recurred. A positive view of cancer treatment gave hope about its effectiveness even after the disease recurred.

The third story was told when the cancer had spread to Mari's brain. Over time, Mari had grown accustomed to the idea that cancer was part of her life. She had tentatively reflected on the possibility that there would not be a treatment that would cure the cancer or slow its progress, but she had not talked about death with her family. When the metastases were diagnosed in her brain, Mari had to once again reassess her life history. It now seemed more and more likely to her that she would die of the disease. She reflected on the impermanence of life and it made her feel afraid. There seemed to be no foundation for planning the future.

Cautiously we began to talk about Mari's everyday life, what worked in it, and what became more difficult as new symptoms arose. We increased the support services provided for her at home. This made everyday life for Mari and her family easier. Additional appointments at the hospital psychiatry clinic were arranged in this new stage of the disease. In spite of the gravity of her situation, the tone of Mari's third and last narrative was positive as she still had a will to fight the disease. Her attitude toward the future was realistically optimistic.

A spoken narrative is made up of words. An inner narrative is built on the basis of a person's stock of stories. In Mari's case this stock of stories included, for example, the teachings of her grandmother, who was important to her; the survival strategies that her mother had used; her sister's experiences of cancer, medical tests, and results; and the images of cancer created by the media and literature. The inner narrative provides the foundation for a new life history. The inner narrative also guides the narrator's actions and choices, which create change in the person's lived situation, which, in turn, causes changes in the inner narrative.

Over the course of the disease, Mari found her own way of dealing with problems. Besides her optimistic outlook on life and her fighting spirit, she learned to accept the support that was offered to her in the hospital. She also dared to ask for support and recognized that she and her family could cope better with such help. Mari also saw that it was permissible to talk about problems with the people closest to her and that they all benefited from it. Most of the time, Mari was able to fill the narrative gap on her own as she had the energy and desire to do so. The social worker was chiefly a listener who presented options and supported Mari's chosen solutions. In other words, I helped Mari find justification for the use of outside help and support and advised her in the use of various service systems. In our discussions, I encouraged her to attend to her own well-being and to the maintenance of her marital relationship.

Mari's cancer was incurable and she died in the hospital ward a little over a year after the disease was first diagnosed. Mari gave me three gifts during our time together. These were the narratives of her life as she saw it at three important junctures. Each narrative offered rich learning for the listener and an affirmation of the resilience of the human spirit.

Discussion

In this chapter, I have described how a narrative approach offers a good basis for psychosocial work with cancer patients. I have tried to describe the use of narrative from the viewpoint of social work, applying it to the situation of Mari to show how a spoken narrative can be useful as a social work method in health care settings.

During their encounters with a social worker, patients or their family members are encouraged to speak about events that occurred prior to diagnosis of disease. This is appropriate because seeing a social worker often requires a broad mapping of the situation. Patients often reflect on the reasons why they acquired cancer, and their narratives illustrate how they respond to this crisis and the survival strategies they resort to.

A serious disease makes people reflect on the reasons it struck them. Sometimes patients or those close to them have a narrow interpretation about the factors that led to the disease. It is a social worker's task to seek new interpretations that make recovery possible. Narrative work, aided by a trained facilitator, helps the patient to construct a plot. He or she can also start to construct a future from this point forward (Bardy 2000). When listening to a patient narrating his or her story, a social worker can point out subject areas to be specifically addressed. These areas depend not only on the social worker's work experience and knowledge, but also on his or her own stock of stories.

The use of narratives in psychosocial work is an effective method of a social work in health care. The helping process is based on the narratives as told by the patient, making it possible for the patient and the social worker to focus on particular parts of the narrative for their work together. This method helps patients to find motivation to plan their future while they are also being heard and valued. Instead of being passive objects of therapy, they become active subjects creating their own narratives or life histories.

Not all cancer patients can be cured. In many cases the disease leads to death in a short period. A social worker practising in an oncology ward must be motivated for psychosocial work, even when he or she knows that the patient's life will not last longer than a few more months. Increasing attention has been given to palliative, symptom-related care in the past several decades. Even though there is no curative treatment, a great deal can be done to relieve patients' symptoms and to improve their quality of life. In palliative care, a narrative approach makes it easier to explore what type of support is most appropriate for patients.

Reflection Questions

1. What particular personal qualities and skills are required for social work with cancer patients?
2. How is your own narrative (life story) relevant in social work practice?
3. What have you learned about human resilience from Mari's story?
4. What kind of stock of stories would you have at your disposal to work with Mari? How are these related to the kind of survival strategies you learned in your childhood home?
5. The use of the patient's story as the basis for psychosocial work can help to motivate the patient. Besides motivating the patient, what other grounds for the use a narrative approach can you think of?

Notes

1. Translated from Finnish to English by Pirjo Kuuselo.
2. The term "rehabilitation" is used in this chapter to signify recovery or enhancement of well-being to the greatest degree possible for a particular patient.

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CHAPTER 19

THE EXPERIENCE OF RECEIVING A DIAGNOSIS OF CYSTIC FIBROSIS AS AN ADULT:

Drawing upon Individuals' Stories to Inform and Guide Social Work Practice[1]

Eileen Widerman and Lois Millner

Introduction

Two young women with cystic fibrosis (CF) are seated in the waiting room of a hospital specialty clinic. They appear to have much in common. Both are in their mid-twenties, and, as they wait for their appointments, they chat about their lives. Yet, these two women, Molly and Laura, are very different. They respond differently to having CF and to their medical care providers.

Case Situations: Molly and Laura

Molly is 25 years old. She was diagnosed with CF as an infant when she "failed to thrive," or didn't gain weight as expected. Once she started a treatment regimen, she improved immediately. She grew up living as "normal" a life as possible given that she had to perform four hours of self-care per day (exercise, chest percussion, and inhaled nebulizer treatments), take 14 pills with every meal, miss school because of respiratory infections, and deal with what she considered "overprotective" parents. She received her medical care from a CF centre at a children's hospital until she was 18, and was then transferred to a nearby adult program. Over the years, she was hospitalized multiple times and was frequently ill. Nonetheless, she did well in school and went on to college, where she majored in journalism. Upon graduation, she took a job with a local newspaper and, against her parents' wishes, moved into her own apartment. At age 24 she met Sam and fell in love. Today, they are discussing marriage, but Molly is wary because she knows her disease is progressive and that having children could adversely affect her health. She thinks Sam deserves a wife who can be his active partner, not a sick young woman with an uncertain future. There is so much to discuss and consider.

In contrast, 28-year-old Laura was relatively healthy growing up. She explains that she came from a "normal family" and did "normal things," like taking dancing lessons and swimming competitively in high school. She had a bout with the flu every year and took longer to recover than her friends. Also, she had a constant, annoying cough that her doctor ascribed to "allergies." From an early age, Laura knew she wanted to be a preschool teacher and someday have "lots of children," so nobody was surprised when she eventually majored in education, earned a master's degree in child development, and began teaching in a nursery school. Throughout her studies Laura had been periodically sick, usually with a respiratory or sinus infection. When she began teaching, she became sick often.

At 24, Laura met and fell in love with Steve, a popular and well-known track star and outdoor enthusiast. They were married 18 months later. At the age of 27, Laura and Steve became parents. Their joy turned to shock, however, when their beautiful daughter, Carrie, was born with a bowel condition suggestive of CF. In taking the parents' medical histories, the pediatricians noted Laura's history of respiratory conditions and her constant cough. Within a week, both mother and daughter were diagnosed with CF. Laura was referred to the adult CF program for ongoing treatment, and Carrie was treated at the same children's hospital Molly had attended as a child. Steve and Laura were scared and overwhelmed. Their lives became organized around medical treatments and doctors. Strangely, their usually communicative families seemed to withdraw, showing little interest in their grandchild or in helping the young couple cope. Laura couldn't return to work because Carrie needed so much attention. Steve worried about living on one income and feared that he might lose his wife and child. He was physically and emotionally exhausted.

Background

Most of the men and women seen in CF clinics throughout the United States have been diagnosed in childhood, like Molly, and grow up familiar with their disease and its care. They think of themselves as individuals with CF and are accustomed to interacting with the medical system. The CF team monitors their health status and provides ongoing education and support. However, some adults, like Laura, are referred immediately following an unexpected diagnosis of CF. These adults learn that they are different from most others with that condition; that if they are male, they are most likely sterile; and that others in their family could also have the disease. Most significantly, they realize that many of their life goals and commitments might be unrealistic given the progressive nature of CF and its treatment demands. They learn that little is known about what people diagnosed as adults can expect as they age, and that there are no educational materials that address their unique questions and needs (Widerman 2004).

A Practice Challenge

In the late 1980s, Eileen Widerman served as the social worker on a CF team's adult program. There she became very interested in the issues and needs of men and women, like Laura, who are diagnosed with CF during the adult years. In initially meeting with these patients, the team's focus was to assess their medical status, initiate treatment, and teach about the disease. To their surprise, newly diagnosed adults responded with seeming disinterest in learning about CF, appeared distracted, and were only partially adherent with care recommendations. More medically oriented colleagues wondered why these adults would delay treating their serious disease and labelled them "in denial" or "resistant."

As a social worker, Eileen Widerman drew upon her professional knowledge and posed two questions: What factors might keep these adults from engaging in and benefiting from what the team and clinic have to offer? How can the team respond sensitively and meaningfully to these adults? In exploring possible answers to these questions, she started with assessment, asking these patients to share what they were experiencing. Drawing upon social work's person-in-environment and strengths perspectives to inform her approach, she explored individuals' thoughts and feelings related to their unanticipated diagnoses, histories, family composition, relationships, career plans, finances, and insurance coverage. In doing so, she noted that the experiences, needs, issues, and characteristics of those diagnosed with CF in adulthood differed from those of adults diagnosed as children, and that these differences were affecting their readiness for CF education and treatment.

In listening to their stories, Widerman concluded that newly diagnosed adults must come to terms with and assign meaning to having a serious, progressive disease before they can focus on treating the disease. To help them do so, she integrated supportive counselling into the assessment process. In addition to gathering and clarifying information, she responded to patients' stories and provided the information necessary to help them make sense of their diagnoses. At the same time she began assisting the other team members to understand how the needs and issues associated with an adult diagnosis of CF, some of which were reflected in the case example of Laura, can affect an individual's response to care. It became clear that all team members needed to take the time to solicit and address questions, concerns, and reactions during interviews with those who were newly diagnosed.

Over time it was discovered that newly diagnosed adults ask very similar questions, regardless of their individual circumstances and seek information to help them accept and adjust to their disease. Almost all wanted to know what they could expect in the future, why their symptoms differed from those described in the CF pamphlets they were given, whether being adult-diagnosed means they will live longer lives, and how they compare to others diagnosed as adults. In searching for answers to these questions, the CF team members discovered that little is known about adult diagnosis as a phenomenon. The information to effectively respond to most questions asked by newly diagnosed adults with CF was simply not available.

This practice challenge led Dr. Widerman to systematically study the lived experiences of those adults diagnosed with CF pre-diagnosis, at diagnosis, and post-diagnosis, and their interactions with medical caregivers. This chapter incorporates much of what she found. The intent of this chapter is to:

1. Describe how individuals experience receiving a diagnosis of CF during their adult years.
2. Discuss the extent to which these descriptions are similar to or different from those described in the chronic illness literature.
3. Present recommendations to assist social workers in responding to the many issues and needs associated with adult diagnosis of CF.

About Cystic Fibrosis

Cystic fibrosis is the most common, life-threatening genetic disorder in the Caucasian population, affecting one out of 3,200 newborns in the United States. It exists, but is rare, in people of African descent (one out of 15,000) and in Asians (one out of 31,000) (Orenstein, Rosenstein, and Stern 2000). Symptoms and complications of the disease include chronic cough, recurrent lung infections, antibiotic resistance, diabetes, male infertility, and inability to properly digest food (Cystic Fibrosis Foundation [CFF] 2001). Depending on the stage of the disease and which organs are involved, treatment may include vitamins and enzymes, oral and inhaled medication, chest physical therapy (percussion), exercise, rest, and proper diet (see www.CFF.org/home).

In 2001 there were 22,732 known individuals with CF in the U.S. Just over half were males (52.8 percent). The median age at diagnosis that year was six months (CFF 2002). The median survival age was 33.4 years. In 2000 most deaths (77.6 percent) resulted from cardiorespiratory failure (CFF 2001).

Adult Diagnosis of CF

In 2001, 11.4 percent of individuals with CF in the United States had been diagnosed when they were 18 or older (1,020 men and women), and just under 10 percent of all new diagnoses that year were confirmed in 100 adults aged 18 years or older, at an average age of 34 years. Slightly more males (52.6 percent) than females were diagnosed in the adult years (CFF staff, personal communication, September 17, 2002). Incidence and prevalence data from outside of the U.S. are more difficult to obtain. A study conducted in Spain found that 8 percent of the adolescent and adult subjects had been diagnosed later in their lives (Giron Moreno and Ancochea Bermudez 2000), and 19 percent of 202 adult patients in a French study population had received their diagnoses during their adult years (Hubert, Rivaol, Desmazes-Dufeu, Lacronique, Maurer, Richaud-Thiriez, and Dusser 2000).

As a group, those who are adult-diagnosed live longer and enjoy better health than do adults diagnosed as children. Those diagnosed as adults display better lung function, higher rates of pancreatic sufficiency, fewer complications, and longer life expectancy (Gan, Gues, Bakker, Lamers, and Heijerman 1995; McWilliams, Wilsher, and Kolbe 2000; Widerman, Millner, Sexauer, and Fiel 2000). They are significantly more likely to be married, parents, college educated, and employed full-time (Widerman et al. 2000). That men and women with undiagnosed CF can present with atypical symptoms and differ medically from those diagnosed as children has also been demonstrated in a number of case studies (e.g., Drey, Zinzindohohoue, Cuillerier, Cugnenc, Barbier, and Harteau 1999; Fiel 1988; Gardiner and Cranley 1989; Godbey 1985; vanBiezen, Overbrook, and Hevering 1992; Vilar, Najib, Chowdhry, Bassett, Silverman, Giusti, Rosa, and Schneider 2000) and in the stories of those adult-diagnosed (Widerman 2004). Examples of atypical presentations include pancreatitis (Drey et al. 1999), carriage of a rare mutation (McCloskey, Redmond, Hill, and Elborn 2000), or older age (Bargon, Rickmann, Jacobi, Straub, Arnemann, and Wagner 2000). During a research interview, one young woman described how she was diagnosed at age 24 following a seizure. A man, diagnosed in his early thirties as a result of a fertility work-up, spoke about how he not only learned he had CF, but also discovered he could not have children without medical assistance (Widerman 1997).

CF and Chronic Illness

At one time, those diagnosed with CF rarely lived beyond their childhood years. In 1968, only 8 percent of patients were adults (Orenstein et al. 2000). At that time CF was considered a terminal rather than a chronic disease. In 2001, however, 39.5 percent of those with cystic fibrosis known to the Cystic Fibrosis Foundation were adults (CFF 2002). Therefore, it makes sense that what is known about chronic illness may also apply to CF.

The chronic illness experience has been described by Conrad (1987) as characterized by these recurring themes: uncertainty; illness careers; stigma; biographical reflection and the reconstitution of self; management of medical regimens; awareness of information and sharing; and family relations. More recently, Thorne and Paterson (1998) analyzed studies conducted in the 1990s on chronic illness and written from an "insider" (patient) perspective. They found that their themes could be grouped according to symptoms experienced (e.g., pain and suffering), adjustment patterns (e.g., coping), and social contexts (e.g., others' response to the illness). They also discovered that how individuals experienced their illness was affected by their age, life stage, gender, social location, and ethnicity. Sidell (1997), reviewing chronic illness literature from a social work perspective, concluded that adjustment to chronic illness among non-geriatric adults is characterized by loss and grief, uncertainty, coping, and developmental issues.

Thorne and Paterson (1998) observed that the specific attributes of a disease (e.g., symptoms, treatment, prognosis) affects how it is experienced. Many themes within the chronic illness literature (e.g., uncertainty and adjustment) and important factors (e.g., age, life stage, and ethnicity) appear relevant, but in the absence of diagnosis-specific research, there is no way to be sure that these themes and factors sufficiently explain the phenomenon of adult diagnosis of CF.

Recent qualitative research (Widerman 2004) that describes the experience of adult diagnosis helps us to understand how CF teams can best provide education and support to these men and women. Key themes from this research are taken up in below.

