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University Of Alberta

Personal-Professional Connections in Palliative Care Occupational Therapy

by

Catherine A. Jacknicke ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment
of the requirements for the degree of Master of Science

Department of Occupational Therapy

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Abstract

The purpose of this qualitative study was to explore the personal-professional connections of occupational therapists working in palliative care in order to better understand occupational therapy practice in palliative care. The interplay between one's professional role and one's personal experiences was labelled the "personal-professional connection." Multiple tape-recorded interviews were conducted with 8 occupational therapists who worked in a variety of palliative care settings in an urban Canadian city. The interviews were transcribed, then analyzed for recurring as well as unique themes. Personal satisfaction resulted from patient and family expressions of appreciation, giving, relationships, working on a team, and managing challenge. For some participants, personal hardships accompanied palliative care practice in the form of feelings such as sadness, frustration, and anxiety, and even developed into stress and loss of control. Coping with such difficulties was accomplished through self-expression, self-nurturance, terminating relationships, control-taking, and rationalizing. Spirituality, including what is important in life, was identified as a strong personal-professional connector in palliative care practice. Participants all agreed the professional practice of palliative care had enriched their personal lives. Common themes, while resonating through each participant's story, were experienced in a uniquely personal way by each participant. The result was the discovery of an individualized personal-professional connection for each participant. Through a comparison to the Canadian Model of Occupational Performance, the implications of this study for occupational therapy theory are discussed. Recommendations for future research are included.

Prologue

Ever since I began practicing as an occupational therapist in palliative care in 1995, I have been trying to understand not only the role of occupational therapy in palliative care, but more importantly the effects of working in palliative care on the lives of occupational therapists. Upon entering the palliative care environment, I was very quickly exposed to many varieties of cancer, new occupational therapy treatment modalities, wonderful patients and families, and many deaths. During the first few months, I struggled to identify my role within the palliative care team. I was faced with a lack of guidance, as the literature was limited in its description of that role (American Occupational Therapy Association, 1987; Picard & Magno, 1982; Pizzi, 1984; Strong, 1987; Tigges, 1998; Tigges & Marcil, 1988). Even less available was what effect I could expect this experience to have on me as a professional and as a person. I began to talk to colleagues and to people whom I had met at various conferences and workshops about their experiences working with the dying. The responses were varied. Most therapists experienced great satisfaction and reward, yet they were unable to elaborate or put their experience into words. The usual response of a shrug and a smile was difficult to interpret.

Originally, I thought I would grow accustomed to my daily confrontation with death. Instead, I met patients and families with whom I developed strong bonds, often severed abruptly with the passing of the patient. Though with time I became more comfortable in my role as a palliative care occupational therapist, the question of the impacts of palliative care practice on the personal and professional lives of individuals who work with the dying remained. In talking to family, friends, and other health professionals, I found myself faced with the same curious questions I had posed of my colleagues months before: "Isn't that depressing?" "Don't you find that hard?" I had the same vague response as my colleagues before me. I enjoy my work. I am at times frustrated and sad, yet I do find my work to be very satisfying and rewarding. "Why?" "How?" A simple shrug and a smile was all I could offer.

In order to explore these questions, I decided to make them the focus of my research for my Master of Science in Occupational Therapy. Believing my own experience would complement my ability to understand the personal-professional connections of palliative care occupational therapists, I began my study.

Acknowledgments

There are so many people to thank. Thank you first to the participants of the study. By sharing their experiences, they provided me with understanding and enlightenment. I appreciate all their time and effort. Thank you to the Canadian Occupational Therapy Foundation and the Royal Canadian Legion for the scholarship, which was so helpful.

I am very grateful to my supervisory committee: Dr. Lili Liu for her ongoing support, enthusiasm, encouragement and guidance; Dr. Jeanette Boman for sharing her research experience and knowledge, and her constant interest and excitement about my findings; Dr. Ronna Jevne for her insight and knowledge about qualitative research; and Dr. Vivien Hollis for her input and willingness to be involved late in the process. My committee members granted me the freedom to explore my own creativity and critical thinking, while providing me with honest and respectful criticism.

A special thank you to my family, particularly my husband, Paul Prochnau, who was always patient and understanding, believing in me every step of my journey. Thank you to my many other friends and family who were endlessly supportive and encouraging as I was engrossed in my research.

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Chapter 1

INTRODUCTION

Due in large part to the work of Dr. Elisabeth Kubler-Ross, death is no longer a taboo subject. Still, there remains a tendency in North American society for people to avoid discussions of death and dying (DeSpelder & Strickland, 1996; Gammage, McMahon, & Shanahan, 1976; Rasmussen, Norberg, & Sandman, 1995). Instead, much of North American society appears to have a morbid curiosity about death (Tigges & Marcil, 1988). Spooky children's stories told around a campfire, horror movies of a gruesome, violent nature, eyewitness news accounts, and newspaper coverage often portray death as grim and fearful. Persons with terminal illness are faced by their own impending death. Where do these people turn to experience a peaceful death, a death unlike those in popular North American culture? Who helps the dying travel their final journey? Like Dr. Elisabeth Kubler-Ross, many professionals devote their careers, even their lives to working with the dying. One may ask: how are professionals working with the terminally ill affected by their work with the dying?

The Professional Practice of Occupational Therapy and Palliative Care

It is said occupational therapists practice their profession using a client-centred approach and believe in the worth of all persons (Canadian Association of Occupational Therapists, 1997). Traditionally, occupational therapists view each client using a holistic framework, assessing and treating clients in the physical, cognitive, emotional, social, and spiritual domains (Canadian Association Of Occupational Therapists). Each client is afforded an opportunity to live to his or her fullest potential.

The philosophical base of occupational therapy is enabling occupation with individuals and using occupation as a therapeutic medium (Canadian Association Of Occupational Therapists, 1997; Hopkins & Smith, 1988; Kielhofner, 1985). "Occupation refers to groups of activities and tasks of everyday life which are named, organized, and given value and meaning by individuals and a culture" (Canadian Association Of Occupational Therapists, p. 3). Central to occupational therapy is the belief that occupation gives meaning to life, has therapeutic effectiveness, and contributes to an individual's feelings of empowerment (Canadian Association Of Occupational Therapists). Occupational therapy espouses that occupation facilitates and enables a person to achieve maximum functional performance in the areas of self-care, productivity, and leisure and is committed to helping people live realistically within the limitations of disease by "helping people adapt to ... changing life situations in order to live as fully and comfortably as possible" (American Occupational Therapy Association, 1987, p. 6). "Individuals are encouraged to live within their limitations and to maximize the potential of each day" (Penfold, 1996, p. 76). Through client-centred practice an occupational therapist can help a terminally ill patient focus on what is important to him or her, and thereby enhance what time the patient has remaining.

Palliative care programs are dedicated to maximizing quality of life while providing support when there is little hope for cure. The relief of suffering and the provision of comfort are what each patient hopes for in their final days. A useful definition of palliative care has been suggested by the World Health Organization as cited by Doyle, Hanks, and MacDonald (1998):

> Palliative care: ... affirms life and regards dying as a normal process ... neither hastens nor postpones death ... provides relief from pain and other distressing symptoms ... integrates the psychological and the spiritual aspects of care ... offers a support system to help patients live as actively as possible until death ... offers a support system to help the family cope during the patient's illness and in their own bereavement. (p. 3)

Though palliative care is often discussed in relation to cancer care, it is important to realize palliative care is not a branch of oncology, rather palliative care is a comprehensive philosophy which has developed in parallel with oncology. Regardless of diagnostic category, palliative care focuses on providing symptom relief, emotional support, empathy, spiritual awareness, and maximum quality of life.

Palliative care is provided in the framework of a coordinated multidisciplinary team with an occupational therapist as a member of this team who provides quality care to the dying (American Occupational Therapy Association, 1987; Gammage et al., 1976; Penfold, 1996; Picard & Magno, 1982; Pizzi, 1984; Strong, 1987; Tigges & Marcil, 1988). Pain management, comfort and positioning, mobility, energy conservation, relaxation, and anxiety management are among the duties of the occupational therapist working with the dying (Penfold). Though medical and pharmacological interventions may relieve physical distress, a terminally ill person may continue to suffer embarrassment related to physical changes. The terminally ill person may endure social isolation, boredom, and emotional pain. An occupational therapist can help the terminally ill patient to regain a sense of personhood, a sense of being valued, a semblance of usefulness, and a reaffirmation of living with dignity (Doyle, 1998).

Unlike working with other populations, an occupational therapist working with the terminally ill population may approach assessment and treatment with a sense of urgency. Time is of the utmost importance as death approaches. Even with modern medicine's advancements and achievements, estimating an exact number of hours, days, or weeks a person has remaining is difficult, if not impossible. Changes in medical condition and general deterioration can occur daily and require numerous modifications to treatment plans and interventions. Of course, there is also the dying process and the inevitable death of the client for the occupational therapist to contend with on a regular basis.

Thesis Purpose and Format

This thesis is a narrative account of the exploration of the personal-professional connections of 8 palliative care occupational therapists. The interplay between one's professional role and one's personal experience, I have labelled as the "personal-professional connection." From the beginning, I hoped to be able to convey the experiences of these 8 occupational therapists in general, while respecting the nature and authenticity of the experience of each therapist. Furthermore, I hoped that the description of participants' personal-professional connections would resonate for occupational therapists and other health professionals who work in palliative care, but who were not participants in the study. Validation of one's own feelings and issues can arise from the knowledge that others face the same feelings and issues. For me, I realized that my experience as a palliative care occupational therapist paralleled that of the participants. Each participant, like myself, had experienced a connection between personal and professional experiences. Still, each experience remained unique. It is my hope that the exploration of these connections between personal experiences and professional practice will contribute to the understanding of occupational therapy practice in palliative care. It was a pleasure to be able to bring this unique subject along with these participants' stories to light.

Chapter 2 is a review of the literature which introduced me to some of the possible connections between personal experience and professional practice for occupational therapists working in palliative care. Chapter 3 describes the methods used to collect and analyze the stories generated by the study participants. Chapters 4 through 8 describe the results of the study which are organized according to the themes of satisfaction, hardships and difficulties, coping, spirituality, and personal-professional growth. The rich individual accounts illustrate personal-professional connections in different ways. In the conclusion, implications for occupational therapy practice in palliative care and implications for occupational therapy theory are considered. In the discussion of occupational theory, I describe a current occupational therapy practice model and its fit with the experiences of the participants in this study.

Chapter 2

LITERATURE REVIEW

A growing number of palliative care programs have increased the number of occupational therapists working with the dying. There is a paucity of literature geared to occupational therapists which would provide these professionals an awareness of possible physical, emotional, and psychosocial effects accompanying work in palliative care. Nonetheless, through exploring rehabilitation, nursing, and counselling literature, it is possible to extract some of the relevant concepts, themes, and experiences which might affect an occupational therapist's approach to professional practice, social relationships, and personal feelings, values, and beliefs about what is important in life.

In their phenomenological study with nurses, Rasmussen, Norberg, and Sandman (1995) discovered nurses hope and expect to grow personally from close relationships established with terminal clients and family members, to grow in their feelings, to expand their life experiences and to become more attentive and humble. However, there is a negative side too. Professionals working with dying patients are at particular risk of depleting energy due to the tremendous emotional investment their work entails (Davies & Oberle, 1990; Vachon, 1983). Depleted energy levels may leave professionals with little energy for other areas of life. Chronic grief may compound the energy problem, manifesting in fatigue and a lack of interest in life (Vachon, 1983). In her experience as an occupational therapist facing a family member's dying and subsequent death Thibeault (1997) recognized her own personal vulnerability and her limits of coping. According to

Petrosino (1984), self-realization and awakening to one's own needs can be a very positive release. It is only when one is aware of one's limits that the resources required to manage life's challenges can be appropriately accessed. With awareness, goals and expectations of self can be realistic, avoiding frustration and dissatisfaction (Petrosino).

In discussing the therapeutic role of the occupational therapist, some authors have identified personal feelings therapists may experience, such as satisfaction, hope, sadness, grief, frustration, anxiety, and fear. The literature also suggests that thoughts about spirituality may emerge when one is working in palliative care. The following is a discussion of how each of the areas mentioned above have been discussed in the literature.

Satisfaction

Appreciation and gratitude of terminally ill persons and their relatives have been heralded as some of the most rewarding aspects of working with the terminally ill (Cohen, Haberman, Steeves, & Deatrick, 1994; Rasmussen et al., 1995; Scanlon, 1989). The nature of palliative care is such that caregivers may form close relationships with terminal patients, their families, or both. These relationships may provide the professional caregiver with enjoyment and strength (Rasmussen et al.).

Personal qualities such as honesty, attentiveness, and wanting to give of oneself are fundamental to caring for the dying (Davies & Oberle, 1990; Rasmussen et al., 1995). Care becomes meaningful "once one is permitted to act in accordance with one's own values and outlook on life ... providing the kind of care one would want for oneself and one's family" (Rasmussen et al., p. 353). Providing meaningful care can bring great satisfaction and joy to the professional caregiver (Rasmussen et al.).

Hope

According to Scanlon (1989), "hope is not based on false optimism or benign reassurance, but is built instead on the belief that better days or moments can come in spite of the prognosis" (p. 491). Hope in palliative care is for a good quality of life and for a peaceful, painless death (American Occupational Therapy Association, 1987; Scanlon). Health care providers, through expertise, provision of care, and their relationship to the terminally ill person, can help to "shine light in dark corners, to help find a new perspective, and to facilitate strength in broken places" (Scanlon, p. 491). Reciprocally, terminally ill persons, through their intimate relationships with health care providers, can instill hope and inspiration (Scanlon).

Jevne (1991) wrote a collection of stories of hope from the perspectives of different people in palliative care: patients, caregivers, and the bereaved. In each story, each person has a unique view of hope. For the caregivers, theirs was a hope to maintain perspective, to remain genuine, and to ease the suffering of those who are dying.

Herth (1993) emphasized hope-fostering strategies used by family caregivers of terminally ill persons. Examples of hope-fostering strategies include: (a) sustaining on-going, supportive relationships; (b) cognitive reframing to let go of unrealistic expectations and establish a perspective; (c) setting attainable, realistic goals while recognizing when to redefine these goals; and (d) time refocusing, focusing less on the future, more on the present (Herth). These strategies provide a family caregiver a sense of hope, regardless of their family member's nearness to death. On the other hand, Herth also described hope-hindering factors, those which interfere with attaining or maintaining hope. Hope can be hindered by isolation (physical, emotional, or spiritual), concurrent losses, and poor symptom management (Herth). Though Herth's study did not focus on professional caregivers, it is reasonable to think that these hope-fostering strategies and hope-hindering factors may also apply to professional caregivers. Professionals who work with the dying often work in isolation either in home settings or on hospital units with goals which are fundamentally distinct from goals of other acute or long-term units (Beszterczey, 1977). These may present as hope-hindering factors. Furthermore, professional caregivers are exposed to numerous deaths on a regular basis, some of which may follow a course of poor symptom management despite the best efforts of the caregivers. Thus, hope-fostering strategies may be necessary to allow professional caregivers to maintain their abilities to work in palliative care.

Sadness and Grief

It has been observed that professionals working with the dying often have difficulty letting go of one relationship only to enter another relationship which will ultimately end in letting go again (Beszterczey, 1977; Feldstein & Gemma, 1995; Kiger, 1994; Martin & Berchulc, 1987). With each new patient, each new relationship, a health professional develops rapport and perhaps even a friendship (Rasmussen et al., 1995; Scanlon, 1989). The ultimate death of a patient severs that relationship, leaving behind feelings of sadness and grief (Scanlon). Grief may compound due to unresolved sorrow or sorrow over the constant and often unacknowledged loss of so many patients (Vachon, 1983). Watching families grieve may also heighten the professional's own feelings of sadness and grief (Petrosino, 1984). In addition, this sadness and grief may remind the professional of his or her own personal losses.

Frustration, Inadequacy, and Competence

Vachon (1983) indicated that professionals may not only feel sadness, but also "frustration at having invested large amounts of energy in caring for people who then die, taking this investment with them" (p. 241). Therapists may experience a sense of loss of control and helplessness, feelings of professional ineffectiveness and incompetence (Alexander & Ritchie, 1990; Martin & Berchulc, 1987; Vachon, 1978, 1998). There can be a degree of uncertainty when a patient passes away, especially if their passing is sudden and treatment goals remain unmet. It is not necessarily clear "whether the lack of accomplished goals is related to one's own limits regarding knowledge, skills, understanding, and courage or to the nature of dying itself" (Rasmussen et al., 1995, p. 352). Thus, the interplay between one's personal and professional limits and abilities can contribute to feelings of frustration and inadequacy.

Care providers may be preoccupied with thoughts of what they could have done differently for a particular patient after that patient dies (Beszterczey, 1977; Martin & Berchulc, 1987). For occupational therapists working with dying patients, Bennett (1991) recognized a need to re-evaluate the criteria for successful therapy. Beszterczey suggested self-esteem and self-confidence may be fostered only when expectations become congruent with the limitations inherent in caring for the dying. In essence, professional caring inspires the personal self.

Anxiety and Fear

A common theme in the literature was the high degree of anxiety experienced when working with dying patients (Alexander & Ritchie, 1990; Feldstein & Gemma, 1995; Martin & Berchulc, 1987; Scanlon, 1989; Stowers, 1983; Tyler, Carroll, & Cunningham, 1991; Vachon, Lyall, & Freeman, 1978). Working with patients who experience extreme pain or psychological distress can raise anxiety of a care provider, be they a family member, friend, or health professional.

A professional's own conduct may be a source of anxiety. Working with terminally ill patients often means making care decisions under time constraints without available consultation (Petrosino, 1984). Martin and Berchulc (1987) indicated a therapist may not know what to say to the dying person and their family, how to act, or where the limits of professional behaviour lie, thereby increasing tension and anxiety for both therapist and patient.

Build up of anxiety over time can manifest in stress and burnout (Feldstein & Gemma, 1995). Stress may be manifested in areas such as sleeping difficulties, weight gain, headaches, abnormal social behaviour, mood swings, and risk-taking behaviour (Petrosino, 1984; Vachon, 1978, 1983).

Working with dying people is a blatant confrontation with one's own mortality as the finiteness of life and the inevitability of death are faced (Petrosino, 1984; Robbins & Moscrop, 1995). Family, friends, and health professionals alike may feel a sense of fear of the unknown, fear of the loss of others, and the loss of self (Martin & Berchulc, 1987; Schrock & Swanson, 1981). Again, one's personal experiences are closely related to one's professional experience.

Spirituality

Spirituality can take many forms beyond religious beliefs. Spirituality may be experienced as an appreciation of each moment of one's life, or the development of an insight or meaning for life due to the nature of work in palliative care. Most nurses who participated in the study by Rasmussen et al. (1995) "learned to value each day and to live it as fully as possible" (p. 350). Thibeault (1997), in reflecting on her personal experience with death, expressed a realization that nothing is definitive and one must live for the moment. Davies and Oberle (1990) discussed the importance of reflection — reflecting on what is important to one's meaning of life.

DeHennezel (1997), a psychologist who has devoted much of her career to palliative care, indicated her work has caused her to be more attentive to the people around her, with her own sense of aliveness being more intense than ever. She stated, "I had no conception of how proximity to suffering and the death of others would teach me to live differently, with greater awareness and greater intensity" (p. 48) and went on to say that working in palliative care has enriched her life, providing her "moments of incomparable humanity and depth" (p. 69). Clearly, for this palliative care professional, her work with the dying connected her personal with her professional life.

The Research Question

Existing literature from rehabilitation, nursing and counselling addressed a number of questions worthy of investigation in this area. How does palliative care occupational therapy affect the therapist on a personal level? Are the feelings and associated issues identified by authors such as Martin and Berchulc (1987) and Vachon (1978, 1983) relevant in today's palliative care environment? What is it that provides the palliative care occupational therapist with feelings of satisfaction and hope, if any? Rasmussen et al. (1995), through their phenomenological study, were able to articulate the impact of palliative care nursing on the nurses themselves. Will a similar qualitative study illuminate the personal-professional connections of palliative care occupational therapy?