The Experience of Adult Diagnosis of CF

Overarching Themes

Thirty-six men and women, all diagnosed with CF at age 20 or older, were interviewed. From their stories, themes emerged that reflect most of their experiences and those associated with their gender, illness severity, and encounters with medical care providers.

A powerful theme, as might be expected, was **awareness of death**. Although, as a subpopulation, individuals diagnosed with CF as adults live longer than those diagnosed as children, they still have abbreviated life expectancies. For instance, the mean age at death of those diagnosed as adults who died in 2001 was 43.7 years (CFF 2002). Those whom Widerman interviewed said that, upon diagnosis, they became aware of the probability of a shortened life span and most responded with fear. A married mother of two recalled, "I thought I was going to die. I really thought my days were numbered." A male in his late twenties commented, "I started to pick out shrouds." Their fear was in part prompted by the often outdated educational materials they consulted shortly after their diagnoses. A woman explained, "I immediately went to the library the next day and looked up CF, and everything said you were going to die by the time you were 16. And here I was 40, and I was like, you know, this is it!" Also, many did not understand the meaning of "mean" or "median" and thought the life expectancies they saw cited were the actual ages they could expect to live.

Although their immediate fear subsided as they learned more about CF, began treatment, and developed coping strategies, the awareness of a shortened life span remained persistent, although not constant. One woman said, "Depending on the day—I can go days and not think about it. Then I get a call, or someone will ask me about it." Another woman said, "I flip-flop between denial and self-consciousness."

Change was another pervasive theme in the stories of the men and women interviewed. Once diagnosed with CF, they were confronted with new information about themselves. One woman recalled, "I was amazed at how life can change so quickly. One day you think everything's fine and the next day you think it's all over." Most had to re-evaluate plans, careers, and lifestyle choices. A woman diagnosed in her mid-twenties had been unhappy in her marriage. She thought, "Okay, if I'm going to have a shortened life span, then I better get my act into gear and make the changes I need to make." She filed for divorce within a month of receiving her diagnosis. More than one participant changed careers. Others moved to be nearer to a CF centre.

Almost all also described how CF brought positive changes into their lives. As one woman explained, "CF brings gifts with it." Because of their diagnoses, many began valuing time and relationships differently, respecting the fragility of health, and developing a sense of purpose. A young man reflected, "I was speeding through life. I enjoy life now."

A profound sense of **difference** characterized how participants said they felt following diagnosis. They repeatedly used the word "different" to describe themselves, and their stories reflected an overwhelming sense of difference. First, they felt different from other adults with CF. Commenting on a friend diagnosed at age six, one woman related, "He grew up with it [CF]. He was comfortable with it. It was like a little blanket. To me it wasn't. It was threatening." Another woman mused, "They [Those diagnosed as children] have all their decisions to make. Do I get married, have kids, go to college? I didn't get to make those decisions." Their sense of difference was often heightened and occasionally defined by physicians, who were said to have stressed the rarity of adult diagnosis or of individuals' atypical symptoms. One woman said she was told, "You're not a normal CF person anyway because you weren't diagnosed until this age." A man in his early twenties was reassured, "You're going to live to 30 or 40 or 50." Although many experienced their difference as distancing them from others, they also drew upon their difference to develop and maintain an optimistic outlook: If they were truly different from those diagnosed as children, then their prognoses and their lives would also be different.

Participants also felt different from those with other diseases. One woman commented, "Diagnosis as an adult is different than a diagnosis of cancer. You didn't just get it. You've always had it. You've been sick and didn't know it." A number of respondents commented that, unlike those with AIDS or lung cancer, they "didn't do anything" to "cause" CF and viewed themselves as "innocents" or "victims." One man reflected, "Hey, I didn't give myself cystic fibrosis. My parents were carriers."

Finally, participants felt different from those they termed "normal," for all of the reasons that chronic illness can change lives, symptoms, appearance, treatment demands, dependency, and shortened life expectancy. Another man mused, "I have an uncertain future. What's important to me is different than what is important to others."

Widerman noted an interesting phenomenon in the stories of many of the men and women she interviewed, one she termed, **distraction**. Most participants were diagnosed in their late twenties when important life events, many common to the early adult years, were also occurring. The urgency of these events distracted them from thinking about having CF. A 35-year-old man explained: "In that first year we were having a family crisis. It just so happens that my father was diagnosed with cancer in January. I was diagnosed a month after him. So, um, there were a lot of other things going on in the household that took away some of the dramatics. We were dealing with other issues."

In this man's case, he and his family were absorbed in caring for his father, in anticipating his father's death, and in supporting each other. He kept clinic appointments, but he said he did not reflect on the meaning of having CF until months after his father died. Another man was struggling with sexual identity issues when he was diagnosed. "Well, I was very preoccupied with coming out, so that was the thing even bigger on my mind than my CF diagnosis." Other participants were distracted by the demands of college, career, or children. Dealing with life events and dealing with a new diagnosis simultaneously, with equal energy, was impossible. The phenomenon of distraction was adaptive. While distractions relegated CF to the periphery of awareness, they afforded men and women time to "ease into" the reality of their adult diagnoses.

Although there is some disagreement in the literature about how having a child with CF impacts family functioning, there is strong evidence that parents tend to be very involved (Blair, Freeman, and Cull 1995; Foster, Eiser, Gades, Sheldon, Tripp, Goldman, Rice, and Trott 2001; Wiseman 1996). Surprising was the discovery that **family indifference** was a prevalent theme in the stories of the men and women interviewed. Most said that at and before their diagnoses, their birth families showed little interest in their health and were rarely helpful or supportive. A young college student recalled that her first thought at diagnosis was, "Thank God, someone is saying it's not in your head because that's what my parents were saying: 'It's all in your head. You're making this up. It's just a nervous cough.'" Over and over again individuals said that their parents ignored or minimized symptoms and accused them of malingering or of seeking attention. Participants were angry, sad, and confused by their families' reactions and lack of help or support. One woman said, "My first thought when I was finally diagnosed was that I wished my mother were still alive to finally know that it really was something!" Another indicated she was sure her family will "feel bad" after she dies, but went on to say, "I want involvement now, not when I'm dead."

Another theme describing how the men and women Widerman interviewed experienced their adult diagnosis was **intrusion**. Cystic fibrosis was seen as an intrusion into lives planned without awareness of CF. One man related, "I was building my life. We had been married for three years. We were preparing to build our home. We were getting along successfully, financially speaking. We saw life optimistically ahead of us." Rather suddenly, he learned that the sinus problems he had suffered throughout childhood were actually symptoms of CF. He was advised by his physician to consider a less stressful career and move to a warmer area of the country. He had to begin a time-consuming regimen of self-care and treatment. He was resentful that CF would affect the flow of his daily life as well as his future planning. Others also saw the necessary self-care and physician appointments as intrusive. A young woman remarked, "Maybe because I wasn't brought up on medicines, on physiotherapy, with a viewpoint toward illness, being constantly aware you have this monkey on your back."

Participants in Widerman's study (1997) said that they minimized their socialization and consequently felt **isolated**. The time necessary for CF self-care, their feeling "different," embarrassment related to CF symptoms (primarily coughing), and the effects of the disease, such as fatigue and shortness of breath, all contributed to their pulling back from interacting with friends, attending church and clubs, and/or participating in recreational activities. The emotional and often physical withdrawal of families further contributed to a sense of isolation.

The study participants did everything possible to maintain their pre-diagnosis routines of work, church, parenting, and other activities and to pursue plans made pre-diagnosis, thus **normalizing** their lives. When they were diagnosed, at an average age of 28, participants had existing obligations (particularly children and expenses) that required them to maintain a high level of daily activity. Pursuing normalcy, however, was not just a response to established demands, it was a way of "proving" to themselves and others that they were indeed different. Cystic fibrosis would not define who they were and how they lived their lives. Study participants repeatedly expressed that they really had not changed upon diagnosis, but a label had simply been applied to them. "I was so used to [my symptoms] that whatever they called it, it was still the same," was a young woman's comment. A man explained, "I'm the same guy as the day before I found out."

Participants reported that, following diagnosis, their **sense of time** changed and their conception of "future" became more restricted. Even though many thought they would live a relatively long life given their already older age and their mild symptoms, almost all said that they lived "day to day." Participants also said they had difficulty "finding" the time necessary to care for themselves, given their busy lives. One woman sighed, "There's not enough hours in the day."

The theme of time was related to another theme, **uncertainty**. Participants were uncertain about what lay ahead, both in the long and short term. From one day to the next, they could not be sure how they would feel. One woman ruefully commented, "I've learned not to let [CF] rule me and take over my life. Ha Ha. But it's hard to make plans, buy tickets, because I never know if I'm going to be sick." Participants were even more uncertain about the long-term future. A man explained, "I'm not looking forward to retirement because I don't know if I'll even make it that far."

Additional Themes

The 10 themes described above (Awareness of Death, Change, Difference, Distraction, Family Indifference, Intrusion, Isolation, Normalizing, Time, and Uncertainty) refer to the experience of being diagnosed with CF as an adult. Some themes not common to all respondents' experiences were strongly related to **gender** or to **illness severity**.

Women who were mothers spoke of the difficulty of parenthood. The physical and self-care demands of CF made taking care of their children difficult. A number of women said that if they had known they had CF, they would not have had children. None indicated plans to have additional children. One woman said that she was raising her children "from the couch." Others said they were "cheating" their children because they could not play games with them, volunteer for school functions, or be sure they would live to see them graduate or get married. Few had families willing to help them. Although a number of the men in the study had stepchildren or they adopted children, none identified their parental role as difficult.

There were themes that described male experience. Almost all men with CF are incapable of having children without medical assistance, and the men interviewed were devastated by sterility. In some cases, infertility was more disturbing than the shortened life span associated with CF. A 32-year-old married man recalled, "The actual CF part wasn't bad. I dealt with that part really well. But still the infertility thing made me feel like less than a human, less of what I am." Another man, interviewed over 30 years after his diagnosis, said "It's the worst of the worst [news] ... for a man to find out that he can't father children."

Although CF can affect fertility in women, most women with CF are not infertile because of the disease. None of the women interviewed expressed concern that they could not have children or might have difficulty conceiving and/or carrying a baby to term.

The three male respondents who said they were gay all expressed a fear of rejection. They were interviewed in 1995, when HIV was considered a more deadly disease than it is today. They feared that their CF symptoms (malnutrition, frequent pneumonia) and treatment (antibiotics) could be mistaken for the symptoms and treatment of HIV/AIDS. One explained, "With the sickness I have [the people I meet] are immediately going to think about AIDS. So, when I think it's going to become an issue with that person, I'll look them in the eye and say, 'Look, I have this and it's not a big deal.' And that's when you don't hear from them anymore."

Themes related to self-assessed illness severity were also expressed. Although awareness of death was an overarching theme arising from the stories of those interviewed, the awareness was not constant for most. But, those who experienced ongoing symptoms and were frequently hospitalized said that they were acutely aware of the probability of an early death, which they found depressing. Some were receiving or considering applying for disability benefits. A 26-year-old man acknowledged, “I guess I’m always getting worse. That’s a simple fact, though. You know, no matter how much I do, the bottom line is you’re getting worse.” A few were being evaluated for lung transplantation and recognized that, without a transplant, they would not survive more than a few months or years. A woman in her forties explained, “When you do get bad, and you are looking at a [lung] transplant, it’s another world. It’s someplace I never thought I’d be.”

Those study participants who were moderately or seriously ill experienced self-pity and found themselves wanting sympathy, particularly from family members and caregivers. They said that they tried very hard to meet their obligations, to lead “normal” lives, and to take care of themselves. Yet their struggles seemed, to them, rarely understood or appreciated. One woman said, “Once in a while, I’d like someone to feel sorry for me.” Participants said they envied and resented the concern of the public for CF “poster children.” But, because CF is not outwardly apparent in most adults, participants felt their families, friends, and co-workers underestimated its impact.

Those whom Widerman interviewed who described themselves as mildly ill were believers in the importance of exercise. They described their routines in great detail. Determining and maintaining a challenging activity level were consciously employed not only as a means of improving health status but also to reassure themselves that they were not “getting worse.” For example, one man ran 5 km every day. As long as he could run those 5 km, he had “evidence” that his CF was not progressing. Despite the lack of supporting research and their physicians’ skepticism, those who exercised were convinced that vigorous activity could stop, or even reverse, the progression of CF.

Themes Describing Interactions with CF Caregivers

Participants, almost without exception, wanted information at and after diagnosis. They said they were either given no information on CF or were provided with cartoons directed at a pediatric audience. Few adult-focused materials were available, and nothing was available for those diagnosed as adults. “It seems there is not enough information for me to research on my own out there. I want to know about adult stuff,” said one man. A woman wanted directions on how to do chest percussion; she was given a booklet with illustrations of an infant.

Participants were not particularly interested in biomedical descriptions of CF, or even instructions on self-care. One man explained, “We need more on everyday stuff.” A woman lamented that her CF education involved “technical things” and “nothing about what life would be like.” Participants wanted information on longevity, treatment options, and research directions, information that would help them construct hope. “I want to know ... how not to think I am going to die soon so often,” explained a young man. Also, seeing themselves in educational materials helped participants accept having CF. A man diagnosed in his thirties recalled, “We started hitting the books and getting all the information we could about CF. And, um, very single thing about it pertained to me, except in a very mild extent.”

A number of those interviewed described medical insurance worries. Even as their health deteriorated, many had to continue working full-time so as not to lose medical coverage, an important concern in the United States where health care coverage is not universal nor certain for many. Some felt trapped in unsatisfying jobs because they feared that their pre-existing condition would prevent them from being covered by health insurance if they were to move. Others struggled to meet medical co-payments or to afford uncovered prescriptions. Some fought with health management organizations (HMOs), which refused specialized CF centre care, rejected requests for newer models of medical equipment, or denied home care as an option.

Participants expressed that they wanted to feel that their physicians knew them and cared about them. They valued personal relationships. One woman said, “I tell you, I don’t care how good the doctor is. If you don’t feel safe or you don’t like them, you won’t want to go back.” Another woman explained, “If I get sick between visits, I want to feel that [my doctors] care and are interested. It is very important to me.”

To an adult never before treated for a chronic disease, the prevalent clinic approach to CF treatment can seem more like being processed than being cared for. One man described a trial visit to a CF centre that offered adult care within a pediatric setting. “These CF factories, factories, they see 10, 20, 30 CF kids a day. They just bring them in and turn them out.” Instead, he opted to receive his care from a pulmonary specialist in private practice in his community. A woman commented that at her CF centre she felt “pushed aside and brushed through like cattle.”

Discussion

One goal of Widerman’s study was to learn about the phenomenon of adult diagnosis of CF so that caregivers could draw upon her findings to better understand and respond to their patients' experiences and needs. What she discovered (Widerman 2004) were similarities across stories that suggested 10 overarching themes, as well as themes influenced by gender and illness severity. Although each theme is presented and discussed individually, the authors want to stress that they must be appreciated as an interrelated cluster, each affecting and affected by the others. For example, individuals' needs to change their lifestyles to accommodate CF resulted in their experiencing CF as an intrusion that affected the time they had available to socialize, thus resulting in isolation.

Another goal of the Widerman study was to determine the extent to which prevalent themes in the chronic illness literature capture the experience of people diagnosed with CF as adults. Most of the themes in her research were similar to or subsumed by themes in the overview articles reviewed above, although they may have been articulated differently. We certainly see Conrad's (1987) themes of uncertainty, biographical work, family relations, and managing medical regimens in these stories of the men and women. We also see the relevance of Sidell's (1997) themes of uncertainty, coping, and development issues. However, some themes from this study (Widerman 2004) are not evident in the chronic illness literature, such as awareness of death, distraction, and normalizing. Thorne et al. (2002) pointed out that how a disease is experienced depends on the individual's personal characteristics and on the features unique to that illness. Thus, people with CF may be reflecting these factors in their descriptions of living with CF. The themes drawn from these stories illuminate the experiences, thoughts, and feelings of the 36 individuals interviewed. They can serve as guideposts for social workers working with people who have CF and perhaps other chronic illnesses, but each individual and his or her experience must be appreciated as unique.