This study addressed the last of these questions and explores the personal-professional connection of palliative care occupational therapists, by interviewing therapists directly, going to "the source" of the experience. The personal effects of professional practice in palliative care are important and relevant to any therapist working or hoping to work with the dying. As such, the experiences of these therapists merit research in their own right. Simply stated, is there a connection between the personal and professional lives of palliative care occupational therapists, and if so, what might that be?

Chapter 3

METHODS

Qualitative Research

Martin and Berchulc (1987) conducted a literature review to study the effect of dying and death on therapists. Thibeault (1997) used a personal story to reflect on the experience of dying and death from the perspective of a family caregiver as well as a therapist. Rasmussen et al. (1995) used a phenomenological approach to analyze the experience of becoming a hospice nurse. Each of these studies or reflections contributed significantly to the methodological choice for the present study. I chose a qualitative descriptive approach based on the collection of narratives to yield a rich description of the interplay between personal and professional experience in palliative care occupational therapy.

Qualitative research is usually conducted to explore problems about which relatively little is known (DePoy & Gitlin, 1994; Morse & Field, 1995). Often, research topics are generated when "qualitative researchers ... draw upon their own experiences as a resource" (Denzin & Lincoln, 1994, p. 199). Research questions are exploratory in order to yield rich description and understanding of a situation or event. Because qualitative research methods are particularly useful when describing a particular phenomenon from the emic perspective — the perspective of the person who is experiencing the phenomenon (Morse & Field, 1995) — a qualitative descriptive inquiry was chosen as the most appropriate methodology for this study.

The therapists who participated in this study provided detailed descriptions of their experiences that could be shared with other people in similar situations. There was no right answer, no tangible measurable quantities; rather, a complete description of the experience from each participant's point of view, "different and discrepant perspectives ... considered (as) a part of the context" (Morse & Field, 1995, p. 142).

Background Preparation for the Study

My first step in conducting this study was to explore my own preunderstandings. Using my research journal to record my thoughts, I wrote my first entry:

> Working in palliative care changed my life — pure and simple.
> Working with the dying was satisfying, knowing I helped someone in a time of great need. The gentle touch from a special patient was a wonderful thank you. The fast pace of palliative care was frustrating at times. I did not have time to just “sit” with a patient. I felt guilty for not being able to see all patients in short order. ... I learned not to put off until tomorrow what I can do today. I believe I became a better listener. ... I became more creative in my practice — a necessity to meet the varying needs of my patients. ... Though family and friends were always appreciated and valued — now with even greater depth. The saying, "Life is short" became vividly real. I made a more conscious effort to be with, to talk to those people I cared about. ... I worried about death — worried not that something would happen to me, rather to someone I cared about. ... I became more tolerant of life's small problems — because they were just that. I grew to appreciate all that I have. I gained a clearer understanding of what is important in my life — family, friends, and health.

Throughout my research I considered my own experiences. I recorded my own feelings and thoughts in my research journal as I progressed. Still, I was very careful to ensure that it is the stories of the participants that resonate throughout this work, not my own preunderstandings. Having so noted, one must also be aware that as a researcher involved in dialogue with the participants, I inevitably helped each participant to develop his or her own personal story through my questions and responses. The nature of discourse, of interview, and of the research relationship was such that my responses to participants and participant responses to me undoubtedly affected one another (Potter & Wetherell, 1987). These influences were continuously considered and reflected upon in consultation with the participants.

A pilot interview was conducted with a social worker who was employed in palliative care. The pilot interview assisted me in estimating the time commitment required for the initial and subsequent interviews, determining how easily understood guiding questions were, and discovering the potential for my questions to generate rich data. In addition, I discovered the equipment quirks and details necessary for accurate recording of interviews!

Conducting the Study

Ethical Safeguards. The study received ethical approval from the University of Alberta Health Sciences Faculties, Capital Health Authority, and Caritas Health Group, Health Research Ethics Board. The study was conducted in a manner which ensured each study participant agreed to participate under his or her own free will and with full knowledge regarding the nature of the research process. Consent was obtained at the outset (Appendix A). Participation was voluntary and each participant reserved the right to withdraw at any time or refuse to answer any question, without consequence. Nonetheless, all participants completed the study.

Each participant kept a copy of the Consent Form, the Information Sheet (Appendix B), and the Invitation to Participate (Appendix C) including my contact phone numbers. The nature and purpose of the research were clearly explained to all participants. Participants were invited to contact me at any time during the study process with any questions or concerns he or she might have related to the study.

Interviews were conducted in privacy, with the exception of one interview which took place in a coffee shop at the request of the participant. All recordings and transcripts were stored to ensure confidentiality in a locking cabinet and pseudonyms were used, chosen by participants themselves. Participants were instructed not to reveal identifying remarks about past or present patients. Any identifying names were removed during the transcription process, replaced by phrases such as: name of hospital, name of therapist, and name of client.

There were no anticipated risks to participants' health and well-being; however, some participants indicated a feeling of "sadness" and were tearful as they related their experiences working in palliative care. Research activities of reflection, discussion, reviewing transcripts, and reading the completed study (most participants accepted an invitation to read the completed research results) always has the potential to affect a participant's self-awareness, life-style choices, and priorities. The discussion of personal experiences may have raised an awareness for participants, an awareness which may not have occurred outside the research environment (Bergum, 1989). When copies of the completed study are provided to participants, though textual passages are written anonymously, each participant may re-read the study at a later date which may in turn lead to more reflection (Bergum). As Bergum indicated, a study of this nature "point(s) to ethical commitments that have life-long obligations, which do not end with the signing of the voluntary consent form and clearance from a university research ethics review committee" (p. 54). At the end of the final interview, a list of general bereavement resources (Appendix D) useful for clinicians and clients alike was provided to each participant for their interest and in appreciation of their participation.

At study completion, thank you letters were mailed to all participants. Participants did not receive any monetary payment for their participation; however, I did offer to pay any parking expenses incurred for interview sessions.

Participants and Recruitment. The personal-professional connection of palliative care occupational therapy was studied with those who worked in a palliative care setting. In qualitative research, the assumption is that one can never replicate an experience in another setting. A change in context is a change in the experience itself; differences are to be expected, though similarities to other related situations can extend knowledge. Qualitative inquiry "makes us more empathetic and provides insights into others' experiences while enriching our own" (Morse & Field, 1995, p. 192).

I used a purposeful sample (Morse & Field, 1995) of participants who were selected based upon their specialized knowledge and ability to provide useful information regarding the topic of inquiry. At first, I contacted potential participants by telephone. Following this initial contact, I met personally with each potential participant to discuss the study and the research process. Following a time period of 1 to 2 weeks, I telephoned potential participants again to confirm continued interest in participation. Once verbal agreement was obtained, the initial interview was scheduled. Consent forms were signed prior to initiation of the initial interview conversation.

I had two or more interviews of at least 45 minutes with 8 palliative care occupational therapists: 7 female, 1 male. Three of the 8 participants were married with children; the remaining participants were single with no children at the time of the study. Participants were employed in a variety of palliative care settings including multi-institutional and community based settings located within a large urban city in western Canada. The mean age was 35 years; average time in occupational therapy practice was 8 1/2 years, ranging from less than 1 year to 25 years; and average time in palliative care was 3 1/2 years, ranging from less than 6 months to 10 years. All participants had a minimum University Bachelor level degree in Occupational Therapy. The names participants chose for themselves were: Ann; Betty; Joan; Karen; Ketya; Megan; Mickey; and Ziggy. Throughout the remaining thesis, participants will be referred to by these names.

The Semi-Structured Interview. "Respondents often reveal information during an interview that they would not discuss in a (self-administered) questionnaire" (Sorrell & Redmond, 1995, p. 1120). The flexibility of an interview allows respondents the freedom to discuss what they feel is important and appropriate, and to provide contextual details and explanation as they deem necessary. I conducted audio-taped, semi-structured interviews with the aid of an interview protocol and a selection of possible cues and prompts (see Appendix E). Interviews were conducted either at a participant's home or a place of mutual convenience. Timing of interviews was dependent upon participant schedules and time most limiting to the possibility of interruption.

After each interview, the interview was transcribed by a third party who was not involved in the study process itself. Two days to 1 week prior to a subsequent interview, I provided the participant with a transcript of the previous interview. The participant had time to read the transcript to re-orient him or herself. Each participant was invited to elaborate on and clarify the transcript at the beginning of the subsequent interview. Once the participant thought the transcript was an accurate representation of our previous interview, the interviewing process continued. Points raised in the previous interview, as well as new points that arose, were discussed in more detail.

The interviews continued until theoretical saturation occurred, when certain information consistently emerged and less and less new information was being discovered. At this time when information was a "repetition and confirmation of previously collected data" (Morse, 1994b, p. 230), the interview process was considered complete. Seven of the 8 participants were interviewed three times, the 8th participant twice. The interviews lasted between 45 minutes to 2 hours.

Though the nature of discourse necessitated that I interact with participants to explore their experiences, I tried to let the participants' data guide the interviews. My personal thoughts, feelings, and observations were recorded throughout the study at the end of each interview and in my research journal in an effort to identify and separate my input from the participant data. Striving for self-awareness, I wrote as freely as possible to catch all impressions and initial insights. Some participants expressed a curiosity about my experience as a palliative care occupational therapist. In order to avoid influencing participants' discourse, I shared my experience at the end of the interview process.

Data Analysis. Thematic analysis was concurrent with data collection to allow interviews to focus on qualities of the experience as they were identified. In thematic analysis, VanManen (1990), defines a thematic phrase as one that "serves to point at, to allude to, to hint at, an aspect of the phenomenon" (p. 92). A theme is an essential aspect of the phenomenon under inquiry. VanManen recommended trying to imagine the phenomenon without a particular theme to verify whether the theme is essential to the phenomenon. Marshall and Rossman (1995) explained "the researcher does not search for the exhaustive and mutually exclusive categories of the statistician, but instead to identify the salient, grounded categories of meaning held by participants in the setting" (p. 114).

A disciplined and systematic search was conducted in a process of reduction in which "every statement initially (was) treated as having equal value" (Moustakas, 1994, p. 97). Irrelevant and repetitive statements were left out leaving only "textural meanings" (ibid.). Morse (1994a) described this process as *sifting*, "the process that shakes off insignificant 'noise' from the aggregate stories, leaving only the common but important features" (p. 31). Passages, paraphrases, and quotes that describe a significant aspect of the experience were identified, highlighted, "cut," and "pasted" into the appropriate category. Analysis continued until each participant indicated that a rich, coherent, complete, and detailed description of his or her unique experience had been created.

Analysis was continually verified through member checks, whereby participants were given the opportunity to elaborate or clarify the analysis I had made of their data. In addition, through informal discussions I debriefed my developing ideas with colleagues not involved with the study. This discussion assisted me with the identification of gaps in data and refinement of my thinking.

The resulting text was rich with description and vivid detail. Though no significant change was made in the cited dialogue, and direct quotes were used whenever possible, some quotes have been changed to protect anonymity or to make the excerpt more clear and concise.

Through descriptions provided by participants, I was able to identify common themes in the experiences of these palliative care occupational therapists. Though these common themes resonated for all participants, each participant experienced each theme in a personal way. Each participant's story was a unique collection of feelings and experiences. Each occupational therapist's experience with palliative care was shaped by both common and individual realities, which created unique personal-professional connections. Chapters 4 through 8 explore each common reality (satisfaction, hardships and difficulties, coping, spirituality, and personal-professional growth) as well as the individual realities of Ann, Betty, Joan, Karen, Ketya, Megan, Mickey, and Ziggy.

Chapter 4

SATISFACTION

Satisfaction was the initial sentiment expressed by 5 of the 8 participants in this study, with the remaining 3 participants discussing satisfying aspects of palliative care later in the interviewing process. Therefore, personal satisfaction was expressed by every participant. This satisfaction resonated for those participants who continue to work in palliative care; one participant indicated palliative care had not been as satisfying as she would have wished and consequently left her position as a palliative care occupational therapist during the course of the study. Many sources of satisfaction were identified in the study including expressions of appreciation, giving and relationships, working on a team, and managing challenge.

Expressions of Appreciation

As Rasmussen et al. (1995), Cohen et al. (1994), and Scanlon (1989) indicated, receiving the appreciation and gratitude of terminally ill persons and their families is reported by professional care providers as a very rewarding aspect of work in palliative care. According to study participants, their contribution to the care of the dying was valuable when patients and their families expressed their appreciation. This sense of being valued and appreciated translated into a feeling of satisfaction. The appreciation expressed by the patient, regardless of the outcome of the treatment, proved to be a source of great satisfaction for Megan:

> Even though we didn't accomplish the goal — that would have been the ideal — but even though we didn't, I still feel as though I did what was best for [the patient]. I know she was grateful for all I did and that, in itself, is rewarding.

Betty affirmed this expression of personal satisfaction arising not from the success of the treatment as much as from the gratitude expressed by the patient's family:

> I can do a lot of work with an individual, and the outcome might not be any better than what we started with. But because the family member is grateful for the time that I spent, is grateful for what I had to offer, that is satisfying.

Palliative care requires a team approach, each discipline relying on the others, with no one discipline possessing all the skills required to independently care for the dying patient. Recognition for a job well done and expressions of appreciation from colleagues were sources of satisfaction for Betty:

> There are lots of pats on the back. People give each other lots of acknowledgment for work done. They might say, "You did a really good job of positioning so-and-so in their wheelchair." That can make a big difference in your day-to-day work. A social worker one time thanked me for working with [a patient] so diligently on a splint and making sure it was comfortable. ... Definitely makes you feel more satisfied with what you've done for the [patient], that [your role] is important, and you receive acknowledgment for that.

An expression of gratitude conveyed by another person, be they a patient, family member, or colleague, was a source of satisfaction for both Megan and Betty.

Giving and Relationships

Davies and Oberle (1990) and Rasmussen et al. (1995) indicated that the personal quality of giving of oneself is fundamental to caring for the dying. Although she used a rehabilitation assistant to carry out many prescribed occupational therapy treatments, Betty expressed that the giving of herself in time spent in one-to-one contacts was key to the satisfaction she received in her work with the dying:

> It's not just getting to know [the patient], but it's having the time to spend with them, on something that ... I need to do, not the assistant. Sometimes, you might see somebody for an initial [assessment]. The assistant will take over the [treatment]. ... That degree of satisfaction isn't there, as if it was something that I had to do, I couldn't pass on. [When] I spend time with the person, that is satisfying.

Participants described a reciprocal giving which takes place when one works in palliative care. A palliative care occupational therapist will get to know a patient and the family while forming therapeutic relationships. In the building of these relationships, the giving of oneself is met by the giving of another person, a reciprocating experience which is satisfying to both parties. Karen expressed it well when she said:

> While I'm getting to know someone, somebody is also investing in this relationship and sees that it is valuable to them. ... It's a reciprocal giving. There was a woman who was quite depressed, hardly ever smiled, and she was a pottery teacher ... I've never really done pottery. I asked her to teach me so that I can do it with other patients. She loved doing that. Everyday [she] would be up and showing me the different paints and paint brushes. She got a lot of joy out of it.

Rasmussen et al. (1995) suggested that close relationships are the core of palliative care. Many participants expressed that the close relationships they formed with patients and their families left the therapists feeling satisfied, even after the patient had passed away. Ziggy explained it as not only being in a close relationship, but the rapid formation of that relationship which provided her with a feeling of satisfaction:

> You establish quick relationships with [patients]. You get to know [patients] really quickly because you don't have much time to get to know [them]. They don't take long in revealing some of the neat things that they have done in their lives, who they are, what they're about, and maybe what plans they might still have. ... I find that really rewarding.

The participants described giving as not only giving of themselves, but giving through the provision of the occupational therapy service and treatment. By providing a variety of occupational therapy treatment interventions, Betty had the opportunity to improve a patient's quality of life:

> She had ALS[1] ... she couldn't speak for the longest time. I worked a lot on her wheelchair seating, getting her comfortable in her chair. I worked even longer on her communication. A special keyboard that she was using had tiny little letters and she couldn't punch them with her fingers, because she had no control of her wrist. So, I made a splint with a pointer at the end so she could press the keys [and] she could communicate with her husband. I worked a lot with her, because she changed every few days. ... I did a lot of inservicing for the staff on how to communicate with her. That [experience] was really satisfying, because I know I made a big difference for her.

A central goal of palliative care is the alleviation of patient suffering and pain. The alleviation of suffering through the provision of occupational therapy intervention created a feeling of satisfaction for Mickey:

> Relaxation therapy, that's where you see the progress. Some people are [admitted] onto the unit, they cannot cope, and you can see the tension and the stress in their eyes. After a session of relaxation, they feel relaxed — just to see the progress and the change in the results, it's really satisfying.

---

[1] ALS is Amyotrophic Lateral Sclerosis or motor neurone disease.

Ann pointed out that she did not need to be present for the positive results of her occupational therapy interventions; rather, the simple knowledge that she played a role in providing quality care left her feeling satisfied:

> I think of a relatively young Dutch woman, who had five or six kids. [She] wanted to still get out to school meetings, and out to one or two of the boys' hockey practices. She had a lot of bone metastasis, so her mobility was really hampered. It seemed like any time we tried to get her out, that stirred up everything, so there was a big price to pay for the things she did. I got her fitted in a wheelchair that was reasonably comfortable. Her husband ended up making her portable ramps, and family members got involved — it got to be a bit of a family project — they scouted out the arenas where the practices were in and looked at the pros and cons of different arenas. We figured out which one was going to be potentially most accessible for her to go and still be able to see the ice. ... [She] did get out to one of the neighbourhood rinks that was the most accessible, not for a whole practice — she wasn't able to tolerate the cold and the sitting — but at least a part. ... It's rewarding to have helped out in a little way.

In the above scenarios, satisfaction resulted when a therapist gave one's own time, provided professional services, and gave oneself in forming relationships. The focus of satisfaction did not appear to be patient progress, but the process of giving.

Working On A Team

The occupational therapist is a member of the multidisciplinary palliative care team which provides care to the terminally ill patient. Two participants in the study described being part of a cohesive group as a source of satisfaction. Whenever Karen reminisced about team interactions she would smile. She stressed the enjoyment she received working in a team environment of sharing, reciprocal support, and interdependence:

> I have come to appreciate how much can happen when people work together. Approaching someone who is in a really difficult situation, if I was the only health care person it would just be overwhelming for me. But knowing that this person has access to a number of people ... I think working [in palliative care] definitely shows me the saying "The sum is greater than the parts." I believe working together can do a lot more than working individually, and there is satisfaction in seeing that happen.

Mickey professed a similar satisfaction arising from an effort to work collaboratively. He indicated participation in a team was more efficient and saved him much work and much time when compared to other occupational therapy areas in which he had worked as an isolated individual care provider. By trusting in the judgment and skills of other team members, Mickey gained a sense of confidence. As a part-time therapist, Mickey could rely on his colleagues to continue his efforts and treatments in his absence. Upon his return to the unit, Mickey was able to carry on his treatments. The patient had not lost ground thanks to the collaboration of the palliative care team.

Managing Challenge

As new and unique problems arise in the context of palliative care, occupational therapists are faced with developing new and unique solutions. Ann and Ziggy identified being able to manage challenge while facing the urgency of palliative care as satisfying. In Ann's case, it was being creative and coming up with innovative solutions to new problems:

> I much prefer the challenge of something that is unique and different. It does require stretching the imagination to come up with a unique solution.

To Ziggy managing challenge was related to facing time pressures:

> You have to meet [a patient's] demands quickly. ... I like that. ... You can't be taking 5 weeks to carry out a treatment intervention. Usually, the client's needs were 2 days ago, and it is not something where, you know, Oh, well, eventually down the road they can use this. They usually need it *now*. It keeps you on your toes, makes you think quickly.

For Ziggy, the solution to a problem was determined by time. The rapid progression of a patient's disease process meant that an occupational therapist had a limited window of opportunity within which to work.

Satisfaction, a commonly expressed feeling, simply stated, had turned out to be a complex myriad of personal expressions. The sources of participants' satisfaction were varied, as each participant connected their expressions of personal experience to their practice. Participants experienced satisfaction as a consequence of another person's expression of gratitude, an act of giving, the team environment, and an ability to meet challenges. Along with the rewarding aspects of palliative care occupational therapy, participants discussed difficult aspects of palliative care occupational therapy. As was found with satisfying experiences, hardships and difficulties were numerous, some were common and others were individual experiences.