Implications for Social Work

Themes describing experience, such as the 10 described in this chapter, not only help social workers understand what their clients are facing, but can suggest goals to explore with them. Figure 19.1 illustrates six challenges arising from the 10 themes: Staying Positive, Adapting to Change, Maintaining Normalcy, Dealing with Non-CF Life Issues, Fighting Loneliness and Isolation, and Managing Time. These are some examples; no doubt others could be formulated.

These themes and challenges illustrate that those who receive a diagnosis of CF as adults are as concerned about and affected by psychosocial issues as they are bio-medical ones, perhaps even more so. As a consequence, the social work role on CF teams is important and multifaceted. Brown, Krieg, and Belluck (1995) have recommended that CF team social workers help patients deal with the cumulative effects of a chronic illness and mobilize coping abilities. To do so, social workers must ask questions that will enable them to understand how CF is affecting individuals and elicit their own perspectives on their disease and its treatment. They must, as Sidell (1997) encouraged, adopt a client-centred approach.

Figure 19.1: Challenges Faced by Individuals Diagnosed with CF As Adults

- Staying positive
- Adapting to change
- Maintaining normalcy
- Dealing with non-CF life issues
- Fighting loneliness and isolation
- Managing time

The roles of social workers who provide services to patients who have CF must go beyond direct patient interaction and include intervention at the clinic level as well. They need to ensure that the CF team understands the impact of adult diagnosis and the challenges that these patients face over time. In addition, social workers must assess the extent to which CF centre routines and patient-provider interactional styles are responsive to individual patients' needs. Finally, CF social workers need to join with their medical colleagues to locate and/or create educational materials expressly for those diagnosed as adults.

The social work role in health care is both unique and critical. It is unique in that its focus is the individual who has a disease, not an individual's disease. It is critical because this focus positions the medical social worker as a bridge between the patient and the medical setting and between the medical setting and the patient's world. In assuming this position, social workers employ a person-in-environment perspective that allows them to understand the lives of individuals. When effective in this role, the medical social worker helps to meet institutional goals (e.g., to provide services efficiently and to provide medical and medically related treatment) and patient goals (e.g., to benefit from treatment and to have input into treatment). Given these multiple responsibilities, social work in health care settings can be a challenging field of practice, especially when working with young adults who have a serious, progressive disease like CF. Therefore, it's important for social workers to find ways to cope and avoid "burnout" (Coady, Kent, and Davis 1990).

Research that focuses on patients who experience one type of illness or condition can be enlightening. Rather than make explanatory assumptions, social workers can ask adult-diagnosed men and women to talk about their experiences and to let the CF team know how to best assist them. In doing so the social worker follows the cardinal social work principle, "Starting where the client is," and draws upon the value of client self-determination. Although the issue of CF illness experience was approached from a research perspective, other means to the same goal are available to social workers who cannot engage in practice research. Employing careful observation, sensitive assessment questions, and relationship-building skills can also lead to understanding individuals' experiences and needs, and to developing plans to meet them.

To understand the lived experiences of patients, social workers must listen and observe carefully, attending to tone of voice, body language, choice of words, emphasis, and sequencing of a story's elements. But, social workers must do more than just listen and observe. They must try to enter the life world of individuals in order to determine and understand the meanings that clients assign to their experiences, bringing with them their professional knowledge, values, and skills. Then they must step back and look for meanings in what they hear. Through using such a method, social work practitioners can identify common themes in the stories of their clients who face similar challenges and better understand how they can help them.

Reflection Questions

1. Re-read the case example describing Laura's experiences prior to, at, and following her adult diagnosis of CF. Which of the themes from the study are reflected in her story?
2. What aspects of Laura's current situation, if any, might interfere with her ability to adhere to or to benefit from recommended treatment? If you were her social worker, where would you start?

3. How can findings from a research study, such as the one described in this chapter, be helpful to social workers working with adult-diagnosed individuals with CF?
4. Is your approach to practice focused on gathering stories and finding themes similar to what is described in this chapter? If so, in what ways? If not, how might you adapt a thematic approach (one that draws from issues common to many facing the same condition) to your work with clients?
5. What limitations or constraints can you identify in an approach such as the one described in this chapter (focusing on stories and their analysis)? Can they be overcome in the health care setting you know and, if so, how?

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CHAPTER 20

APPLYING A STRENGTHS PERSPECTIVE WITH BURN SURVIVORS:

Resiliency and Adaptation to Trauma

Nancy R. Williams and Maureen Davey

Introduction

> He is probably the only reason that I am still here. He doesn't whine and he tells me the truth. He really does look out for me. He started to get emotional when I told him that I was "finished." He doesn't pass judgment on me. He doesn't make me right or wrong. He weighs everything I say, and then gives it back to me, and re-words it, and gives it back to me so that I can see where the gaps are, and then allows me to be a part of the plan. (Joe,[1] age 44, burn survivor, describing his therapist)

No one knows better than a person who has suffered a serious thermal injury, a burn, how much one moment can forever change an individual's life. Joe's story is a familiar one in the burn survivor community. As a former emergency medical technician, Joe was an ambulance driver for 22 years before he was injured when an oxygen cylinder he was working on blew up. Drawing on his training, his first thoughts were for the safety of others. Thus, he did not "stop, drop, and roll" as he was taught to do because he was on fire. Since there were other cylinders around him in a populated area, he walked to a vacant spot to douse the flames. Still in his professional role, inside the ambulance and strapped onto a stretcher, he dictated his own treatment on the way to the hospital.

While a true hero to his co-workers, Joe lost more than physical abilities the day his life was changed by fire. He lost his identity, his life's work, his community, and his reason for being. To the burn unit staff, Joe was the patient they fought to save; to his former co-workers and family, Joe changed from someone to be honoured into someone to be avoided. He made others feel uncomfortable because grief and rage poured out of him. To himself he was nothing, no longer the "ambulance guy," the person who rescued other people. It was with a professional helper, however, that Joe, after a serious suicide attempt, began to rebuild a sense of self-worth that allowed him to create a context for all that he had lost, giving him his first motivation to live (Williams, Davey, and Klock-Powell 2003).

Survivors of severe burn injuries have much to teach helping professionals about adaptation to extreme trauma, the process of recovery, and factors related to resiliency. As the human services field shifts to a focus on strengths and assets models of practice, there is an increased emphasis on the study of resiliency, generally defined as the ability to transcend adverse life circumstances (Walsh 1998). Burn survivors are forced to confront overwhelming challenges as they adapt to their injuries. Although a serious thermal injury itself is difficult to endure, burn survivors also have a long path of emotional recovery ahead of them. They face not only a painful and extensive physical recovery process, but must also cope with losses in personal relationships, lifestyle, occupation, and personal identity. These changes can be compounded by incurred social stigma if they have a disfiguring injury resulting in self-esteem issues, even if the injury is hidden from public view (Carter and Petro 1998).

In Joe's case, the losses that he suffered as a result of his burn injuries left him with a sense of hopelessness that brought him to the brink of suicide. It was the relationship that he shared with a helping professional that ultimately helped him to "hang on." What can be read between the lines was his need to regain a sense of control, self-esteem, and a sense of hope. For a man like Joe, whose main identity was derived from his professional life, the fact that his enormous emotional pain could be tolerated and that he could feel safe was important. Being heard by a compassionate professional, while being held accountable for his behaviours, launched a turning point in Joe's life. An important aspect of this helping relationship was the genuine sense of caring Joe experienced. He really felt that he mattered and that he would be missed even in his current state of self-perceived worthlessness.

The purpose of this chapter is to address the processes that affect burn survivors in their recovery and the role that helping professionals, particularly social workers, can play in supporting a burn survivor through the processes of adaptation to their trauma. Drawing from interviews with adult burn survivors who describe what the experience was like for them, what they needed, what helped, what their challenges were, and from the extant literature on burn injuries, this chapter will address the following issues:

1. The processes involved in recovering from a severe burn injury
2. The personal and environmental factors that influence survivors' recovery process
3. The role that social workers can play in the recovery process

The Burn Experience

A serious burn is one of the most devastating physical traumas a person can experience. According to the American Burn Association (2002), there are over a million burn injuries per year in the U.S. alone. Forty percent of burn-injured children have injuries that require hospitalization (American Academy of Pediatrics 2000). Additionally, 3 percent of burn-injured children are affected by massive burns, defined as burns involving more than 70 percent of their body surface depth (American Academy of Pediatrics 2000). Injury to the skin can occur in a multitude of ways, including direct exposure to fire, caustic chemicals, electricity, or flesh-destroying diseases. Exposure can be accidental or intentional, including self-inflicted immolation or through an act of aggression. Despite the differences in causation, Thornton and Battistel (2001) indicate, however, that all burn survivors share similar stages in the early physical recovery process:

> Burn survivors often face overwhelming issues of adjustment and multiple stresses during the recovery process. These issues may confront them for the duration of their lives. Treatment may be prolonged and painful, perhaps involving years of re-hospitalization, skin grafting, plastic and re-constructive surgery. Their scars are often visible and disfiguring, their emotions are psychologically painful, and the burn event may be re-lived in flash-backs, dreams and nightmares. All burn patients face the task of adapting to survival with

> fear of disfigurement, physical pain and prolonged convalescence. (Thornton and Battistel 2001, p. 93)

One of the inevitable outcomes of deep thermal injuries is the scarring of the body. The severity of a thermal injury is determined by the percentage of total body surface area burned (TBSA), the depth of the burn, and the amount of time that the skin was exposed to the burning agent (Patterson, Everett, Bombardier, Questad, Lee, and Marvin 1993). For many, burn injuries and the scarring that often results, conjure up images of deformed monsters in the horror movie genre (Carter and Petro 1998). Although there are numerous losses faced by those who survive burns, the physical scarring that often occurs can affect people's self-image and their process of recovery. Health care providers have been known to reflect this attitude by assuming that burn victims with impaired appearances will experience serious psychological problems for much of their lives (Patterson and Goldberg 1994). Dire predictions have been made in the psychological community regarding the "psychological morbidity," of the psychological recovery of a burn survivor. One researcher cites estimates that "at least 30–40% of burn patients will suffer from marked and persistent psychological disorders" (Tarrier 1995). Pre-burn personality issues have also been addressed as obstacles in healing; burn survivors were commonly thought to have personality characteristics or psychiatric conditions that made them more vulnerable to being burned in the first place (Tarrier 1995). This was the prevalent thinking in the 1970s and 1980s. In addition to the physical challenges, Bernstein (1988) describes the social process of disfigurement, particularly the social isolation that can occur: "We have come to recognize the demoralization, the loss of social network, the loneliness, and the bereavement that accompanies much disfigurement. There is a sense of 'going it alone'" (p. 5). The term "social death" (McGregor 1982) was coined to describe the effects of disfigurement that burn survivors experience.

Tarrier (1995) suggests that the pre-burn cognitive style of the survivor may determine the way they integrate and interpret their current circumstances. Other individual factors that can influence recovery are: age when burned, gender of the burn survivor, ethno-cultural background, social class, body image, and pre-burn issues such as quality of life both at work and at home (Bernstein 1985; Patterson et al. 1993; Fauerbach, Heinberg, Lawrence, Bryant, Richter, and Spence 2002).

The type of injury and length of recovery are factors that affect how burn survivors adapt and recover. Also important are the quality of social supports at home and in the community, impact on family roles, community response to the burn (for example, reactions to scarring), and body image issues (Doctor 1992). Despite the obstacles facing a burn survivor, there are indicators that many individuals with severe burns adjust to their changed situation (Patterson et al. 1993). Holaday and McPhearson, based on their study results, assert, "According to the burn survivors, everyone has the gift of resilience within themselves" (1997, p. 355). They call for health care professionals, particularly those in counselling roles, to pay attention to a survivor's strengths, "rather than focusing our energies on pathology and weakness, we should be looking for ways to enhance resilience" (p. 355).

We view resiliency not as an end product but as an ongoing process of development and adaptation. The concepts of adaptation and resiliency are used to imply a process of recovery that is individually determined and unique to each survivor of trauma. As discussed in this chapter, survivors of severe burn injuries have much to teach us about adaptation to extreme trauma, the process of recovery, and intrapersonal and interpersonal factors related to resiliency.

Stages of Burn Recovery

Burn survivors often are pulled back, literally, from death's door and are surviving today when they would have died from similar injuries in the recent past. Seriously burned patients may linger precariously on the edge between life and death for days and sometimes weeks. Pain is an inevitable by-product of a burn injury. Mercifully, patients are typically kept in a coma-induced state while the body tackles regeneration and a life-saving treatment called "debriding" is conducted. This treatment involves scraping away the dead skin to allow the body to breathe, which, while necessary, has been described by survivors as excruciatingly painful. While physical pain may be difficult to describe in words that adequately capture its experienced intensity, the life of a burn survivor early in the recovery process is focused equally on sheer survival and pain management. Burn survivors, like all victims of loss and trauma, undergo a process of recovery that allows them to incrementally adapt to the reality of their situation. Watkins, Cook, May, and Still (1992) delineate seven identifiable stages in the early burn recovery process that include: (1) survival anxiety; (2) pain problems;

(3) a search for meaning; (4) investment in recuperation; (5) acceptance of losses; (6) investment in rehabilitation; and (7) reintegration of identity.

Sometimes the burn survivor may have to deal with the issue of survival when someone close to them, or other accident victims, or even a potential rescuer has died. The term "survival guilt," coined in the 1950s to address Holocaust survivors' guilt, may be an issue. In the aftermath of the September 11, 2001, tragedy in the United States, this concept is particularly relevant. It speaks to the core of spiritual understanding that begs the question, "Why did I live?" and further down the road, "What for?" When bad things happen to people, they frequently ask themselves why a particular event had to happen to them. Existential questioning is the norm as patients attempt to acknowledge the enormity of their situation. Viktor Frankl, a psychiatrist who was himself a survivor of extreme trauma as a concentration camp survivor in World War II, notes this phenomenon in his classic work, *Man's Search for Meaning* (1959). He described treating more than 3,000 clients by purposefully "forgetting" everything he learned from psychology. Instead, he focused on listening to his patients and learning from them and, as a result, he began to uncover their unique ways of finding a way out of their suffering. This experience created the foundation of Frankl's approach, which he named "logotherapy," in which people discover their own possibilities as they explore actual and universal meanings in their experiences.

Post-traumatic Stress Syndrome

Post-traumatic stress disorder (PTSD) involves a cluster of symptoms following exposure to an extreme traumatic event where intense fear, helplessness, or horror has been experienced (American Psychiatric Association 1994). A key element of PTSD is the process of reliving the experience through recurrent and intrusive memories of the event, resulting in extreme psychological distress. This disorder was first officially recognized in 1980 when it was included in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association). Burn survivors often experience flashbacks, a re-experiencing of the trauma as if it were occurring in the present. Fireplaces, bolts of lightning, and even fire crackers are common fear triggers for flashbacks among burn survivors. There are indications that some burn survivors suffer from the symptoms of PTSD years after the event (Fauerbach, Heinberg, Lawrence, Munster, Palombo, and Richter 1999). Therefore, working through the trauma and any symptoms of PTSD are especially important with this population of patients.

The Grief Process

Grief is a natural emotional, physical, and cognitive expression in reaction to a loss or trauma. Dealing with the grief that comes with the aftermath of a severe burn injury is crucial as the survivor is inundated with massive and sustained losses that include loss of function, loss of relationships, loss of identity, loss of control, and often loss of vocation and all that is associated with one's work. The act of "bearing witness" to another's pain is as potent as it is natural, but can be overlooked in a practitioner's zeal to help a survivor move forward.

The stages of grief work with adults are moderated by whether the traumatic event was expected or unexpected. If an event was expected or anticipated, then the effects of the event are reduced because adults are able to mobilize their internal, endogenous resources to defend against the shock of the incident. Each individual manifests his or her grief differently based on the circumstances, background, and history. The social worker must be able to understand the unique dynamics involved in traumatic grief and respect the power of "bearing witness" to the individual's story in finding healing for the enormous losses and adjustments that burn survivors face.