Chapter 5

HARDSHIPS AND DIFFICULTIES

As I spoke with participants, it became clear that along with the rewards and satisfactions of palliative care practice, the occupational therapists must endure hardships and difficulties. Many of the experiences discussed in this chapter have been described in numerous prior research studies. Here, the naturalistic approach used in this study puts those experiences in context through vivid examples.

Sadness, Grief, and Loss

Part way through the data collection and analysis phase of the study I came across an article written by Rashotte, Fothergill-Bourbonnais, and Chamberlain (1997). In their study with intensive care nurses, Rashotte et al. described a variety of reactions to the death of a patient. I was enchanted by their description of the difficulties of palliative care, specifically, death. These authors described nurses hurting and feeling a "cluster of emotions" (p. 377). I was struck by the resemblance to the present study, in such a way that this previous study helped me to make sense of my data. Feelings which Rashotte et al. labelled as hurting included sadness, grief, and loss. These same feelings resonated in the discussions with participants in this study.

In discussing the death of a patient, I found all participants reflected upon difficult experiences and a variety of accompanying emotions in a serene, undisturbed manner. Sadness and grief were not described with the same intensity as in Martin's (1998) study of grief in which parents described being overwhelmed by sadness when their baby died.

Some tears were shed as participants discussed the passing of patients; however, when I probed further, it was clear that these tears were not a disturbance for the participant; rather, a simple expression of regard. Typical expressions of sadness and loss included the following quotes from Karen and Ketya, presented in that order:

> I'm sad. I'm sad when they're gone. It makes me want to cry. ... Sad, but not a real disturbance.
>
> 'Sad' is ... [long pause] sort of an emptiness.

Karen and Ketya indicated it is not only their own sadness and loss which they feel, but an empathy for the sadness and loss of the patient's family. As Petrosino (1984) indicated, the professional's grief may be heightened through contact with the grief of the patient's family. Karen reflected upon the loss a patient's family experienced whenever she discussed her own sense of loss, indicating a family's loss is "much greater." Reflecting upon personal losses, Ketya identified feeling compassion and concern for what she knew a patient's family would likely endure:

> [Death is] a great loss and there is nothing that can fill it. It takes time to go through all the emotions that are involved, that are related to losing a loved one. It takes a long time, and you never really get over it. Knowing that process myself, knowing how long that takes, and how much time, effort and suffering is involved — it is just sad to know that [the patient's family] is going to have to go through that.

It is understandable that someone who, at a young age, lost her father to cancer would empathize with a dying patient's family and be sensitive to their grief.

An occupational therapist does not develop a strong, individual relationship with every patient. However, when a patient passes away and the therapist had reached a strong level of intimacy with this patient, a more profound sense of sadness and loss was felt by the participants. Karen's sadness became more profound when a patient with whom she had developed a close relationship passed away:

> It was like I could just sit down and sob. It was just so sad that it could really shake me ... almost like a loss of control.

Karen described this sadness as being "deeper than an intellectual level." Furthermore, the number of deaths which occur over a short time span was identified by Ann and Ketya as a contributing factor to increased feelings of sadness, grief, and loss:

> Some days you can feel pretty devastated if you lose a couple of people fairly close together in time, where you have been quite involved. You can feel like the bottom is dropping out on you.
>
> I had gone home for Christmas. ... We have a board where notices are for death and who has been hospitalized. I came in and looked at the board. I didn't know *how many* of my patients were up there, had passed away. That was the first time that I [felt] — you know, that sort of a pang.

In other words, during the 10 days Ketya was away from work, many of her patients died.

Vachon (1983) indicated the grief experienced in working with the dying can compound over time. It is with repeated confrontations with death that palliative care occupational therapists are at risk for accumulating grief and feeling overcome by it. In the present study, it was only Ann who identified a slow building of her grief to a point when she felt overwhelmed:

> I often think it is like having a garment that you wear multiple times before you launder it. If I have a light-coloured coat, the light-coloured coat looks just fine for 6, 8 weeks. Then, one morning I get up and look at it and think, "My Gosh! This is filthy! It needs to be dry-cleaned." Somehow, the emotional component of the job and the stress of the job is like that. It is like the little bits of fluff and rub marks that stick on a coat, a little today, a little tomorrow, a little the next day. None of it seems significant at the time, but 6 or 8 weeks later, all of a sudden ...

Megan discussed not feeling the sense of sadness, grief, and loss which she expected. She stated that she did not usually "react" when a patient died, therefore she thought, "I'm a monster." It was only later, at times when death was identified in concrete terms, that she experienced the feelings she expected to occur at the time of the patient's passing. Megan's response to death appeared to be a delayed reaction, rising to the surface only when Megan was confronted by the stark reality of death:

> One day, I was walking through a graveyard, and I got this funny feeling. I realized all those people at work that are under the ground right now ... Then another instance happened where I was on a sort of a tour with the maintenance man, and he showed me the morgue. In the morgue they have this big black book, and in the book they have the names of the people who have passed away — who have gone into this morgue. So, I opened this book and it was *amazing* how many names I recognized [as those of previous patients]! ... It bothered me more at that moment than when they had first died.

A graveyard and a morgue are both concrete physical reminders of death. A funeral is a symbolic social tradition related to death. While serving many cultural and religious purposes, a funeral provides an opportunity to acknowledge the reality of a person's death. Megan provided a vivid example:

> A lady passed away who had been on the unit for a long time. She passed away and they had a funeral for her downstairs. ... I thought, I'll just sneak in for a few minutes and stand in the back. I couldn't stay. ... I went into the stairwell, and I cried. ... This reaction is how I thought I'd react when people died. But, I don't. It is not until I go to a funeral and to *see* that it has really happened. ... You see the family there, you see people grieving, and you realize she's dead. ... I can't tell you why I don't cry when [death] happens, but I cried that day. I just don't know why.

Vachon (1987) indicates that professional caregivers do not necessarily grieve in specific amounts at specific points in time. Each professional grieves in an individual and personal way. For Megan, grieving was delayed until she was faced with evidence of the reality of death.

Interestingly, Karen did not describe grief and loss negatively. Although she admitted facing death is a difficult task, Karen was able to weave the experience to a positive end:

> Definitely for a family member, it is tragic. But, for me as a worker, it isn't tragic. ... A lot of [patients] have added to my life, they haven't taken away from my life. I don't have all the associations that a family member has with that person. The loss is nowhere comparable to their loss when the person does go. ... [Patients] come into my life, and they go. I have the satisfaction of knowing their death was peaceful or they were well cared for.

The sadness, grief, and loss identified to this point are very real emotions that therapists experience. However, Megan described a type of grief — what she called "unnecessary grief." This was a kind of grief that consumed Megan's energy and prevented constructive actions. For instance, as a patient was added to her case load, Megan would sometimes personalize the experience. She would imagine herself in the position of the patient's family. As a result, Megan found herself grieving for the loss of her own loved ones, loved ones who were in reality strong and healthy!

> Sometimes I think about [dying] a little too much. ... It is grief that [I] don't need. I don't know how to explain it, but I'm grieving for something that hasn't even happened. Like, sometimes I will literally go home and I will imagine [my fiancé] personally, and I'll start to cry. And I'll think "Whoa. He's not dying. What am I doing?"

I have chosen to present in this section only strong passages of sadness, grief, and loss. It is valuable to note, however, that in relaying experiences of death, all participants inevitably explored feelings of sadness, grief, and loss to some degree.

Paranoia

Gray-Toft and Anderson (1986), in a study with hospice nurses, found that frequent exposure to death precipitated anxiety about the nurses' own health. Many feared that any physical pain they experienced was related to cancer. Joan described "paranoia" as her professional role as a care provider to the dying turned into a personal concern that she herself was, in fact, dying:

> I thought I had cancer — I just did! And I thought, This is it! I was coming to terms — all these kind of things. "It just hasn't been diagnosed yet." ... I think in palliative care you see so many people with all kinds of cancers, and you do start to think it's a normal thing to have cancer. ... Sometimes you feel you've got a lump, and you think, "Oh my God! I'd better get that checked out." So, sometimes, it's a little paranoia.

I am happy to report Joan did not have cancer, but it was clear her daily confrontation with death proved so difficult that she internalized this hardship in a very personal way. Joan began to visualize herself not as a palliative care professional, but as a patient!

Joan's discussion of paranoia resembled Megan's discussion of unnecessary grief in that both were energy-consuming reactions to imaginary situations. The two reactions differed such that paranoia was related to the loss of one's own health and unnecessary grief was related to the dying and death of a loved one. Gray-Toft and Anderson (1986) warned that such unsubstantiated fears can become a source of stress for the palliative care professional.

Challenge, Urgency, and Stress

The challenge and urgency of palliative care have been discussed as providing some participants with feelings of satisfaction when they had the ability to meet their challenges. Nonetheless, these concepts warrant repetition at this point as contributing to the hardships experienced by some of the participants. The challenge of new and unique problems which was a pleasure to Ann and Ziggy was difficult for Karen to endure:

> What's challenging about [palliative care] is ... to see people who are so distressed. ... Cancer in particular, is not a disease that has a certain course. To hear all the things, all the variety of ways it can affect the body is not a pleasant thing. ... Just how the disease is and how it affects the body, makes it a little more challenging to physically be working with these people.

For Karen, it seemed that the uncertainty and the unknown course of the disease process presented challenges for which she was not sure she had the resources.

Karen indicated that the sense of urgency, the limited time of opportunity, and the feeling one needs to address concerns sooner rather than later, all contributed to a hardship she labelled "stress — a lack of energy":

> I think [stress] is the feeling I get from trying to do too much in the time that I have. That tires me. I can feel [stress] when I start getting more and more impatient, because I think everything has to happen now.

It was a sense of not having successfully or fully met a challenge which became a source of stress for Karen.

Mickey and Joan also labelled one of the feelings which arose from their work in palliative care as "stress":

> Usually when I'm under stress, I don't eat well, don't sleep well. [I] don't think clearly in most of [my] decision-making. [I] don't feel well, and this affects me in terms of [my] physical performance. ... I feel grumpy, and tired, and fatigued.
>
> I start being impatient with my fellow workers. I find that I'm not remembering to do things, that I've forgotten things. That is my first indication that I'm feeling stressed. Feeling that I'm not coping well with my time arrangement, time management skills. ... I find not sleeping at night — not very often for me that happens — I'm usually really good at sleeping! Those are some of the indicators.

"Stress" is a term generally used to describe what upsets a person, the response to this stimulus, and the interaction between a person and their environment (Cohen et al., 1994). In light of this definition, the examples suggest that participants experienced stress in response to difficult and trying issues of palliative care practice and to unmet challenges.

Anger and Frustration

Contrary to what Vachon (1983) reported, none of the participants expressed frustration at the nature of establishing temporary relationships with clients. Nonetheless, I did hear themes of anger and frustration resonate in the stories of over half of the participants. Generally, there were two areas that appeared to foster feelings of anger and frustration: the palliative care system and the non-compliant client.

The palliative care system consists of a number of administrative and bureaucratic levels, including the multidisciplinary team or the home care manager, the regional consult team, and the provincial government. Each level of administration provoked expressions of anger and frustration for the participants. At times, the multidisciplinary team was the focus of anger and frustration. A break in the communication of the multidisciplinary team was a source of frustration for Joan. She indicated that improperly-conveyed information interfered in her ability to keep her treatment up-to-date. Ziggy reported that members of the team would sometimes take on the role of the occupational therapist inappropriately:

> It frustrates me. It really frustrates me, and I'm seeing it happen more and more and more. As people become familiar with occupational therapy, they think, "Oh, yeah, that's simple, we [can] just do that." I think, "No." There's more thinking involved here, more of an evaluation or assessing a client's ability than [simply providing] a raised toilet seat — sending one out without even looking at the shape of the toilet, for heaven's sake! Does it even fit on the toilet?

Mickey, who reported that working on a team was very satisfying, also reported that it was frustrating. Being a part-time therapist, Mickey, at times, had to rely on other team members to carry out treatment interventions in his absence. Mickey reported that treatment was not always carried out according to his instruction. Incomplete treatment goals would leave Mickey feeling frustrated:

> You don't see the progress of the treatment or you don't see the effects on the patient that you wanted to have.

Members of the health care team, including patients and families, can place demands upon the therapist which leave the therapist angry and frustrated. Mickey reported that the demands for the professional's equipment and time can leave the professional feeling frustrated by his or her own limitations. The limitations are most often imposed by the higher administrative levels such as the funding available for palliative care. Ketya and Ann explained:

> There is more that I would like to do, but due to time constraints I'm not able to. Some patients actually pass away before I even get a chance to see them. ... I am angry at the inefficiencies and the lack of funding.
>
> Some days it leaves me really frustrated — angrily frustrated. It is the bureaucracy of the system. Yes, you can theoretically provide for the individual who is on [government assistance], but only after you have gone through a whole series of steps to meet the demands of the bureaucracy. That individual, depending on their diagnosis, may not live to see anything, because the system does not move fast enough.

An occupational therapist assesses a patient and makes recommendations which he or she believes would be in the patient's best interest. Not all patients and their families chose to follow the occupational therapist's advice and suggestions. These "non-compliant" patients and their families can contribute to the occupational therapist's frustration. Ann stated simply:

> You can be angry at patients and caregivers. You have given them good, sound advice and they have opted to ignore the whole works.

Ziggy was able to provide an example of feeling frustrated by her interactions with a non-compliant patient:

> We have a fellow with cord compression. ... [He was always] sitting on the couch. Skin was intact, but you know there's going to be an ulcer developing there. Sure enough, we have an ulcer. Then you've taken everything out possible Roho[2] cushions to Geomatts[3] and — doesn't like 'em, nope, doesn't like 'em, doesn't like 'em. So anything that you suggested, no, no, no, don't need them. Well, now, he's got this horrific ulcer that's — we're so afraid of it getting infected and causing other kinds of problems. Now, he's starting to listen. It's just sort of frustrating that could have been prevented and the person didn't see that as meeting his needs. So what do you do? It's frustrating. ... It could have been prevented.

Ketya felt angry when she interacted with a family member who was in denial and anger. The relative put her own needs before those of the dying patient:

> This [patient] had stomach cancer, and [his] wife was just angry at [her] husband. It was just so apparent. She didn't want anything in the house. He couldn't get to the bathroom and she didn't want a commode because — what would it look like? ... When I was putting in some equipment, a system for transfers to help him with bathing, she didn't want it there. I was a little miffed. I didn't show it, but I just thought, "He's dying here. He needs this!"

The personal anger Ketya felt was a result of her professional actions being blocked by the needs of the patient's relative.

Working within a system which is not perfect or working with patients and families who do not choose to accept the occupational therapist's advice lead to feelings of anger and frustration. Regardless of the source, anger and frustration were described as difficult aspects of palliative care occupational therapy. Although these difficult times were vivid and troublesome, all participants who expressed feeling angry and frustrated also stated that these feelings were rare.

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[2] Roho is the brand name of a pressure reducing cushion.

[3] Geomatt is the brand name of a pressure reducing cushion.

Guilt

In addition to feelings of anger and frustration, the lack of funding, the lack of time available, and the urgency so evident in palliative care practice can also lead to a feeling of guilt. Vachon (1998) used the label "role overload" (p. 924) to describe a professional's feeling when there is too much to do in a job. With decreases to health care funding, some professionals must carry a case load that is larger than ideal. Such was the case for Betty:

> I do feel I'm pulled in all directions. With palliative patients it can take me half an hour just to check in with my [assistant] every week just to find out how everybody is. Swallowing assessments take at least 45 minutes. Seating assessments take at least another 45 minutes. By the time you get all the equipment out and do all your phone calls, it's not a lot of time. I have time for the very, very basics, and that's it. ... Sometimes I do feel guilty that I can't spend as much time with everybody that I'd like to. ... I'd like to check in with them a little bit more frequent to find out how things are going, because things change so quickly. ... I'm not accomplishing the degree that I would like to accomplish, because I [only] do the basics for everybody. I'd like to go into a little bit more detail with some people, spend more time with some people, but I don't have that luxury. ... It can make me feel pretty guilty some days, pretty bad, especially if I leave on time. And honest to goodness, I'm probably here about half an hour every day extra, or some days, I might even be here an hour.

The urgency in palliative care, stemming from the rapid deterioration and fragile condition of the palliative patient, was brought to light again in the exploration of guilt. If treatments are not provided in short order, those treatments are often no longer required, the problem having grown, or as Megan explained:

> Sometimes [I feel] ... guilt. Say I was asked to put a splint on somebody. Then I find out the next day that when they were rolling her over [in bed] they sprained it. I do worry, because these people are more fragile than the general population. Neck collars is another good one. … What if I don't come right away, and then [the patient] fractures their neck, or something?

At times, it was not external demands placed on the participants by the system or nature of palliative care, but the occupational therapist's own behaviour which led to guilt. In Joan's story, it was her professional conduct which led her to experience what she defined as guilt. Joan entered a patient's home, aware of his diagnosis and prognosis, and began discussing his inevitable deterioration. Without first checking the patient's level of understanding or coping, Joan immediately made a number of suggestions to a patient regarding possible equipment needs he could expect to encounter as his disease progressed. When Joan had finished listing the equipment, the patient asked Joan, "I'm really sick, aren't I?" Joan suddenly realized she may have made assumptions about this patient's insight into the disease, hence she interacted with this patient inappropriately:

> I felt really, really, really bad. I felt, for one, I hadn't really read the situation. I wasn't tuned in as well as I should have been. I felt he needed the equipment and it would have been helpful for him, but I always have to remember that I have to look at what my goals are, what I want, and what the patient needs and wants. [I need to] be more sensitive to that. ... I felt I had really not done a very good job of understanding where that person was at. He was a younger man, and his diagnosis kind of came soon. He was a new, quick diagnosis, and he really deteriorated quickly and there was so many things going on. I could have been more sensitive to that. I felt guilty.

Guilt was described as a difficult emotion, one that the participants struggled to endure. As participants explored this emotion, their faces were strained, they shifted in their seats, and often looked away.

Anxiety and Fear

The common theme of anxiety and fear found readily in previous literature was touched upon only by Ketya. Martin and Berchulc (1987) pointed out that working with terminally ill patients necessitates that an occupational therapist confront death and, in turn, his or her own mortality and losses. In discussing her anxiety and fear, Ketya related these feelings not so much to the professional role she played with the dying patient, but to her personal experiences with dying and death. Ketya talked about the night before she had to meet with a patient who had a diagnosis similar to that of Ketya's father who had passed away years earlier:

> [I felt] sort of an anxious feeling ... knots in my stomach, those sort of physical symptoms ... headache ... anxiety, and you sort of think, "Why am I feeling this way? Why am I anxious?" ... I knew my visit was the next day. I didn't really recognize it at the time, but that day, I didn't feel very comfortable, had some knots in my stomach, and I thought, "What's going on? Am I getting sick?" Then I went to the gym and I had some time to myself and thought about a lot of things, and made things a little bit more clear about what was going on. ... I was fearful that when I saw this fellow it would bring up old memories and then I wouldn't be able to do my job.

Ketya went on to discuss a fear that "old memories" surrounding the death of her father would resurface when she met this patient. It was difficult for Ketya to face these memories and relive the hurt and grief of her past. Her work in palliative care had reopened wounds which she thought had healed long ago.

The remaining 7 participants did not discuss anxiety and fear as such. Instead, palliative care experiences brought up difficult feelings that they labelled as sadness, grief, loss, and frustration all of which have already been discussed earlier in this chapter. Thoughts of mortality were explored by all participants. There was a consensus that a confrontation with death led to an examination not of anxiety and fear, but of spirituality. I will defer the discussion of spirituality to Chapter 7.

Loss of Control, Competence, and Expectation

As Alexander and Ritchie (1990), Martin and Berchulc (1987), and Vachon (1978) found, participants expressed feeling a loss of control and uncertainty at their level of competence in working with the dying. A palliative care occupational therapist may do his or her best to meet the needs of a dying patient, but the end result remains: possible deterioration and inevitable death.