Children interpret the world and communicate about their feelings differently from adults (Howard, Dryden, and Johnson 1999). Researchers consistently report that social support is a strong predictor of emotional adjustment in children who have survived burn injuries (Barnum, Snyder, Rapoff, Mani, and Thompson 1998; Blakeney and Robert 1998; Holaday and McPhearson 1997). Social support has been linked to developing a positive body image, greater self-esteem, and less depression in the burn-injured population (Orr, Reznikoff, and Smith 1989). In fact, social support has been deemed critical to overall adjustment (Pruzinski and Doctor 1994). In a recent study of long-term outcomes of children treated for massive burns (Sheridan, Hinson, Liang, and Nackal 2000), it was found that the quality of life of burn survivors was no different from that of other young people. "Hope," a positive psychosocial outcome, seen as related to social support, was reported to be a powerful antidote among children who experienced psychological and physical scars as a result of a burn injury (Barnum et al. 1998). Thus, it is imperative that intervention strategies reflect the fact that children's response to grief and loss will vary depending on stage of development, past experiences with grief and loss, the influence of the family's handling of loss, and peer acceptance.

The Role of Spirituality in the Healing Process

Spirituality has been described as a striving for meaning and union with the universe and all things; it extends to experiencing power beyond the individual that is intrinsic to human nature (Smith 1995). For some burn survivors, spirituality has been a key factor in their ability to transcend their difficult circumstances, providing comfort and nurturance at a time of suffering and great change in their lives (Williams et al. 2003). Spiritual wellness has been defined as "a continuing search for meaning and purpose in life; an appreciation for depth of life, the expanse of the universe, and natural forces which operate; a personal belief system" (Myers 1990, p. 11). Burn survivors have the opportunity, like others who have faced near-death experiences, to utilize their experience as a catalyst for spiritual growth. The spiritual dimension provides a framework for hope and is an important resource in helping survivors make sense of the events of their lives and allows them to recreate a new one. Ganje-Fling and McCarthy (1996) describe the functions of spirituality in the lives of trauma survivors as follows:

- to help a person understand or deal with what is unknown or uncertain
- to provide hope and reassurance, especially in the face of uncertainty or distress
- to address and meet important personal needs
- to provide connection with others

The Family System

It is essential to consider the burn survivor in the context of his or her family environment and community. According to family systems theory (Bowen 1978), the condition of one family member influences the condition of other family members. The family represents a set of interdependent units that continuously maintain a dynamic level of functioning that balances both constancy and responsiveness.

Systems theory also states that all subsystems (parental, marital, child, and sibling) interact and influence each other, and that this systemic interaction determines the level of psychosocial functioning and well-being of family members (Issel, Ersek, and Lewis 1990). The concept of “family” needs also to include those persons who are not related by blood or marriage, but are people who are perceived by the burn survivor to be very close to them (e.g., a trusted, life-long friend). Sometimes these people may actually be more essential or important in the burn survivor’s life than kin.

All burn survivors are embedded within a family system that needs to accept, adjust, and cope with changes that occur as the result of a burn injury (Bernstein 1988). When a member of the family is severely burned, all family members are affected by the burn injury. Emotional processes such as guilt, resentment, shame, a sense of helplessness, and grief are often intermingled with the formidable tasks of adaptation to the physical realities of the survivor and financial and time constraint pressures on family members. Paying close attention to the burn survivor’s familial context is, therefore, important because just as the individual needs to recover, so too do the survivor’s family and friends in the community.

According to Frank (1995), people make sense of an illness by casting it in a narrative form. Virtually every known culture has a version of the storytelling process that teaches through example and helps people make meaning of experiences. Although people who have been severely burned may have similar physical injuries, how they and their families (and significant others) understand these injuries in the context of their lives and the many factors that shape the experience for them can influence their adaptation. Many have described the process of converting their difficult life experience into a narrative as a primary way for people to make meaning of what has occurred (Bruner 1990; Mishler 1986). Reissman (1993) claims that this is especially true when people are dealing with the impact of trauma because the telling of narratives “opens up the forms of telling about experience, not simply the content to which language refers” (p. 2).

Narratives provide a way of understanding emotional experiences, not just activities and they “offer insights into understanding how people cope with traumatic events in individualistic ways” (Rossiter 1999, p. 82). A social-constructivist approach in which stories of survivors of trauma are used to understand the processes of recovery and resiliency can be particularly informative (Markward 1997). An approach to therapy that makes use of narrative seems to be a good fit for burn survivors and their families as they are reconstructing their life stories during the recovery process (Frank 1995). Such an approach also enables and justifies a strengths-based orientation approach to practice in which the family system's unique coping process is viewed in context (Bachay and Cingel 1999).

The Role of the Social Worker

Physical recovery is just one aspect of the battle for survival. With the massive job of physical recuperation and multiple reconstructive surgeries, less emphasis is typically placed on the potentially healing role of effective listening. According to Williams, Davey, and Klock-Powell (2003), the social isolation and loneliness of the survivors' experience, the need to be listened to, is a huge challenge. It is a need to be heard, to have someone listen to stories of painful losses and feelings of rage and grief, while knowing that the listener still believes in the survivor's capacity for resilience. However, the emphasis in Western medicine is on "fixing problems" rather than tolerating a patient's experience of pain that cannot easily be fixed, especially relevant for burn survivors. Frank (1995) describes the process of "bearing witness" to suffering as being a healing gift in itself because a major source of suffering is the real sense of loneliness and isolation that accompanies it. Therapeutic empathy from a social-constructionist position has been defined as "a relational process, a step-by-step co-construction by counselor and client of the life-narrative of the client" (McLeod 1999, p. 377). The concept of empathy is a key construct in the therapeutic relationship and particularly relevant when engaged in the process of active listening (Mahrer 1996).

Social Work and Burn Recovery

Social workers in medical settings often are responsible for specific case-management tasks, including discharge planning and coordination of services, in their work with patients recovering from severe burns (Horejsi 1987; Thornton and Battistel 2001). The social work profession's emphasis on empowerment and a strengths-based focus seems to be particularly well suited for working with a population whose members often feel stripped of their former selves. Social workers are taught early in their practice training about the importance of the therapeutic relationship and the utilization of this relationship as a healing tool. They can, therefore, play an active role in helping burn survivors and their families navigate through the often long, arduous, and complex recovery process.

An ecological perspective views trauma as a transaction between a human being and his or her environment, characterized by the interaction of an event and the context of larger social forces. This theoretical perspective, adopted by many social workers, is helpful in understanding the complex relationship between people and their environments, and helps the worker comprehend the traumatic event and appreciate the survivor's capacity, within a unique environmental context, to overcome the impact of adversity.

Social work professionals are ideally positioned to negotiate the complex terrain for those directly and indirectly affected by a traumatic event such as a serious burn injury. Application of a generalist framework with a strengths-based approach to practice and embracing the values of self-determination and empowerment are useful. As Miley, O'Melia, and DuBois (1998) affirm, when working with trauma survivors it must be acknowledged that there is no one way to deal with issues. Indeed, those who survive trauma draw from the strengths they have developed themselves to survive and cope. Social workers, taught to draw from a multidimensional theory base in their generalist training and to focus on developing professional skills on multiple levels, are uniquely equipped to better understand the impact of the burn experience in its myriad forms and to support the survivor in his or her required feats of resiliency in the aftermath of the trauma. Questioning one's reason for surviving and seeking meaning and purpose in one's life after the burn injury are important for recovery from trauma (Janoff-Bulman 1992). When viewed in the context of the loss and pain that burn survivors experience, it is understandable, predictable, and appropriate for them to struggle on many levels. Fear, grief, and anger must be seen as normal rather than pathological or dysfunctional.

Case Situation: Sharon's Story[2]

Part One: The Accident

Sharon was a happily married 42-year-old mother of two who awoke in flames from a fire cause by faulty wiring in her electric blanket. Her husband, Ken, was out of town on business at the time and her two children were asleep on another floor of the house. Sharon vaguely remembers putting the flames out from her own burning hair with wet towels from the bathroom and then proceeding to squelch the fire, saving her home and the lives of her children. She even had the presence of mind to call 911 [emergency help number] before collapsing. Sharon was rescued by the firefighters and paramedics who responded to the call.

Prior to the accident, Sharon had a successful job as a hairdresser that she combined with raising two daughters (one from her first marriage) with Ken, her second husband. Sharon was active in the community and had a large group of friends and close relationships with co-workers.

She derived particular enjoyment from singing in her church choir, where she was often a soloist.

Part Two: The Recovery Process

Sharon recalled little of the first six weeks of her recovery as she was immediately placed in an induced coma, where she remained for the first month. Her burn injuries were severe and included third-degree burns to her scalp, ears, neck, and hands and second-degree burns on her torso and face. She remained in the hospital for three months. Sharon's husband, an insurance salesman, spent as much time as he could at the hospital, but needed to resume work to deal with mounting financial pressures and to provide for the care for their eight-year-old daughter, Cindy. Ken's stepdaughter, Anna, went to live with her paternal grandmother.

Sharon described those early recovery months as a blur and recalls some of the physical pain as she was confronted with difficult physical realities that included severe impairment in both hands, making a return to her former occupation as a hairdresser highly unlikely.

Challenges in Recovery

While Sharon had a strong family support system, family members and friends seemed to feel awkward and uncomfortable about how to talk to her. Sharon was the third of seven siblings. Many lived out of town and had difficulty dealing with Sharon's altered appearance. They were fearful also of the impact of the news of their sister's situation on their elderly, widowed mother who lived in a nursing home. Ultimately, they opted not to tell her. She died a few years later without ever having known of Sharon's injuries.

Sharon, whose occupation was making other women look beautiful, had always been praised for her own physical attractiveness. She had been particularly proud of her glossy, long brown hair. Her hair had been completely burned off in the fire and she was to learn that her scalp was so deeply burned that her hair follicles had been destroyed. She would never again be able to grow hair on her head and, in fact, the damage was so severe that she required massive reconstructive surgeries on her scalp in an attempt to close up the wounds. As Sharon struggled to adjust to intensive physical limitations, she also had to confront her feelings of horror about what she now looked like and the apparent discomfort of her friends and family.

Sharon's friends and former co-workers seemed to be at a loss as to what to say to her and often wanted to change the subject in their attempts to "cheer her up." Sharon was also aware of the stress her husband was under and was concerned about shielding him from her despair and fear. Likewise, the former physical intimacy that she had enjoyed with her husband was completely altered. The reality was that in the early stages of recovery, Sharon could not bear to be touched because of the pain. She also worried about her children, recognizing that Cindy and Anna were frightened and displaced, now living in different places. She was aware that she could not offer her daughters the comfort and reassurance that she knew they needed. One of the darker moments in this experience came when she saw the fear in her younger daughter's eyes when she first saw her mother after the accident.

As Sharon faced what became years of multiple reconstructive surgeries, financial demands and challenges, loss of her former livelihood and career, awkward reactions from family and friends, and a strained marital relationship, she went through many emotional ups and downs. Sharon experienced many moments of rage and intense emotion with crying spells and deep feelings of depression when it seemed that all was lost. She also felt guilt for the burden that she was placing on her family and a pervasive sense of worthlessness, both as a woman and as someone who could contribute to society. What she yearned for, she reported, aside from waking up from this nightmare with her former life intact, was someone who could listen to her, who could understand what she was going through, yet believe that what she was feeling, what she now looked like, and what she now was incapable of doing did not define who she really was as a person. She needed someone who could hear and understand her pain while believing in her potential.

Part Three: Life Goes On

Seven years later, as Sharon sat poised in an interview, she radiated a serenity and beauty that belied the trauma of the massive scars that were visible. She no longer had the use of her hands. Her ears were in the process of being reconstructed and were not fully complete and she had recently decided to give up the wig that covered the bald areas and still-open wounds on her scalp. How is it possible that a woman who had suffered so intensely and lost so much could radiate such inner peace and, yes, beauty?

Sharon talked about her gains through the accident and spoke, even with gratitude, for what she has received through such a tragedy. She described, with apparent pride, her new role as choir director at her church and the gains that she made in realizing her self-worth in terms of who she is rather than what she looks like. Small victories took on huge meaning as she learned to appreciate her accomplishments as a survivor. Sharon felt strongly about giving back to others and had begun a local chapter of a burn-support group. She recognized that her recovery is a continuing process, that she still has her "down days," and that she is still working with the aftermath of the accident and its impact on her family, particularly her daughters.

Today, flashbacks still plague her and she often wakes in the night, drenched in perspiration, screaming out in her sleep. But she also says that the fire has brought her more than it has taken away, has made her aware of the fragility and preciousness of life, and allowed her to discover her strengths in new ways. Sharon attributes much of her ability to survive and thrive, despite this trauma, to her spiritual faith, the skill and empathy of several helping professionals who supported her through the years, and the kindness and support of her community. She is, in fact, making plans to return to school to become a social worker.

Clinical Implications

Social workers and other clinicians can play a key role in helping burn survivors navigate the challenging adjustments and transitions into which they have been thrown. Several key factors are important in the assessment and treatment process: (1) addressing contextual determinants influencing burn survivors such as their constructed memory of the pre-burn past, especially as it relates to their perceived losses in life; (2) assessing their current stage of recovery and their life-cycle stage at the time the injury occurred; (3) evaluating family and other relationship supports and the impact that family members' coping processes can have on the burn survivors' own recovery, including self-esteem; and (4) exploring whether and how the loss of occupational roles affected survivors' sense of self-worth.

Holaday and McPhearson (1997) claim that burn survivors share similar coping mechanisms and factors that can influence resiliency. Depression appears to be a common response in the recovery process. Helping professionals can assist burn survivors by understanding, validating, and accepting this process of feeling sad and mourning the loss of their perceived old self before the burn injury. It is also important for professionals to understand the powerful role that spirituality plays for those burn survivors who embrace it and to support its use in the healing process. Promoting and encouraging clients who have survived burns to develop new friendships, for example, by reaching out to other burn survivors, can also be of benefit. It is essential for the social worker to support these processes and to recognize the need to mourn the old self before the reconstruction of a new self can occur. Recovery can be enhanced by support from peer groups, family members, and specific organizations that focus on building community by normalizing the experience, such as the Phoenix Society for Burn Survivors: www.phoenix-society.org), which represents burn survivors worldwide. The Internet has also been an important source of linkage for people, and burn survivors can access support as well as information within easy reach of their homes: www.burnsurvivorsonline.com).

Another factor to consider in social work treatment of burn survivors is the importance of the survivor's developmental stage. For example, when treating toddlers or children who have been burned, it is important to include family intervention in order to help the family deal with potential guilt issues, including not having been available to supervise and to prevent the burn accident. It is also essential to help the child to feel like other children and prevent parents from overprotecting the child who is recovering from burns. Other siblings might be jealous as the child in recovery receives more attention from parents and family. There are now "burn camps" for families as well as children. These are safe places where children can feel connected to others who have also been burned. Camps for burn-injured children have emerged over the last 20 years to address needs in this population for social support in a safe, normalizing, and activity-focused environment. There are over

40 camps in the U.S. today; they are also available in Canada, Europe, Australia, and New Zealand. Social workers can provide psychoeducational support to these families by providing information about useful resources that can be consulted in their local communities.

Most important, however, skilled helpers are needed to listen without pity and to tolerate stories of indescribable loss, as they can provide needed support during a long grief process. By sharing their stories, burn survivors can simultaneously make sense of the enormity of their experience while allowing others to witness the reality of their ordeal. The healing power in the act of simply listening seems to be significant in alleviating suffering that comes with the loneliness and isolation involved in the long burn-recovery process. Mental health care providers such as social workers are well suited to play this important role in the ongoing recovery process of burn survivors.

Conclusion

Burn-injured people are confronted with enormous challenges in their recovery process at physical, emotional, psychological, and spiritual levels. Resilience is an adaptive outcome in response to a crisis or some other form of stress. Different constellations of protective factors (both within the individual and in relational contexts) can serve as possible buffers for individuals who, like burn survivors, are exposed to trauma. Current research on resiliency has shifted from an initial focus on the successful adjustment of children and adults under "the threat of disadvantage and adversity" toward one in which resilience is seen as a "common phenomenon that results, in most cases, from the operation of basic human adaptational systems" (Masten 2001, p. 227). Implied in this perspective is a belief in the inherent capacity for healing and positive growth in the human experience and resiliency as an innate quality (Benard 1996). Similarly, burn survivors are a population of patients who have the capacity to be resilient by accepting, adapting, and rewriting their life narratives. Social workers and other helping professionals' ability to bear witness to this long journey of recovery and rewriting can provide invaluable support to both adults and children who have been severely burned.

Reflection Questions

1. What is your personal definition of resiliency?
2. What might prevent a social worker from being effective with people who survive burns?
3. What are the unique challenges of working with this population?
4. How is grief a complex issue for burn survivors and which areas of life do you think it most affects? (It will help you to identify a client with whom you have worked and to consider this question as if he or she were a burn survivor who is now recovering at home.)
5. How does the social worker's personal attitude toward appearance and comfort level with emotional and physical pain help or hinder the recovery process of a client?
6. What roles can hospital-based social workers play when working over a long term with a firefighter who has been seriously burned?

Notes

1. "Joe" is a fictitious name.
2. "Sharon" is a fictitious name.

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CHAPTER 21

"A PARTICULAR LOVE; A DOUBLE HURT": Learning from a Grandparent Bereavement Support Group

Deanna Angelico and Jane Sullivan

> There is a different bond with that child that only grandparents and the grandchild understand. Where does that particular love go that was meant to be shared with that child? (Grandparent Bereavement Support Group member)

Introduction

The grief that results from a child's death affects all family members in profound, continuing ways. Family and societal expectations are disturbed by the assault to the natural order of life's rhythms. In particular, it is never expected that a grandparent will live longer than a grandchild. Drawing on our work in accompanying bereaved parents, siblings, and the extended families, together with our clinical experience within a pediatric hospital, we recognized the unique needs of bereaved grandparents. As an initial response to these needs and a way of gaining further insight about their grief, a single session group was initiated to provide support for bereaved grandparents.

This chapter explores the development, nature, impact, and evaluation of an inaugural grandparent bereavement support group conducted by our Social Work Department's Family Bereavement Support Program (FBSP). Reflected throughout are the bereaved grandparents' experiences and wisdom. Practice insights from our learning, which may be of benefit to other social workers, are also discussed.

Social Work and Bereavement Support with Families in a Pediatric Hospital

Traditionally, social work practice and service development identify and respond to clients' needs within an ecological framework (Germain 1991). Within an acute care tertiary pediatric hospital, social work practice incorporates this framework through interventions, which focus on patients (or clients) in their bio-psychosocial contexts. In this setting the social worker's client is both the patient and his or her family. Accordingly, this perspective encompasses the child or young person, parents, siblings, grandparents, and extended family members as they encounter issues related to health and illness, treatment and adjustment, and survival and death. Social work practice also integrates an understanding of a family's social and community networks as resources or hindrances as the family responds to these experiences. Additionally, social work practice is heavily influenced by its organizational context and mission.

Our social work services accompany the family throughout the illness trajectory, including at times of palliation and death. This is encompassed in what we consider to be social work's professional and moral responsibility "to humanize the care of the dying and bereaved" (Davidson and Foster 1995 p. 12). Ongoing bereavement support is an essential element of social work's commitment to continuity of care. Davidson and Foster (1995) also argue that "Social work expertise in dying and bereavement helps to promote patient satisfaction and a seamless continuum of care from diagnosis through acute care to chronic and hospice care" (p. 13). In our work with bereaved families we observed that for some, an ongoing connection to the Royal Children's Hospital remains significant, while for others the hospital holds less meaning or has too many difficult connotations for them.

Initiatives in the Bereavement Program have developed from an integration of clinical experience, theoretical knowledge, and client requests.[1]

Review of Selected Literature

The literature on grief, grandparents, and support groups, reflects significant concepts, theories, and themes. The death of a child leaves an enduring grief for all family members (Kissane 2000; McKissock 1998; Ponzetti and Johnson 1991; Raphael 1982; Worden 1987). As

Moffitt (2001) asserts, the death of a child is "devastating not only for parents, but other close relatives" (p. 152). Family members are affected in unique ways, which are influenced by several factors, including their relationship with the child prior to the death (Ponzetti 1992), the meaning and understanding of the death, the mourner's personality, coping strategies, previous experiences of loss and supports, and resources available (Worden 1987). Ponzetti (1992) found that most research "has dealt with the bereaved person as an individual and ignored the context in which the person grieves" (p. 63). As clinicians, we integrate the principles of social work practice based on its theoretical underpinnings and individual assessment in order to understand the quality, dynamics, and meaning of grief within the family. In considering grandparents' grief, Ponzetti and Johnson (1991) found that the experience of bereavement for grandparents was different from that of parents. Grandparents' isolation is noted in some literature. Gyulay (1975), for example, stated that "grandparents are often more alone than any other person in the grief process" (p. 1478).

Grandparents occupy particular and at times complex roles in families. Historically, the description of grandparents may conjure up many images and stereotypes such as retired, knowledgeable, elderly, or frail. However the contemporary grandparent does not always fit these descriptions (Burns and Madian 1992; Germain 1991). Nussbaum and Bettini (1994) explain that, within the family, "grandparents' function in their grandchildren's development is taking on an increased importance" (p. 68) and the "diversity of the grandparent role has not been fully explored" (Nussbaum and Bettini 1994, p. 68). As with any family, relationship assumptions cannot be made about the nature and quality of members' connections.

The grandparent's age, personality, geographical distance from the family and frequency of contact does not always equate with the meaning or quality of the relationship with his or her grandchild and the family. The form and significance of relationships are varied. Family history and dynamics shape the nature of relationships and interactions. For some grandparents there may be a strong emotional bond. As Nussbaum and Bettini (1994) point out, "grandparents typically report having strong attachments to their grandchildren" (p. 69). Some are actively involved in the care, support, and encouragement of grandchildren. Relationships may be constant and mutually enjoyable. Alternatively, there may be little psychological involvement or social contact. There may also be differences in the practical assistance that grandparents offer to families. Some grandparents are almost always available to families, while others have no role at any time. A family crisis may precipitate a grandparent's involvement, which may ordinarily be limited. The need for sensitive familiar support is amplified when a family is in the midst of a crisis such as bereavement (Kissane 2000; Raphael 1982).

Reed (2000) found little literature for bereaved grandparents and supports further exploration in this area. There are, however, recurring themes in the literature. One is that the grief of grandparents following the death of a grandchild has been largely unrecognized. They have been the "forgotten mourners" (Gyulay 1975). Their grief is "disenfranchised" (Doka 1989, p. 4), unnamed, unacknowledged, and unsupported. Burns and Madian (1992) described grandparents as "highly concerned, often overwhelmed and overlooked family members" (p. 18). Commonly their experience of loss is unseen and unheard in the private world of the family or in the public domain. As Reed (2000) described, "many would deny me my grief" (p. 18).

Another frequently discussed characteristic of grandparent bereavement is the experience of "double hurt" (Moffitt 2001; Reed 2000). Reed's (2000) research confirmed that "grandparents suffer a dual loss when a grandchild dies" (p. 25). Grandparents reported that they were grieving for the parent and for their grandchild. Others described the grief as being "three-fold": for the grandchild, their son or daughter, and for themselves (Gyulay 1975; Ponzetti and Johnson 1991). Grandparents are also often caregivers, placing the needs of others ahead of their own. Grandparents frequently act as a support to their children and surviving grandchildren (Ponzetti 1992). Even though they may need support, they may not feel that they can share their feelings with their adult children "because they did not want to add to the parents' burden" (Burns and Madian 1992, p. 18).

The death of their partners, peers, or even themselves could be anticipated in the grandparent cohort life stage. The widely held assumption of the life cycle is that children should outlive their grandparents and parents. A grandparent who survives a grandchild can evoke a myriad of confusing and distressing feelings and responses. As Reed (2000) described, "… death, out of the natural order of life, brought grief, confusion and anger" (p. v). It can be seen as "unfair … unnatural" (Ponzetti and Johnson 1991, p. 157). Rando (1985) explained that the "unnaturalness" is understood by the order of the death as being "out of turn" (p. 20). "Survivor guilt" can be a feature of the grandparents' grief as they, along with other adults, struggle to find meaning in the death of a child (Ponzetti 1992; Reed 2000).

Their age and life experience place on the grandparents the expectation that they will have wisdom and authority to comprehend and explain life events. Others may "think they should cope better, have all the answers, control the situation, and be an example" (Gyulay 1975, p. 1478). They can be seen as role models for the family (Reed 2000). Despite these assumptions, Ponzetti (1992) suggested that "age does not appear to make the expression of grief or bereavement any easier" (p. 64).

Some observations about the effect of gender were noted in the literature. Hockey (1997) discussed the impact of social conditioning in traditional sex roles, with males conditioned not to express their feelings and females' comfort in expressing grief. Females are, however, less able to express feelings of anger. Ponzetti (1992) added, "… that mothers and grandmothers … talk about the child more than fathers and grandfathers follows from traditional gender role socialisation" (p. 68). Nussbaum and Bettini (1994) pointed out that the connection between grandparents and grandchildren is influenced by gender, with grandfathers tending to be more involved with grandsons and grandmothers with granddaughters. Ponzetti and Johnson (1991) found that grandfathers were less likely "to report feeling numbness, shock or disbelief than grandmothers … [while] grandmothers were more likely to report physical symptoms … [and a] greater desire to talk about the deceased grandchild" (pp. 162–163). However, the authors did not find any differences between feelings of grandmothers and those of grandfathers with regard to helplessness, anger, or understanding the meaning of the death. When exploring the nature of the relationship, they also found that there were "no significant differences between maternal and paternal responses to the death of a grandchild" (p. 165).

Group work has been incorporated in social work practice since the middle of the 20th century (Cramer 1999). The value of group work as an intervention for particular populations has been well documented (Northen and Kurland 2001; Vugia 1991; Yalom 1985). Frequently, the aims of group work are to provide opportunities for participants to meet others in similar situations, decrease isolation, normalize experiences and feelings, and provide information and support (Burns and Madian 1992; Shulman 1999). As Northen and Kurland (2001) assert, "effective group work, in which people interact personally to support and challenge one another … understand … respect, and build upon each other's experiences … is needed today more than ever in our increasingly depersonalized world" (p. vii). According to Yalom (1985), some of the features of group experience, which lead to positive outcomes for participants, include universality, sharing information, interpersonal experience, and feelings of altruism and group cohesiveness.

In responding to the needs of those who are bereaved, social workers have drawn upon a range of interventions, including individual, couple, family counselling, and group work (Johnson, Rincon, Gober, and Rexin 1993). Group work in intervention has often been employed and generally is regarded as being beneficial for those who are bereaved (Glassock 2000; Goldstein, Alter, and Axelrod 1996; Klass 2000; Heiney, Ruffin, and Goon-Johnson 1995; Reed 2000). In support of group work for those who are bereaved, Kliban, Hanig, and Schnitzer-Newson (1984) report participant satisfaction and "apparent functional improvement" (p. 18) after the relatives of hospice patients completed an eight-session bereavement program.

Davis, Hoshiko, Jones, and Gosnell (1992), when researching effectiveness of groups for bereaved people, found a considerable reduction of stress and concluded that, "the support given in groups can have a mitigating effect on bereavement outcome" (Davis et al. 1992, p. 38). Group work for grandparents facing loss and grief issues due to separation, divorce, or diagnosis of disability is emerging. Burns and Madian (1992) noted that for grandparents of children with disabilities, parallel themes are evident: "double sadness … double grief … difficult problem … [and obtaining the services of] professionals to meet their needs for information and support" (pp. 17–18).

A single session, open psycho-educational support group facilitated by leaders holds considerable promise (Cramer 1999). There is evidence to support the acceptance and effectiveness of such groups whether they are formed to carry out a particular task or to deal with a specific issue (Cramer 1999). An opportunity to "tell their stories" (Reed 2000, p. 23), and to "talk about their grandchild following the death" (Ponzetti and Johnson 1991, p. 162) were experienced as helpful and supportive interventions. Burns and Madian (1992) found from a group they conducted that "meeting the direct emotional and informational needs of the grandparents was an important outcome" (p. 21). Additionally, groups offer bereaved grandparents the opportunity to discuss the socially sensitive, taboo subject of death (Shulman and Gitterman 1994).

In social work, there has been a long history of evaluating practice (Gibbons 2001). This is necessary for accountability, enhancement of service and to establish the validity of interventions (O'Neill, Cleak, Brown, and Goodman 1999). Practice evaluation can be conducted in many ways, from informal questioning and reflection of service to rigorous research. Both qualitative and quantitative data are utilized in practice evaluation (O'Neill et al. 1999) in health care and other settings. Northen and Kurland (2001) support the use of evaluation methods that "do not interfere with the service being given … [and] rapid assessment tools … [that] can be constructed quickly and used easily" (p. 442), for example, a client satisfaction method "in the form of interviews or questionnaires for securing the members' opinions for practice and outcome" (p. 443).

Genesis of the Grandparent Bereavement Support Group

In our family-oriented practice setting, the value of supporting grandparents in their role is acknowledged as highly significant. Through the provision of services and requests from families over our years of practice, it became evident that there were unmet needs for grandparents who were mourning the death of their grandchildren. Bereaved parents, in the midst of turmoil and emotional depletion, often find it difficult to support their own parents' grief. Clinicians noted that sometimes bereaved mothers and fathers were mindful of their parents' needs, but were struggling to manage their own grief. Given this limited availability of support from their families, grandparents may feel a lack of understanding and care.

Through our work in "accompanying" grieving families, we came to recognize the unique experiences and particular needs and concerns of grandparents. We found that a significant theme among our grandparent clients was a perceived acknowledgment and neglect of the grief they experienced. Often this unintentional consequence was difficult for grandparents to endure. The grandparents we met were a diverse group ranging in age, health, employment status, and other characteristics. Often they were in the midst of different life stages and in transition between several stages. Further, they might have been active and regular care providers to their grandchildren or perhaps only occasional visitors. Their role seemed complex as both supporters of the bereaved and the bereaved themselves.

We wanted to understand more comprehensively the bereaved grandparents' experiences and needs within their altered family environment. Related aims were to explore whether formal services were needed or available for this population and, based on our findings, to develop services. The identification and understanding of need is fundamental to program development and services in social work. A formal needs assessment can be conducted in a variety of ways (Grinnell 1988). For practical reasons of time and resources in this acute setting, we were unable to conduct a needs assessment. Partly, we did not have direct access to this population from our case records. Instead we relied on our clinical knowledge, the "pressure of requests" from parents in the parent groups, and suggestions of some grandparents attending memorial services to guide us. Where bereavement services in the community have expanded over recent years, we were careful not to replicate these existing services. However, we were aware that there were few community services for bereaved grandparents.

The Group's Purpose and Structure

A group work approach brought out the collective voice of bereaved grandparents. The group could identify needs, share information in a structured way, and lead to better understanding of bereaved grandparents' concerns and experiences. Such a group would concurrently provide support and information to members and validate experiences. The inaugural group, held in November 1999, provided information on the needs, experiences, and concerns of bereaved grandparents. The data generated would be used to explore and determine possible future interventions. Within these broad goals were a series of more specific, individual aims for participants. These included an opportunity for participants to share experiences, lessen isolation, and normalize feelings and responses in a safe, supportive environment. Group participants were also given information about grief and relevant resources to help sustain them as they grieved.

The parent and sibling groups offered by our Family Bereavement Support Program are open, educational support groups facilitated by social workers. While the opportunity to offer a series of closed, ongoing sessions may have many benefits, our experience has been that participants are unable to commit to regular ongoing groups. One reason may be because the hospital is a state-wide service, and some families who use its services live far away from the hospital, thus making regular visits impractical. Another reason may be that returning to the hospital after the child's death can be difficult for some families. Ongoing groups also require a considerable commitment of resources. Consequently a single-session model used for our current Bereavement Groups was adapted for the grandparent group. Offering such a group was seen as a small beginning that recognized the predicaments and difficulties of the grandparents and provided a limited service that responded to their needs.

Seeking Group Participants

To reach grandparents, we used the Family Bereavement Program database and mailed invitations. A covering letter asked parents to pass on the invitation to the grandparents.

Thirty grandparents of 19 children, who ranged in age from a few hours to 18 years, attended the first group of 21 grandmothers and nine grandfathers. The time since the children had died ranged from three months to three years. The causes of the children's deaths included acute illnesses, accidents, congenital conditions, and cancer. This greater proportion of female group participants was expected, based on our research and experience of bereavement groups.

We did not collect detailed demographic data, such as age, ethnicity, or whether they were paternal or maternal grandparents. This was because our emphasis was on providing a bereaved support service and obtaining information about needs. However, gathering such information may have been useful for the development of future services.

The Group Program

> "Just talking when the world … wants to be silent on the death of a grandchild."
>
> "Interacting with other grandparents and knowing that what we're feeling or experiencing is shared by others."
>
> "[It helps] to know that we're not alone."