Joan reported that one client with whom she felt a loss of control was the client who was most memorable in her many years as a palliative care professional:

> There's been one specific [patient] that always stayed with me. We had a young woman, she was about 33, and she had two little kids. She really wanted to stay [at] home. But she had to go [into a hospital]. She had a quite aggressive physician who wanted to do something and brought her into the hospital for some surgery. It just went bad from there. So, her last wish was to come home. Well, they did send her home. I remember it was the night of that winter parade on [street name]. I know her kids. They were there and I was there. [The patient] was coming home from the hospital, they were sending her home with a special KCI[4] bed — you know, one of those big-to-do — pumps, everything. She came back home pretty much unconscious. She knew she'd asked to be taken home, and she came home and her kids were going out to the parade. [It] was probably good to get them out of the house for a little bit. But, I just thought it was really a shame that she had to come home like that. She died that night. If it hadn't been so ... It was sort of against her wishes to go into [a hospital], but she agreed reluctantly, and then that happened. That always felt bad, because it didn't necessarily have to go that way. It felt awful, especially when they had to bring in that bed. It was so big, if you can imagine one of those big beds coming in, delivery, setting it up. There are five people there that aren't family members, and there's me, and the doctor comes in ... Yeah, that one kind of stayed. That one never felt good. ... [At

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[4] KCI is KCI Medical Canada Incorporated, a medical supply company and manufacturer of pressure relieving mattresses and beds.

> the time] I felt kind of helpless, because I totally lost control over that situation, because that's beyond our control. Really, really sad that somebody who had tried so hard and struggled for a year at least ... and was young and was such a brave person to keep this up ... It was very sad for her, and disappointing.

Martin (1998) discussed "obsessive reviewing" (p. 13) when parents of a deceased baby review every aspect of their care to see what went wrong, what might have been missed. Similarly, the preoccupation with the death of a patient, the questioning of what could have been done differently, the wondering about one's own competence in practice was evident in the words of Joan, Ziggy, and Ketya, presented in that order:

> There is always the question if you should have gone in [to the home] sooner, if you should have contacted the doctor, or did you not, or everything just sort of falls apart at the end and did not work out the way you expected or hoped it would work out. I guess I feel like I haven't done a very good job.
>
> At first you think, "Could I have done it differently?" You know, sort of put it on yourself. Is there a different approach? How else could I have tackled this?
>
> Sometimes it is sort of an unexplainable feeling you get. You just go over in your mind what you have said and convince [yourself] that what you said was okay.

Megan, in questioning her professional competence, attributed lack of progress or unavailability of adequate occupational therapy intervention to unrealistic expectations of other team members:

> The intent is, the idealistic view is, that I should be assessing everybody who comes on the unit. I think that was the intent. When I started to work, I realized that it was impossible. I said, "Excuse me, there's no way I can assess every single person that comes on this unit, because I won't *treat* anybody. It's just impossible." ... That is something that I struggled with when I first started ... I can't see everybody [on the palliative unit]. ... I was worried that [other health care team members] might think that I wasn't doing my job.

Times of loss of control and times when participants questioned their own abilities were times explored through discussing difficult aspects of palliative care. What is noteworthy is the fact that those participants who indicated that these difficult times were an aspect of palliative care occupational therapy also indicated that these times were few and far between.

Whether expressed as a loss of control, anxiety, guilt, anger, or grief, it was clear that all participants had experienced hardships and difficulties stemming from their professional practice in palliative care. My exploration of participant stories turned to what palliative care occupational therapists do in difficult situations with difficult feelings. What do occupational therapists do with or about the hardships and accompanying feelings they experience in their role as care providers to the dying?

Chapter 6

COPING

Through continuous professional exposure to dying, death, and other hardships, the professional who cares for the dying develops and refines his or her own personal coping strategies. An occupational therapist working in palliative care must deal with his or her own difficulties, the difficulties of the patients and their families, and the great number of losses he or she encounters. All participants discussed openly their ways to cope with the work of palliative care. Each participant had a unique repertoire of methods. As found by Cohen et al. (1994) in their study with oncology nurses, coping responses vary according to the situation and an individual's personality. The coping strategies identified by the participants in my study included self-expression, nurturing self, terminating actions, control-taking behaviours, and rationalizing.

Self-Expression

Self-expression is a term used by Rashotte et al. (1997). These authors described self-expression as ventilation of feelings helpful in working through the death of patients. Seven of the 8 participants who took part in this study used coping strategies that involved some form of self-expression like talking, writing, crying, and using humour.

Talking was a form of self-expression where the participants in the study openly spoke about their experiences with death and loss. When the opportunity presented itself, it was important for Ketya to talk; however, Ketya pointed out it was important to place limits on her expression. She indicated that it is sometimes more therapeutic for her to talk for only a short period of time, in order to avoid taking too much of her energy and allowing the experience to become overwhelmingly negative. In some cases, participants described the benefits of speaking publicly in team meetings and group situations:

> I'll usually wait for the team meeting and talk about some thoughts and feelings, how [a death] went, what went on. ... All the team members talk about their experience. That is really therapeutic to do that. The debriefing part of it is helpful and if [a death] happens and we are not having a team meeting, I will often just talk it over with one of the team members, especially somebody else who was involved. We kind of reminisce about things and that helps.

At other times, participants spoke privately with someone with whom they had a close relationship:

> I talk. I will go to a social worker and talk. I will talk to a friend. I will talk to my supervisor or one of the nurses that knew that person and we can talk about how tough it is. So there is a lot of opportunity. I personally do a lot of talking about it, about feelings. I think I have worked out a lot of [grief] that way.

Writing was a medium used by Karen and Ann. Written expression provided participants with an opportunity for self-reflection, for conveying emotions in a thoughtful manner, for venting. A release of emotion rather than sharing of emotion seemed to be the motivation behind writing. This was evidenced by participants who admitted they did not always share their writings with other people. Whether through a journal, diary, or cards, each therapist had a unique way to acknowledge the hurt and loss. Ann and Karen explained:

> Journaling, for me, is just a marvelous media, because I can rage, I can ponder. I can write key points down and go back over things and look at how I could have done it differently. I don't necessarily journal in a traditional sense of writing a "Dear Diary" sort of thing. I journal on standard 8 1/2 by 11 sheets that then get hole-punched and slotted in a binder. I'll sometimes just diagram out a scheme of events and put notes and feelings out around that, so it ends up being a kind of matrix drawing.

> What I often do is write a card or write in a journal. ... When I write a card, it is usually for the [patient's] family. I share it with their family. I think it means a lot for the family. We also have a board at work, and that's sometimes quite effective, to write down whatever we want about a person.

Robbins and Moscrop (1995) identified crying as an emotional discharge in a natural healing process. Spencer (1994), in a study with nurses on an intensive care unit, identified crying as a separate and unique coping strategy for dealing with patient death. In the present study, Ketya and Megan identified crying as a coping strategy. Ketya indicated she would "just have crying spells," after which she felt relieved. Megan stated simply:

> It's amazing what a good cry can do. You cry and you get [grief] out of your system.

Showalter and Skobel (1996) encouraged palliative care professionals to use humour as a mechanism for coping and surviving loss. Three participants identified using self-expression through humour as a coping strategy. Karen saw humour as a way to "lighten up the atmosphere." She believed humour, albeit sarcastic in nature, helped her to put a situation into perspective:

> I remember one man said he really wanted to leave [the unit], very badly. He asked what would happen if he cut his hospital identification badge off. The nurse was looking at me, like, "What do you think would happen if he cut his badge off?" ... Anyway, then she said, "Have a good afternoon." He was going on a pass, and he looked at her and said, "How could I possibly have a good afternoon?" I felt like saying, "Well, go have a miserable afternoon, then, and you can get a good start on it. It's pouring rain."

Rashotte et al. (1997) found that black humour was used by intensive care nurses when they felt particularly challenged by grief. In their study, using black humour was seen as more acceptable than crying. Ziggy and Joan spoke of using black humour when they felt particularly challenged in dealing with the sadness and grief they encountered in their work. Many comments Ziggy made during our three conversations were barely audible on the audio-cassette. She would lower her voice and mumble to herself, usually making jokes. She later said she did not want to offend the transcriber. Joan stated that she was aware of perhaps appearing callous to other people, often restricting her black humour to interactions with her palliative care colleagues: "We know more people that are in the cemetery than not!" I was reminded again of the study by Rashotte et al., where participants were quick to point out black humour must be used carefully and only in the presence of colleagues.

These various methods of self-expression helped participants to manage their difficult feelings and facilitated the release of stress. Participants faced the feelings and stresses of their professional experiences in whichever manner was personally acceptable. Self-expression, whether in a public or private domain, was helpful as a coping strategy in dealing with the difficulties of palliative care occupational therapy.

Self-Nurturance

Another category of coping strategies identified by Rashotte et al. (1997) was self-nurturance — doing something special for oneself. I heard this coping strategy repeated in the stories of the participants in the present study. Ketya identified participating in physical exercise as a time for reflection, a time to express herself when words would not suffice. Betty used leisure activities not only for pleasure, but to "forget what might have happened that day, trying to put that behind, or just to think about something [else]."

Both Joan and Mickey used relaxation techniques as ways self-nurturance helped them to relieve "stress" they encounter in their professional lives:

> If it is a really sad [day] ... I will take that home and feel sad. ... Try to find a way to cheer myself up. Like trying to take some ... stress-free time ... doing some relaxation will help.
>
> Doing other activities besides your work, to relax yourself. Go out and play a sport or just sleep! You are done after 4:00 and that is it.

While Rashotte et al. (1997) described self-nurturing activities as "mindless, requiring little concentration and energy" (p. 381), participants in the present study focused on the pure enjoyment of activities. The health professional self-nurtures by doing something pleasurable to help release emotion.

Termination of Relationship Activities

The category "termination of relationship activities" consists of all those activities that help therapists establish a sense of closure after a patient has passed away. Rashotte et al. (1997) used this term to encompass activities such as following-up with family members and attending funerals. Participants in this study took part in similar activities as a way of coping with their work in palliative care.