The group program was designed to provide grandparents with information about grief, opportunities to meet other grandparents, and the chance to share experiences in a supportive and safe environment.

Facilitation by a social worker has been a feature of the Bereavement Program. As is supported in the literature, "knowing that a professional caregiver understands and supports the grieving process can help bereaved families cope more effectively" (Moffitt 2001, p. 154). From our practice, we have found that a structured group guided by a social worker helps to lessen apprehension in such new situations. We assumed that grandparents are unfamiliar with group processes and may be uncomfortable about discussing distressing personal matters. The group structure was of a containing nature, creating a comfortable atmosphere in which boundaries, expectations, and roles are clear. The program included a welcome, a formal presentation, a small group discussion, and a closing ritual. Time was set aside for participants to make connections with others informally over refreshments and to complete a brief evaluation. Participants were asked for written consent for the use of photographs and non-identifying information about the group, should these be later used in publications or presentations.

To lay a foundation for discussion and to foster a sense of engagement, the day began with a presentation by an expert on grief and loss. His presentation set a context for the group program and validated the grandparents' experiences. Comments from group participants' evaluations indicated that the presentation was helpful to them.

Following the presentation, the grandparents divided into small discussion groups of six. The small groups were co-facilitated by two social workers or one social worker with a social work student. Grandparents chose which small group they would join. Some grandparents who attended the group as couples took the opportunity to participate separately in different small groups, while others chose to remain together as couples.

The small groups had a semi-structured format. Grandparents introduced themselves and their grandchild and explored a series of questions, aimed at eliciting grief experiences, insights, and concerns. These questions acted as a guide for the group leaders.

- Introduce yourself and your grandchild. Tell your story relating your experiences as grandparents.
- What is helpful? How do you care for yourselves?
- What resources have you drawn on?
- What would other grandparents in similar situations need to know?

Grandparents were encouraged to speak about their grandchildren, their experiences since their grandchildren's death, and to think about what they had utilized to help them through their grief journey. The stories and observations shared during small group discussion were then gathered and developed into a pamphlet. This became a resource for other bereaved grandparents, family members, and the professionals working with them. The pamphlet was a tangible outcome of the group. Contributing ideas for it generated constructive energy and a focus within the small groups. Providing help to others has been shown to be a positive element of group work (Yalom 1985).

Reflection on Group Activities

We noted that most grandparents relished the opportunity to introduce their grandchildren, to meet others who understood, and to be heard. Some were initially reluctant to focus on themselves, choosing to speak about their adult children and grandchildren instead. The grandparents struggled to express their own grief without being perceived as diminishing their adult child's grief.

As with the parent and sibling bereavement support groups, some grandparents brought photographs and other mementos as a way of bringing their grandchild to the group. These were shared with others during the group. At times there were displays of emotion with tears and laughter, and expressions of pride, frustration, sorrow, and regret. The grandparents' comments, reflecting these feelings and ideas, include:

> "Sometimes I think I'm losing the plot."
> "… feeling that you are not doing anything for the children in their grief."
> "The world keeps going, but your life and family are never the same again."
> "Pain, anger, frustration … grieving for the children."

During the discussion, the social workers recorded the grandparents' comments, themes, and issues. These were displayed and made available to the entire group to see during the break. A review of the grandparents' comments brought out some key issues. Evident in their comments was that the death of a grandchild challenged their understanding of the natural life and death order, the perception that their experience of grief had been minimized, and that they lived with a "double hurt." These themes are echoed in the literature. The ideas of the group participants are mirrored in the quotations below:

> "Living longer than your grandchild doesn't feel right."
> "It is difficult to imagine the death of a child so young."
> "Seeing your own child hurt … [is] a double hurt."
> "Parents sometimes think that we grandparents could not understand what they're going through and therefore they minimize our pain."

Group participants lived with "double hurt," meaning grief is experienced simultaneously for a grandchild and for an adult child. Their experience of grief seemed to reflect the complexity and ambiguity of the grandparents' position within the family. They were mourners, carers, and survivors. Their grief was for their children, their grandchildren, and themselves. The natural expectation was that they would pre-decease their children and certainly their grandchildren. Furthermore, given their age and life experiences, grandparents usually offer wisdom and reassurance to other family members, yet they themselves are amidst the chaos of grief and need help and support. Grandparents also reported feeling that their grief was not understood or acknowledged. They described confusion about their role in grieving and, at the same time, supporting other family members.

The group also explored what members had found helpful in dealing with their grief. This topic generated an exchange of ideas and resources regarding what they had found to be supportive. Information sharing is a positive feature in many groups (Yalom 1985). Grandparents shared their strategies about living with grief:

> "Allow yourself time and space to grieve."
> "Find a safe way to express your feelings."
> "Allow yourself to laugh and remember the good times with your grandchild."

In their response to the question "What do other grandparents need to know?" participants gave a number of suggestions. Illustrative of these were:

> "Be open and honest with your children—don't try to hold back your tears."

> "Realize that you are not alone, share your experiences with others that grieve."
> "Take one day at a time."

These comments suggest that the grandparent grief had been hidden and that there was a need to have their grief recognized and attended to by themselves and others.

Further connections between the grandparents were made as they mixed informally over refreshments. With pride, the grandparents continued to comfortably share photographs, mementos, and anecdotes of their grandchildren.

"Grandparent Grief: A Unique Experience—Caring for Self, Caring for Others," a helpful pamphlet for bereaved grandparents, was developed from the grandparents' comments. The process of creating the pamphlet affirmed and honoured their experiences of loss and grief. The group participants appreciated being able to offer something to other grandparents who were experiencing grief. Through this act, the grandparents expressed their care and concern for others. It was a purposeful activity that enabled the grandparents to contribute constructively to fill a need for resource material that had previously been unavailable. The pamphlet was an enduring, tangible outcome of the grandparents' bereavement support group.

To conclude the day and prepare for the ending of the group, the hospital chaplain led a reflection. A series of visual images, accompanied by music, was used to guide a reflection on their relationship with their grandchildren, remembrance of their special times together, and their grief journey. As one grandmother, who had had two grandchildren die from neuromuscular disease, commented: "It was a very special experience … [as though] I held two grandsons' hands as I walked through 'the reflection' and it was wonderful."

The grandparents were given a bookmark with a poem written on it as a memorial of their grandchild and a symbol of their group participation.

Evaluation of the Group

Evaluation is a regular process within the groups conducted by our Social Work Department. It was important to evaluate our first Grandparent Bereavement Group to learn about its effectiveness. To provide information that is both current and focused, a short client satisfaction tool was used. The participants were asked to respond to the following questions:

- What has been helpful or valuable in this group?
- What would you like to see done differently?
- Would you come again?

Another section for further comments was also provided on the form. The following comments of participants were reflective of the tone and contents of the responses:

> "For me it was helpful to see how many ways there are to cope with grief and loss. The lesson for me is to try to take care of myself and try not to be superman."
> "Knowing and talking to others in the same situation, knowing that we are not the only ones that have lost a darling grandchild [is helpful]."
> "Sharing time and thoughts with others who share my grief, it helps me to see things more clearly."
> "The whole experience was both helpful and valuable to me. I was able to cry and yet not be really sad."
> "To know we are not alone [helps]."

Overall, the grandparents who participated in the group reported finding their experience of the group valuable. Their evaluations have been used in planning subsequent groups. Only one grandparent indicated that they would "probably not come again," although the person mentioned being "very glad I attended the morning." Overall, the further comments section of the evaluation form tended to be positive: "Enlightening." "Today has helped a lot, I would enjoy more days like today." "It brought feelings to the surface, hopefully that's part of the healing process." and, "Well done, we gained much consoling and learnt some consoling ways." Three suggestions for changes in future grandparent bereavement support groups were: (1) having age-related groups; (2) offering a series of groups; and (3) allowing more physical space between the small groups.

Implications for Social Work Practice

Several significant practice insights were generated from the first grandparent bereavement support group. Broadly, these fell into two main areas: (1) key issues in grandparent bereavement, and (2) practice considerations in conducting such groups. These insights have shaped our understanding about the needs of bereaved grandparents and the design of future groups.

A primary theme that arose was the lack of validation for grandparent bereavement, which may be a feature of the disenfranchised nature of their grief. Grandparents, after the death of a grandchild, may often perceive themselves as unacknowledged and unsupported, which may further undermine their sense of being a legitimate mourner.

> "We quietly grieve."
> "They [child's parent's] were going through more than me."
> "Sometimes we are living in hell."

In holding a Bereaved Grandparents Support Group, the hospital makes a clear statement that grandparents grieve. The message legitimizes their grief. Once acknowledged, other issues emerge. Grandparents, like parents and siblings, can benefit from recognition, support, and the opportunity to express their grief and make connections with others. The accommodation of grief is to be promoted as healthy grieving to prevent impaired bio-psychosocial well-being and functioning (Klass, Silverman, and Nickman 1996).

When they are unacknowledged in their grief grandparents may find themselves in the midst of role confusion. As Nussbaum and Bettini (1994) discuss, "lack of a concrete or specified role for the grandparent is problematic and at times stressful" (p. 68). Is their response normal? What is their role? Are they mourners or are they care providers or are they both? The distress that accompanies this uncertainty is yet another hardship. Gyulay (1975) observes that grandparents "when after all they have offered advice, financial aid, care, babysitting, experience, and help is not accepted, asked for, or is even rejected, they feel guilt, frustration and anger" (p. 1478). Perhaps as a response to this confusion, a grandparent returns to a familiar parental caring role with his or her adult child to deal with an uncomfortable and unknown void. Some families, the grandparents reported, welcomed the care they offered, while others found it intrusive. As the grandparents in the group reflected:

> "I was the backbone. I felt I had to stay and help and support my daughter … your other life before vanishes."
> "Better they lash out on me than each other."

> "[It is] important to be there for them."
> "You do things for your child you wouldn't otherwise do, you push yourself for your child."

Grandparents' performance of emotional and practical tasks for their grandchild's parents or for their surviving grandchildren may distract from their own grief. Reed (2000), however, explains that "waiting until we [grandparents] recover from our own grief is not an option. Experiencing our own grief while simultaneously aiding our bereaved child characterizes grandparents' grief" (p. 55).

Group participants poignantly expressed the distinguishing feature of grandparent bereavement—its dual source of grief. The grandparent experiences her or his own grief for the grandchild who has died and also the grief of their adult child's loss. As grandparents endure and witness the family's turmoil from the death of a child, they are often placed in the complex position of supporting a bereaved adult child while they themselves are immersed in their own grief. In the grandparents' comments, the theme of a "double hurt" resounded strongly: "We feel it for our children and our grandchild … tears flow for them both." These sentiments and the expression "double hurt" were frequently referred to by group members. In addition, feelings of survivor guilt and bewilderment at the disruption of the grandchild's anticipated life cycle complicated their reactions and responses.

> "Why wasn't it me?"
> "It's a hard feeling … we've lived our life."
> Grandparents also spoke of the ongoing nature of grief, similarly experienced by parents and siblings.
> "The sharp edge wears off, but never goes away and you don't want it to either."
> "[You] can't rub it out … [it] never ever goes away."

For some grandparents the continuing feelings of their grief may have been unfamiliar. They may have, like many other people, been socialized to think that grief, given time, resolves. Contemporary understanding of grief has tended to define it as a non-linear, unpredictable, and ongoing process. Loss is accommodated rather than removed (Doka 2001; Klass et al. 1996). "People are changed by the experience; they do not get over it … the change is a transformed but continuing relationship with the deceased" (Silverman and Klass 1996, p. 19). By providing the group, we intended to give grandparents current understanding about grieving and loss, and to dispel common myths and to explore with grandparents how "some people may not realize that attachments endure and that some losses are so big and so painful that one cannot ever get to a place where grieving has ended" (Klass et al. 1996)

Challenges in Initiating New Social Work Programs and Services

The evaluation provided us with useful data about the group's immediate experienced value. More detailed evaluations conducted at a later date might have also been helpful to determine if there were any lasting benefits such as greater awareness of grief and constructive ways of supporting oneself in its wake. It would have also been useful to know whether there were any changes in behaviour, if group attendance precipitated a particular discussion with adult children about their shared grief, and whether any connections between participants during the group sessions were later used for support. Individual follow-up interviews might have addressed these topics and could have enabled additional opportunities for support and clarification of any outstanding issues or questions from the group.

In reviewing the group and in discussion with colleagues, we were mindful that group work may not be helpful for everyone; some may feel intimidated, too exposed, and unfamiliar with the process. Cultural, age, gender, and language factors may also be barriers for some grandparents in using group services. In a multicultural environment, multilingual social worker services could be advantageous. Ideally, bereavement services would offer choice in the form of the service and be sensitive to factors such as ethnicity.

It is often a struggle to obtain adequate resources to expand social service programs and social work intervention when shrinking budgets and competing needs are a reality. The Bereavement Program does not receive funding from the hospital, so the Social Work Department underwrites the program from its own budget. However, a funeral company granted the funding for the inaugural group. The funeral company did not expect to exercise control over the project. A small notation, acknowledging the funding source, was printed on the pamphlet. In some cases, innovative services may need to draw upon private funders.

The Social Work Department maintains that offering ongoing family-centred bereavement support is a highly appropriate and responsible service. Arguably this fits within the hospital's mandate of health promotion and continuity of care for the patient and the family. Increasingly, however, in an environment of "fiscal restraints, reduced timeframes and accountability pressure … social workers sometimes face what they perceive as barriers to offering adequate care …" (Davidson and Foster 1995, pp. 2–3). In their daily work social workers encounter many areas of need, often experiencing difficulty in resolving these dilemmas compassionately and equitably. Although they and other staff may be aware of the significance of particular needs, financial and staff resources constraints may make it difficult to intervene.

While the inaugural group evaluations and encouragement from within our department provide an impetus to offer more groups in the future, such decisions depend on available resources. In practice this frequently means relying on the goodwill and availability of social workers to provide this service in addition to their other work responsibilities. In this group, the assistance and collaboration of social work students was also important. The Grandparent Bereavement Group offered the students a rich opportunity to learn about program design, group implementation, facilitation, and evaluation. Students, in collaboration with social workers, were active in all aspects of the group from budget allocation to co-facilitation (including cleaning up after the group!). However, students are a limited and unsustainable staffing resource, and planning for their involvement requires attention to these constraints.

Conclusion

The profound grief experiences recounted by grandparents, together with practice insights gained during the group, have been invaluable, and these have shaped our understanding of the needs of bereaved grandparents and the value of group work as an intervention for them. The experience confirmed the reality and legitimacy of grandparent bereavement. The complexity of their particular grief, their position within their family system, and their social roles was apparent. The group recognized and responded to grandparents' multifaceted, distinct needs. Participants received acknowledgment, information, and support. Their grief was placed within the context of a normal grief response to a loved one's death. In essence, the group confirmed that the isolation experienced by bereaved grandparents can be reduced by meeting with others who understand the “double hurt” and the disenfranchised nature of their grief, which was seen as real and enduring. As social workers we became more convinced that for the well-being of the whole family, grandparent grief must be acknowledged and honoured. We remain committed to the provision of care for bereaved grandparents.

Reflection Questions

1. How do you think that the social roles of grandparents you have known would make their grief experience after the death of a grandchild unique?
2. What type of group composition, format, content, and other features do you think would be important in a grandparents’ bereavement support group in a hospital? How might a single-session group differ from an eight- or 10-session bereavement group for grandparents?
3. How would a student prepare herself or himself to facilitate a grandparent bereavement support group? (Consider what you would need to know first about grief experiences of grandparents, group formation, and group facilitation.)
4. How can social workers call attention to necessary, yet unmet needs of a particular population in a hospital setting? How might funding and staff resources be generated?
5. How are culture and gender significant in the ways grandparents express their grief? (To help you answer these questions, think of grandmothers and grandfathers you know who are from ethnocultural groups different from your own.)
6. What are some alternate ways to evaluate the effectiveness of group intervention? Name and explain the use of two measures or methods.

Note

1. The FBSG commenced in 1989. The program now includes individual and family counselling, information evenings for recently bereaved parents, monthly parent-support groups, a monthly newsletter, sibling group, grandparents group, an annual memorial service, information provision, referral and education for families, hospital staff, and the community.

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CHAPTER 22

WORKING WITH CHILDREN AND FAMILIES WHERE THE MOTHER HAS A LIFE-THREATENING ILLNESS

Maureen McInerney and Lynette Joubert

Introduction

Social work practice with the children of mothers who are dying is a clinically exacting task. The nature of the involvement and the strategies used depends upon the developmental stage of the child, the nature of their attachment to the parent, and the family and community support structures. Social workers and other health professionals often give insufficient professional and academic social work attention to helping the children of mothers who are dying. The chapter contributes to this area of social work practice with information and resources for generic and specialist oncology social workers who are working with families where a mother is dying. It has grown out of the clinical work and academic experience of two social workers based in Melbourne, Australia. The authors acknowledge that more research and practice development need to be undertaken to further advance professional knowledge and understanding about this topic.

Case examples, a review of available literature, and the authors' reflections on their experiences inform the chapter. Their experience results from work in an acute hospital setting. The practice issues, however, have application in a variety of settings where social workers might intervene with children of families where a mother is dying.

In an acute hospital adult oncology ward in Melbourne, it was found that little attention was given to the children of patients attending the hospital. The multidisciplinary team realized that children's reactions to the illness and often the death of their mothers was largely ignored. The question was posed: "What about the children?" A study of the unit's clinical records indicated that professionals working with the patient recorded clinical and social information about the patient, but little about the family situation and even less about the children of the mother who was dying. Social work has traditionally focused on the dying person. However, the role of the social worker in the oncology ward needs to include a focus on the issues confronting the child during this acute emotionally stressful phase. This focus also involves significant supports in the ecosystemic environment.

Working with the Children of Mothers Diagnosed with a Life-Threatening Illness

The reaction of the partner of a dying mother, their families, and professionals working with them has historically been to shield children from the pain and trauma of the treatment process and the parent's impending death. The other parent and family members are usually so absorbed in their own grief that little attention is given to the children.

The approach proposed in this paper is family-centred, in which the needs of the children are considered along with those of the dying woman, her partner, and other family members. The assumption underlying this chapter is that if children are prepared and have some forewarning about their parent's illness and death, it will improve their capacity to make appropriate psychological adjustments to the mother's death. Further, informing and assisting children in the acute stage of care will help to promote a better quality relationship between the mother and child during this terminal phase of the dying person's life. This can help to relieve some of the stress and anxiety of the dying mother, who is inevitably anxious about the future of her child.

Social work intervention in such situations needs to identify the risk factors and reinforce the resilience and coping skills of children and their families. In this sense social work intervention must be ecological so that intervention takes into consideration the natural family, extended family, and community context of the child. The intervention needs to support normal grieving and the process of saying "goodbye" in a tragic human circumstance. Effective social work intervention requires advanced clinical assessment and therapy skills; the capacity to link the patient's family with extended family members where possible; and community resources that can assist the child with broader ecological support during the period of illness, death, and the early stages of grieving. Children who are forewarned about their parent's illness and death and are encouraged to talk about the issues deal with their sadness in their own way, either verbally or non-verbally, and are more likely to cope with the situation.

During the terminal phase of the illness, the dying mother often experiences intense physical symptoms and moves frequently in and out of hospital. There is considerable sadness and family anxiety particularly when young children are involved. The illness usually results in a disruption of daily patterns of behaviour such as school and sports activities. This disruption of family routine can be disturbing to children.

Social work interventions in an acute setting are often short term in which there is little time to establish an enduring therapeutic relationship. This requires a social worker to do careful planning with the most effective use of limited contact times or opportunities for useful intervention. The practical constraints of practice in the acute setting require flexible, creative, and brief methods of intervention.

Key considerations for social workers providing services to children whose mother is seriously ill include the following:

- Understanding the emotional reaction of a child who is too young to verbally express feelings of sadness and worry about the pain and process of terminal illness that his or her mother is experiencing
- Appreciating the use of children's symbolic language and its meaning in helping them adjust to their mother's death
- The influence of the age and developmental stage of the child on social work intervention
- The importance of not imposing adult concepts of grief and adaptation in work with children
- Identifying risk factors and reinforcing resilience to support the child in coping with bereavement

Review of Selected Literature

The limited research on the impact of parental death on a child reflects the delicate nature of working with people who have a terminal illness and the potentially invasive nature of research. In general, certain factors influence the child's adaptation to the death of a parent. These include chronological age, developmental stage, the nature of the relationship between the ill parent and the surviving parent, the family's social network, and communication patterns in the family. Evidence on the response to death in an adult refers to a process involving anticipation and grieving that enables adults to adjust, and helps both the patient and partner prepare for the loss. The literature, however, is unclear as to whether this applies to children and adolescents. Mireault and Compass (1996, p. 5) conclude, "It is possible that individuals who can anticipate a parent's death are better prepared emotionally and cognitively and will be able to use the remaining time with the parent to put closure on the relationship and to prepare for the loss in other ways." Greening (1992) explained that a diagnosis of cancer contributes to problems in relationships, roles, communication, and quality of life. Few studies have examined the impact that a parent's diagnosis of cancer has upon children's adjustment.

The Impact of the Diagnosis on the Developmental Stage of the Child

There is agreement that the child's developmental stage will have an impact on how the child adjusts (Birenbaum, Yancey, Phillips, Chand, and Huster 1999; Hilton and Elfert 1996; Mireault and Compass 1996). Christ (2000) groups children into five categories related to their developmental attributes rather than their chronological age. The author discusses the implication of these stages in relation to the developmental theories of Piaget and Erickson, exploring in depth the dimensions of affect, cognition, and behaviour within the developmental continuum of children. Understanding these developmental frameworks has significant implications for practitioners when working with children.

Children who are at certain developmental stages at the time of diagnosis may be more at risk of adjustment difficulties. This is significant with regard to the interventions that social work utilizes. Greening (1992) suggested that young children aged between three and five years old are a "hidden risk group" whose problems are often minimized by overwhelmed parents. These children may experience a change in routine and roles within the family when a parent has cancer. In addition they may also experience withdrawal from the parent because of the increase in fatigue as a result of frequent hospital visits during treatment. Hilton and Elfert (1996) noted that the primary concern of many women patients was child care. To protect young children, parents may provide simple explanations to preschoolers, regarding them as too young to understand the ill mother's condition. This assumption can lead to problems for both the young child and his or her parents. Depression and anxiety in bereaved young children has been found to be an outcome of insufficient information given during the terminal phase (Christ 2000).

The loss of a parent whose attachment to the child was strong significantly affects a child's psychological development. The impact on the psychological adaptation of a child when a parent dies depends on the nature of the primary attachment to that parent. Loss in childhood places a person at risk for psychological maladjustment (Mireault and Compass 1996).

Call (1990) described four elements in helping children in families where a diagnosis of terminal cancer had been made. These included working within the social network of the child by helping parents to assist their children, working with parents and children together, working with children individually, and working with children in groups. Call (1990) concluded that children tend to receive insufficient support when a family member is ill. It is important, therefore, for professionals to ask their patients about their children's well-being (Greening 1999).

The Adolescent Response to the Diagnosis of Life-Threatening Illness in a Mother

Adolescents are at risk of maladaptive behaviour because of the impact of illness and especially the impact of bereavement. During adolescence, children often find themselves in a conflict between dependence and independence, detachment and attachment, emotional control and emotional explosion (Christ 2000). These conflicting feelings, common to their developmental stage, influence the impact of the diagnosis on the adolescent and on the adolescent's quality of relationship with his or her family. Christ, Siegal, and Sperber (1994) reported that high levels of distress were found in adolescent girls whose mothers were diagnosed with cancer.

Social networks offer significant assistance to adolescents who value support from a broad range of confidantes. Christ, Siegal, and Sperber (1994) claimed that if adolescents' coping strategies involved a search for meaning and ways to increase awareness about their experience, they would be better able to deal with the emotional effects of loss. Religion was also identified as a factor that influenced a more positive reaction.

Christ (2000) found that children in early adolescence (12 to 14 years of age) avoided seeking information about parental illness and preferred not to display their emotion, thus suggesting particular areas of need in this group. Information about the diagnosis threatened common defence mechanisms, such as denial and determined optimism. Individual characteristics, along with the many biological, cognitive, emotional, and social changes attributed to the early adolescent developmental stage affected their reaction to the diagnosis of terminal illness. Mireault and Compass (1996) noted that adolescents were more at risk because of their developmental stage rather than the existence of illness in the family. Research by Birenbaum et al. (1999) concluded that most adolescents and school-age children of parents who have cancer are well adjusted, but some youngsters are at risk for behavioural problems.

Christ's (2000) research found that adolescents in the 15- to 17-year-old group expressed intense sadness, longing, despair, and helplessness at the parental diagnosis of cancer. The intensity of their emotional response interfered with normal functioning. It is difficult to replace a seriously ill or lost parent, so adolescents in this age group are often expected to accept greater responsibility for household chores, while they are also coping with the turmoil of a reconstructed family. In structured interventions with adolescents (Christ 2000), adaptive behaviour has been shown to depend on the level of grief expressed and the nature of parental guidance.

Gray (1987) argued that healthy adjustment to the death of a parent in adolescents aged 12 to 19 years resulted from high levels of social supports, strong religious beliefs, a positive relationship with the surviving parent, and certain pre-existing personality traits. Further, parental attributes influencing the adjustment of children included the existence of parental warmth, low levels of parental depression, and family cohesiveness. Open communication, especially in sharing information about the parent's death, was associated with better psychological outcomes.

The Impact of Life-Threatening Illness on Communication and Roles in the Family

In order to assist families to cope more effectively with both the emotional and practical issues related to a mother's life-threatening illness, it is important for social workers to communicate and collaborate with other members of the health care team. Such efforts can help to minimize the often disruptive and disturbing effects of treatment protocols, difficult information and explanations, and can foster supportive intervention for the whole family and its individual members (Hilton and Elfert 1996). Identifying as early as possible those families at risk can minimize potential problems later. Such families might include those in which there is marital discord; those that are composed of only a mother and child (or children); and families in which there are adolescents or very young children.

Important family-focused psychosocial assessment with very ill patients and their families is often compromised by the nature of acute care settings and the need for the rapid work it involves. When patients are hospitalized during the terminal stage of illness, the physical symptoms of fatigue and pain make it difficult to engage the patient to conduct an effective psychosocial assessment. It is, however, important to establish professional rapport in order to learn about relationships between family members and their nature and quality. Assessment of family relationships can help shed light on the particular challenges of the mother's illness on the family and experiences of anticipatory grief and bereavement. It can also help to establish any difficulties in communication within the family that might complicate the bereavement process, such as unresolved conflict or strong dependence and attachment of children to the ill parent (Rosenheim and Reicher 1985). In families where there are good communication patterns between the partners and where issues can be expressed openly between them, the opportunity for change and adaptation after the diagnosis is made is greater. Effective communication helps in managing the demands and role shifts affecting children's lives as a result of serious parental illness; it may be especially important in the case of adolescent girls who take on household duties previously assumed by the mother (Hymovich 1993). In some instances there is a blurring of roles and the development of an intense emotional bond between mother and daughter, with the latter involved in direct, physical care of the mother. In a study conducted by Hilton and Elfert (1996) families with open patterns of communication reported that they were satisfied with how they coped with the mother's cancer. Although they felt stressed, they shifted roles within the home as needed to cope with the emotional and physical demands of the situation.

Application to Social Work Practice

The response of the social worker to the identified client, the mother with cancer, the children, partner, and extended family is influenced by the complexity and ambiguity of the emotional experiences confronting the family system. Social work intervention is further complicated by the necessity of brief intervention, usually in an acute care oncology ward. The capacity to deliver a family-focused approach is usually restricted by the physical symptoms of fatigue and pain experienced during the terminal stage of illness. It is difficult in such a situation to engage in conversation and build a therapeutic relationship for patients to divulge and share emotions and existential fears related to the loss of parenting and separation from much-loved children. Patients are often in so much pain that they are not able to engage in conversation for long periods of time. However, observations of family interactions and exploration of non-verbal cues are particularly important at this stage. So too is the development of mutual understanding and support between a social worker and family members.

Psychosocial Assessment

Psychosocial assessment is ongoing and becomes an integral part of the therapeutic relationship and intervention with the patient and her family. Assessment involves the exploration of risk and resilience factors and a detailed account of the social and interpersonal dynamics in the ecosystemic environment of the patient and family. The nature of the acute hospital ward dictates the physical boundaries of the assessment, allowing only limited opportunities for privacy. Much of the assessment needs to be through observation and non-verbal communication with the patient. Children's visits to their sick mother provide an opportunity for the social worker to enter the relationship system and to engage with the children collaboratively. This requires a sensitive understanding of the emotional attachment between mother and child. The usual formalities associated with social work assessment may be experienced as awkward and invasive. Assessment needs to focus not only on the relationship between the ill parent and child but also on the surviving parent, who may be assuming a lonely and difficult task of solo parenting. Relationships in the immediate and extended family system are important sources of emotional and physical support. An effective assessment needs to identify whether there are issues that may complicate the bereavement process, such as unresolved conflict or strong dependence and attachment.

The social worker in the acute setting does not confine her or his assessment only to the immediate emotional issues presented at the patient's bedside. The family's functioning within the broader context of their community system needs exploration. It is important to establish whether and how well families are connected to both informal and formal support systems. The school life of the children and their participation in school and community activities are also important issues to be considered. The social worker needs to work with the family to focus on effective communication and use of resources within the school and local community. Teachers, schools counsellors, and classmates, where appropriate, can be informed of the situation and engaged to support the child in practical and emotional ways. The social worker actively supports the family to gain access to the school community for ongoing support and to involve the school system in collaborative supportive efforts. With the family's consent, the social worker can perform a valuable role as consultant to the school on behalf of the family. In assessment, the oncology social worker also needs to consider the family's strengths and vulnerabilities in dealing with the sensitive and often painful issues related to life-threatening illness in a mother.

Social Work Practice Applications: Helping Mothers with Cancer and Their Families

Ongoing psychosocial assessment of risk and resilience factors, as discussed above, guides decisions about the use of social work practice models. The following table illustrates the key issues to be taken into account in ongoing assessment and subsequent decisions made regarding the approach to be used with the family.

In the following discussion, we integrate the use of selected factors in Table 22.1 with models of practice in social work.

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Using Existing Patterns of Communication within the Family

To establish the nature of communication between family members, the social worker can use both direct and indirect observation during visiting times in the acute care setting. Families that are more open in their communication tend to be more flexible about changing roles and appear to experience less difficulty in the aftermath of the patient's death (Cohen, Dizenhuz, and Winger 1997). The social worker needs to be conscious of when to shift the focus from the dying patient to the patient's family to better understand how the experience of the mother's illness affects family functioning and communication.

Moving from assessment to intervention, the social work practitioner works alongside the family as they acknowledge the nearness of death and tries to deal with both the practical issues related to the death and the psychological and emotional reactions in saying farewell to the patient. This is usually a time of crisis. Supporting the family's effective handling of required emotional and practical tasks by partializing them is useful. Families will then be able to make appropriate changes as needed.

Questions to address during the continuum of assessment and intervention are as follows:

- How is the patient and patient's family adjusting to the terminal nature of the illness?

- What have the children been told?
- What supports do the children have to meet their emotional and practical needs?
- How has the family involved the children in the decision-making process?
- Is there a primary support person available for the children with whom the social worker can work?
- Were there any pre-existing, unresolved issues facing the family before the mother's illness?

A critical issue for social work practice is for the practitioner not to assume that all children in all families require intervention. The ongoing assessment and intervention process as it focuses on patterns of communication requires sensitive and respectful probing to explore perceptions and adaptation, not practitioners' assumptions about family communication. This is illustrated in the following case example.

Case Situation: Mummy and Nana-Mummy

The social worker walked into the 28-year-old patient's room to find the patient's mother sitting next to the patient, who was in bed, asleep with her eyes closed. The patient's mother was sitting sadly and quietly next to the bed. The social worker sat next to her and gently inquired how she was. The older woman bravely replied that she was sad, but coping as well as she could. "What can we do?" she said, as she shrugged her shoulders. Her sadness, her body language, and her brief comment clearly indicated that she was aware of and confronting the death of her adult daughter. At the same moment, the patient, now awake, nodded her assent. The social worker, aware that the patient had two preschool children, then asked her, "What about the children?" The patient's mother answered, "Lisa [aged three years] calls her mum, 'Mummy' and she calls me 'Nana–mummy.'"

These brief words provided the worker with the insight that the child had a primary attachment to her mother, but had also made a significant psychological and practical attachment to her "nana." This suggested some emotional adjustment of the child to the situation, an openness within the family to accommodate shifts in attachment, and ability to communicate about emotional issues. The family was demonstrating to the social worker that they were preparing emotionally for the mother's death. The patient, opening her eyes and nodding, affirmed this. The social worker needed to respond to this subtle form of communication. The fact that the discussion had been conducted in the presence of both the patient and the social worker gave the patient the opportunity to acknowledge her understanding of the issues related to her imminent death. Timing can be an important factor in providing the opportunity to let the patient or family member express profound emotions in a brief and sometimes symbolic manner.

Reflection Questions

1. How could the social worker help the adult patient and her mother prepare for the patient's impending death (in the case of Mummy and Nana-mummy)?
2. How might the children participate at this stage of their mother's illness?

Working with the Chronological Age and Developmental Stage of the Child

Working with young children requires openness in communication, permission from the parents to use a family-focused approach, and an understanding of what the children have been told about their mother's illness. The latter usually reflects existing patterns of communication within the family. When working individually with very young children, for example, those aged three to eight years, the social worker may need to take the children out of the patient's room if the patient is too unwell to participate in the intervention. Spending time alone with the children provides a valuable opportunity for the social worker to develop rapport with the children and establish a supportive relationship with them so that a family-centred approach is fostered.

Where sessions are held in the social worker's office, the following strategies can be useful:

(1) Initial contact with the children can be used to gain their trust: The social worker first needs to establish contact with the children by meeting them briefly over a couple of days during visiting times. The establishment of trust and permission between social worker, parents, and children creates an environment in which the children can withdraw from their mother's room to "play" in the social worker's office.

(2) Play is an appropriate means of promoting the emotional and fantasy life of children: Children play out their emotional experience in a mix of fantasy and reality. This provides the social worker with a variety of creative options in working with this younger age group. These might take the form of decorating their mother's room with drawings and mobiles that they have made. Such activities, with the consent of and involvement of ward staff, can transform a clinical hospital setting into a family-friendly environment. Further, the mother who is ill in her hospital bed is left with a reminder of the presence of her family outside visiting hours.

(3) Symbolic play can become the language of children communicating information about their anticipatory grief and adaptation experiences: Writing stories and drawing are activities easily contained within a social worker's office and often form part of her or his skill base. Such activities promote an ongoing connection between the mother, the social worker, and the child, and also a tangible memory for the child. Story-writing allows children an opportunity to express feelings about their experiences and reactions in either real or symbolic language. It strengthens the emotional link between parents and children by bridging the gap in what is frequently an isolating experience for the children. This is illustrated in another case example:

Case Situation: Emma

Emma, a little girl aged five years, knew her mother would soon die of a serious illness. She was given the opportunity to tell a story to the social worker that they could later share with Emma's parents. Initially reluctant, Emma preferred to play and it was some days before she declared that she wanted to tell a story. The story Emma told revolved around a pink ribbon that she had carefully placed in her mother's room. She drew a picture of the pink ribbon falling out of a tree. The social worker asked her what happened when the ribbon fell and she said that the ribbon didn't hurt. Her consequent calm emotional state led the social worker to think that it was related to the telling of the story. The telling of the story enabled her to express both her fears and her hopes for her mother, while acknowledging that she was aware of the seriousness of her mother's condition.

The acute hospital setting provides opportunities for teamwork with other disciplines skilled in creative interventions with children. Some health care facilities include staff who can conduct music, speech, or art therapy who may be involved as members of palliative care teams.

Reflection Questions

3. How can play, including story-making and drawing, help preschool children express their feelings about the anticipated death of a parent?
4. What could a social worker do to help sustain a child's continued coping in this situation?

The Nature and Significance of the Relationship Between Children and Parents

The nature of the relationship between children and their mother at the terminal stage of illness usually reflects the pattern of the relationships in the home prior to the illness. This can be a complicating factor in the bereavement process, especially for older children, and needs to be incorporated into the social work intervention with both the mother and the family. Sometimes the father may be less comfortable with emotional situations involved in illness and loss, especially if he has had little experience in dealing with emotional issues in the home. Although a time of crisis, there is also the potential for this time to become a rewarding emotional experience for the father if he can be supported and encouraged to participate in the expression of feelings with his partner and children. Without their father's involvement, the children might be expected to deal on their own with the emotional reaction to their mother's illness and death, together with other complex issues related to their developmental stage. They may be unable to express their grief with him and communication might become increasingly troubled.

Teenagers struggling with their own self-identity might find it easier to react with denial about their mother's illness, and may withdraw physically from her as well as other members of the family. The ongoing changes related to the mother's illness affect the security of the existing family support system, creating yet another area of instability for the young person already struggling with individual developmental issues. The social worker can explore multiple and creative ways to encourage the older child to communicate with his or her mother in a safe environment. Discussing the deep emotional feelings of anticipated loss and changed mother-child relationship with his or her caring and concerned parent can help the teenager to participate more effectively in family life without his or her mother. This is demonstrated in the following case example:

Case Situation: Rosa

Rosa, a 49-year-old woman, was admitted to hospital at the end stage of a serious illness. Her adolescent children, aged 18 and 13 years, had no idea that their mother was so ill and their father had not been able to tell them. The family pattern of communication protected members from sadness by completely avoiding disclosure of any information about the illness and discouraging displays of emotion in front of other family members. The 18-year-old son presented as developmentally younger than his age, attached and dependent on his mother. Initially he responded with anger and disbelief, attempting to withdraw from the situation both physically and emotionally. Rosa was heavily sedated and unable to engage in conversation.

In the hospital, the ward staff noted that he wanted to be with his mother, but looked helpless beside her hospital bed. The social worker and nurse encouraged him to apply massage oil to her hands to comfort his mother. This enabled him to sit next to her with a purpose and he became less agitated and fearful of seeing his mother so ill. As he sat with her, he was prompted to talk about his feelings for her.

The reaction of Rosa's 13-year-old daughter to her mother's serious illness was quite different. On being told of her mother's impending death, she attached herself to an aunt. She appeared more emotionally autonomous and actively sought out her aunt for support. The aunt responded by sitting with her niece at her sister's bedside, supporting the girl through the impending separation and loss.

■ Reflection Question

5. How can the unique needs of family members facing the death of a family member be better met in the health care facility in which you have experience? How can social workers help?

The social work intervention allowed the family members the opportunity to grieve for their mother. This was in contrast to their usual pattern of communication, which was characterized by avoidance of emotional issues. Encouraging the children to talk about the impending loss of their parent gave them time to reflect, share, and grieve. The psychosocial assessment explored the attachment that the children had with their mother and provided the social worker with an opportunity to examine any risk factors that might have complicated the grief and bereavement process. These could include poor communication skills, feelings of unresolved conflict, attachment needs, or inappropriate dependence on others.

Summary and Discussion

Social work practice with the children of mothers who are dying involves complex tasks that require knowledge about child development, family relations, assessment of family communication, and the application of an ecosystemic perspective. These are key assessment areas that need to be explored in the social work process. The nature of social work assessment and approaches to intervention are influenced by the developmental stage of the child. The child's developmental stage needs to be evaluated to understand whether and how parental illness affects the child's behaviour, for example, through attachment or distancing.

The social worker needs to be comfortable in the use of practical resources as aids to the intervention plan. A most important resource is literature that is user-friendly and able to be understood by children, parents, and extended family members. Formal support systems, in particular the school, can react with increased insight and knowledge when they are offered a meaningful literature resource. The social worker is presented with the constant challenge of providing a family-friendly ward environment within the acute care setting, reducing some of the children's fears when they visit their seriously ill mother. This requires effective teamwork, participating in the culture of the oncology ward, and facilitating the shift from home to hospital, and from fear to emotional acceptance.

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CHAPTER 23

CONCLUSION

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Chapter Themes

From the chapters of this book, we can draw some prominent themes relevant to health and mental health. These include determinants of health and mental health, and the importance of a combined bio-psycho-socio-structural approach in practice and application of a strengths-oriented perspective in social work.

We have seen that people's health and mental health are experienced in the context of life cycles, stages, and points in time and within networks of interpersonal relationships and physical environments. Social, cultural, economic, and structural environments also affect health, well-being, and life chances. Many of these may not, at first glance, appear related. However, all these are, in varying degrees, determining factors in people's health and mental health.

Poverty, discrimination, oppression, and marginalization can adversely affect the health and mental health of people, those experiencing mental illness or addiction to street drugs, individuals who need to use food banks, women who live in abusive circumstances, and many others. The accounts in the book illustrate how people's problems rarely occur in isolation or one by one. Societal perspectives and meanings of an illness, condition, or injury are reflected, felt, and responded to at the individual level. Both societal and individual perceptions and meanings shape a person's view about herself or himself.

It is our view that the time context of an illness, condition, or injury in a person's life (e.g., life cycle stage at onset, duration, and course of the illness over time) is one important factor. For example, the diagnosis of cystic fibrosis or a mental health problem in adulthood has different consequences than in childhood. The past, present, and/or future is often important in the trajectory of illness and its effects over time on an individual and her or his social networks.

The intensity, severity, or degree of impact of an illness, condition, or injury and the resultant physical, psychological, and emotional effects on a person's life are also important factors. A surgery with good recovery will usually have less impact on a person's life than a serious burn that causes long-lasting pain and disfigurement.

Depending on the client situation, some of these will be more important than others. The social worker needs to work with the clients to identify these, since each situation is unique. In all the situations described above, good social work can be helpful. Social workers in health and mental health care will need to work with and understand situations of, for example, people with severe drug addictions, individuals with rare illnesses who critically question their life goals, hopes, and alternatives; and trauma survivors who experience significant losses.

In order for a social worker to understand, address, and act in complex human situations, a biomedical approach is insufficient. In fact, a biomedical approach is limiting because it cannot consider or address the life problems that cause, create, or exacerbate ill health. Rather, an approach that combines biological, social, psychological, and structural components to understand and respond to life problems is called for.

The strengths perspective in social work stresses people's commitment to growth and well-being and the capacity to overcome difficulties and survive even in situations that may seem hopeless. Frameworks that are holistic, seek connections, cross interdisciplinary borders, build and sustain support, and link individual problems with unjust social structures are needed. Social workers who understand and affirm the struggles and strengths of clients want to practise in ways that offer hope and validation. The central role of client strengths, capacities, and growth needs to be drawn upon when working with those who survive trauma, illness, and injury and those who live with mental health challenges, grief, and loss due to serious illness, bereavement, or incapacity, physical abuse, and other serious life issues. The innovative use of creative tools and methods with people who have mental health problems, for example, can help draw out an individual's striving toward healing and growth. The strengths perspective can also be applied to peer support in social work management in health care, as evidenced in several chapters that discuss social work supervision and conflict resolution. Ethical practice and ethical decision making have been shown to be at the forefront of good social work and in administration of human services.

Future Trends and Challenges

The future of social work in health and mental health rests on a number of factors. At the macro level, these are related to: (1) social welfare policy and fiscal arrangements in a particular nation, region, and/or locality; (2) administration in health and mental health care settings and the perceived contribution of social work in them; (3) existing opportunities for social workers to practise and provide services; and (4) acknowledgment by the public that social work services are beneficial and needed. If conditions are favourable, the continued provision of public and private social work services is supported.

Social work operates in an environment of human problems and their changing contexts. Although problems in living will always be with us, social problems and conditions reflect trends in the broader society at a particular time and place. For example, during a drought in a farming area, people's major problems relate to livelihood and food security. In the inner city of a large metropolis, problems of homelessness and drug addiction may be serious concerns. Social workers in health and mental health agencies and organizations need to understand and respond to the problems and issues that clients currently live with in addition to their health-related concerns. Evident to us is the complexity of social work in health and mental health care settings and the need for social workers to respond effectively. This is due not only to cuts in social spending and reduced provision of comprehensive services by health care organizations (e.g., hospitals), but also to social change and related effects on family and community life and social support.

The complexity and intensity of client problems in social work in health and mental health will continue in the future. Social workers need to know about social and administrative policies related to the situations of clients in the health and mental health care and other social service systems. Knowing how to work across and within systems to obtain information and advocate for needed resources for clients, while navigating through and negotiating for services, are particularly important in an environment of limited resources.

Social work in health and mental health care settings increasingly offers less administrative and supervisory support options and demands more autonomous practice from practitioners. Yet, there is a need to build supportive social environments in workplaces where peer support and collective responsibility can be fostered. Also, the need to participate in interdisciplinary teams to make treatment decisions and provide peer supervision and/or consultation to colleagues has increased and now seems to be an expected part of practice. Responding to difficult client situations and demanding workplace conditions requires creative thinking as a prerequisite for social work practice in health and mental health. Flexibility and good judgment skills applied to practice (e.g., with different ages and life stages of individuals, families, and groups) and knowledge about loss and grief reactions in a variety of human situations are helpful, as is knowing how to work across cultures with clients. In administrative settings, skill in providing peer supervision, working across disciplinary borders, and mediating in conflict situations have emerged as important areas for social work practice.

Effective and rapid assessment and ethical decision-making skills are needed to intervene in multifaceted and troubling client situations. Practice in crisis intervention, loss and grief counselling, and group work methods are especially useful, as are innovative techniques that are suited to particular client groups (e.g., non-dominant cultural groups, users of food banks, rural residents, marginalized people such as those addicted to street drugs, and others).

Implications for Social Work Education and Research

In order to prepare for future practice challenges, social work education will need to examine how best to help students prepare themselves for work in health and mental health care settings. This means that social work in health and mental health must include content on broad topics such as social welfare policy and social problems in urban and rural areas and their impacts on individuals, families, and communities. Social work education must help students not only to work across cultures appropriately and sensitively, but in ways that address discrimination, oppression, and injustice. Our codes of ethics call for social workers to do so. Student practicum need to be designed to provide good exposure to client issues and support to students so that they can learn the skills needed to practise in difficult client situations and practice environments. Important in social work classroom and field instruction is the use of critical reflection in which students are supported to question social work theories and methods and their applications to client situations. Reflection on students' own assumptions, ideas, and actions to enhance practice skills and knowledge as an ongoing activity is essential. It is also important to acknowledge that learning is a continuing process in social work and occurs throughout one's professional career. Clients, peers, supervisors, and many others are sources of valuable knowledge. Striving to build supportive and effective relationships with our clients and colleagues is necessary for professional development and satisfaction in our work.

Research in social work has often involved quasi-experimental designs that examine the effect of practice intervention. This type of research is a means of accounting for social work intervention, offering credibility to the profession. Other human service professions, such as nursing and medicine, engage in research to establish whether and how professional intervention makes a difference to service users or clients. Although research continues to be important, especially in the current social service environment that requires proof to justify funding of social work, we believe that it is equally necessary to carry out research that reflects the stories of clients who are in need of or receive services.

Clients who experience social work intervention are often heard about indirectly through aggregate statistics of users or on efficacy of treatment from the perspective of professional practice. However, we know that much learning comes from social workers' experiences with clients and the feedback received from their clients. Clients' stories about how they experienced social work intervention and what they needed at a particular time provide valuable knowledge. Although theories and skills can be learned from textbooks, educators, supervisors, and one's own practice, it is particularly important to learn from clients. The chapters in this book describe client situations that require help from social workers. However, most do not offer an evaluation of social work intervention from the client's perspective. The profession is in need of this type of research, conducted not to establish client satisfaction at the end of treatment, but to provide a more detailed and retrospective account of what helped and what did not. Qualitative research, which helps to shed light on experience through description and illustration, can teach much about what was most important to clients at difficult times in their lives. Findings from such research are essential for improving social work practice knowledge through critical reflection based on client narratives. Thus, we can apply what we learn from accounts of a burn survivor's fears, a bereaved grandmother's sense of invisibility, a food bank user's feelings of shame, a Chinese woman's positive response to *qi gong* exercises, and others, to our stock of knowledge for social work practice.

Summary

The chapters in the book highlight the resilience and will of the human spirit to acquire help, to make sense of life, and to surmount difficulties. Social work in health and mental health deals with human suffering and, as such, our approach to the work we do involves our attitudes toward fellow human beings who struggle with difficulties and crises in life. Although social work practice is becoming increasingly complex, the profession continues to attract people who have the capacity to rise to the challenge as they continue to develop and grow in skill and knowledge. This book shows that social work's use of approaches that combine biological, psychological, social, and structural components and multiple modes of practice in health and mental health is essential and necessary. It is needed more than ever before.

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