Some therapists participated in public activities such as funerals, wakes, and the lighting of candles in memory of the deceased. Others, like Joan and Ziggy, contacted the patient's family for one final meeting to establish closure:

> I will usually try to follow up with a visit if it's appropriate to the family after. That is very good, to get some closure with the family, check out to see how things are happening for them. ... Make sure that they get connected with some other supports in the system, like bereavement counseling. ... Not too long ago, we had a client that went into the hospital really quickly and died — one of those unexpected ones — and I didn't have an opportunity to call [the family]. I wasn't sure what happened. Finally, I thought, "I'm going to have to find out what happened in the hospital." So I phoned [the patient's] wife. I had a relationship with his wife that I felt comfortable phoning her to find out what happened. She sort of cheered up and we had a nice talk about it. She had a chance to tell me what happened. ... That was good.
>
> Sometimes, it doesn't end by [the patient] dying and you going on with your next case. ... There are some people that like to have a continuing attachment to [team members]; although we don't encourage that because there are certainly lots of other resources for them in the community in terms of bereavement, counselling and bereavement support. Many times, the family would like one last follow-up visit to hash out the situation, hash out that process of dying, what happened after the funeral, and that kind of stuff. It's sort of a way to say good-bye.

One participant discussed a unique method of terminating a relationship not mentioned by Rashotte et al. (1997). This method, which was used by Betty, was a form of private, personal reflection. When a patient passed away, Betty spent a moment in quiet deliberation, remembering that patient as distinctive with some special characteristic. This closing strategy I call *the final image*:

> For everybody that passes on, I just have a final thought about them, whatever it is. If it's a lady who loved flowers, I might just think of a flower [resembling] her. Then, chapter closed and someone else can go into the room. If it's someone I always saw and this is how they always sat, no matter what I did they always sat leaning, then I would just sort of remember that. Then, I'm ready to close and go on again. I remember something about everybody ... no matter how much I worked with them.

I was touched by Betty's personal connection to each patient. The exploration of her experience highlighted the importance of letting go of one relationship so that a new relationship can nourish. Contrary to the findings of Beszterczey (1977), Feldstein and Gemma (1995), Kiger (1994), and Martin and Berchulc (1987), participants did not have trouble letting go of patient relationships. As a matter of fact, terminating relationships became a useful coping strategy!

Control-Taking Behaviours

In order to manage difficult feelings, participants identified the strategy of taking control of their professional practice. To Rashotte et al. (1997), control-taking behaviours may take the form of establishing boundaries, withdrawing and distancing oneself.

Some participants described how they were able to put personal limits on how much they would talk, cry, or reflect, or how much of themselves they would invest in the client-therapist relationship. Ziggy, Ketya, and Betty had learned when they had reached their own personal thresholds, as evident in the words of these participants presented in the order listed above:

> If I would let myself go and look at the negative and get emotionally involved with [patients], then I don't think I would be a coper. ... Maybe it is the fact that I don't have to get that involved with them, that is the strength of staying [in the practice of palliative care] so long.

> I need to think about [a patient's death] and I need to see how I am feeling, but I also at some point need to leave it there. I don't think I would be able to function if I thought about death all the time!

> I set the line so that I don't get too involved. ... When [patients] start not to do as well, I find myself thinking, "Oh, so-and-so isn't doing as well right now, what can I do?" And if they're really not doing well, I wonder for a little while how they're doing, even in the evenings or on the weekends. Then I don't get my break from work. So even though I'm physically not here, I'm mentally at work. That doesn't give me a break, so I go to work tired versus refreshed. If I set the boundary, then I can be giving my all for people when I'm here; instead of thinking about [patients] all the time and not being able to give my 100 percent.

Megan took distancing one step further to what she called a form of denial. Though intellectually Megan claimed to know that patients no longer residing on the palliative care unit had, in fact, died, she claimed that this fact did not "seem real":

> It's not that I deny that they're dead, it's just that I don't ... when I see another name up on the wall, it's posted they've died ... I don't know ... it just doesn't seem real. ... I know they died. But it's just weird — I don't think of it in detail. Like, when I see the name, I don't think, "Did they have trouble breathing?" You know? I don't think about the death process with them. That would be terrible to think of that every time somebody died. So you just think, "Oh, they're not here anymore." ... So, it's not like I literally think they went to another hospital, but that's almost how it feels.

Though denial has been viewed as a maladaptive coping mechanism which is defense-oriented (Cohen et al., 1994; Vachon, 1998), it is clear that for Megan, her conception of "denial" was a useful coping strategy, a way to protect and preserve her emotional self.

Most participants had learned to either regulate their involvement with patients or control their emotions. At no point, however, did participants appear cold, callous, or emotionally detached. Instead, I found participants to be emotionally strong individuals who presented their stories with enthusiasm and confidence.

Rationalizing

Participants identified rationalizing as a valid and useful coping strategy. It was helpful to seek information, either from their own past experiences or from the experiences of others which justified their behaviour. Understanding her role and the boundaries within which she must practice helped Karen to be comfortable with some of the hardships facing her in palliative care practice:

> Recently, we had someone who loves music, who was my age, had some kids, and did have a horrible cancer. [She] had a series of losses. She lost her eyesight. Because of her [method of] breathing, her tongue became very dry and she was progressively unable to talk and drink. She was scared from the beginning. She also had seizures, so that made her afraid. ... She responded really well to relaxation, and she really appreciated me working with her. She had really good tapes and good music. Her mother was wonderful, and put on the music and read. [The patient] really liked it when I came and did a relaxation session with her. But I didn't let myself think that she was dependent on me for the relaxation. ... I guess I wish I would have been in there more frequently for relaxation, but I wasn't. Maybe I was in there once a week or twice a week, which isn't to me a whole lot. Anyway — a lot of it was just the timing — when I would go in, her family would be there and [that] wouldn't be the greatest time [for relaxation]. What was hard was thinking I could have made her life a little bit better by going in a little more frequently. I guess I choose not to feel guilty, because there was no way I could alleviate [her] suffering.

Karen justified her limited time involvement with this patient by considering the time restrictions placed on her by the patient's family visits. She identified her role in helping her patient and the boundaries set by timing. Using a rational thought process, Karen consciously chose not to have personal feelings of guilt due to the limitations of her professional actions.

Following our first interview, Joan and I compared stories of being the team member who was sent back into the hospital room or home to collect equipment after a patient's death. Joan indicated this is often a time of discomfort for her, a time when she feels ill at ease. When I followed this up in our second interview, she helped me to understand that in order to cope with this discomfort she would rationalize and identify the professional and sometimes seemingly practical tasks of her role:

> I lend [patients] equipment, I try and make sure it gets back. Often, it will happen that we have quite a few people dying, and really, exactly what we want to do is get that equipment back. I'll think, "Man, just want the equipment, don't care about the people." I feel like those ladies in that Scrooge movie that were pulling at his bedclothes and stuff. That's how I kind of feel sometimes. I joke about it and laugh, and feel kind of bad that I would just want the equipment back. But then I'm a practical person, too. ... We have to look at the practical things to be able to continue to be able to do our jobs.

Just as there were numerous unique experiences of hardship in palliative care occupational therapy, there were numerous unique methods of coping with these experiences. Participants identified similar as well as individual coping strategies. Some coping strategies involved conscious thought while others involved behaviour. For some participants, coping was a private activity carried out in a personal way. Other participants coped with the hardships and difficulties of palliative care occupational therapy by sharing their experiences and participating in public activities. No matter which coping methods are employed, the goal is to achieve a balance so that the difficulties and hardships of palliative care do not interfere with the function or well-being of the palliative care occupational therapist.

Along with the satisfactions, the difficulties, and the coping skills of palliative care came a sense of spirituality. Spirituality can be defined simply as "the experience of meaning in everyday life" (Urbanowski & Vargo, 1994, p. 89). I turn now to the discussion of spirituality alluded to in Chapter 5.

Chapter 7

SPIRITUALITY

Spirituality, including what is important in life, is a theme commonly discussed in conjunction with personal growth. In exploring this theme with the participants, the majority were not comfortable having it examined under the heading of personal growth. Instead, participants felt spirituality deserved a separate discussion. In keeping with the wishes of my participants, spirituality is discussed in this chapter and personal growth is discussed in Chapter 8.

Thibeault (1997) discussed the experience of gradually losing her father to a degenerative disease. Through the process of his dying, she described learning about herself as a person, a professional, and an occupational therapist. She learned that nothing is ever definite, she must face her vulnerabilities, and she must consider spirituality in her occupational therapy practice. She described spiritual practice as "keeping time, daily, for reflecting and feeling, and marveling at the serendipity of encounters and events" (p. 114). The participants in the present study did not identify changes to their professional practice; rather, they described a personal awakening to spirituality as a result of their professional practice. Spirituality has many forms which can include finding good, clarifying one's religious faith, and finding hope, as described by Karen. Many participants identified an altered sense of fear of the unknown. All participants discussed changes in their thoughts surrounding the topics of dying and death and spirituality in reference to what is important in life.

Finding Good, Faith, and Hope

Karen, through her story of working in palliative care, expressed an awakening of her belief in the goodness of the human spirit. She stated that she had always maintained the belief that people are generally good, but she indicated that working in palliative care had brought this belief to the forefront:

> I recall one time when there were three very despicable characters on the unit. I mean a lot of people ... I couldn't believe what they were saying — all the absolute worst things I would ever want to hear. ... But here, we had three people who, if you looked at what their lifestyle was, or certain behaviours, most people would say, "These are despicable people. They deserve to die a horrible death." or, "They deserve what they got." [Other people] would not have too much sympathy for them. But first of all meeting them, and second of all, seeing how well they were treated, I mean it just ... throws out that thinking. I saw a lot of goodness in that situation. ... It was very moving to see people treated so well. ... The manager said ... "[if] this lady comes back on the unit in the same condition, we're not going to say, I told you so. We're just going to start all over again." I thought that was wonderful.

Karen identified strong religious beliefs, a strong belief in God and her chosen religion. Through her professional practice, Karen indicated she had been able to understand a bit more of what she thought before — the practice clarified it. Ketya also touched upon religious beliefs in her story. Unlike Karen, Ketya did not describe her faith as being clarified. For her, palliative care afforded her the opportunity to contemplate her beliefs, to question what she did believe:

> [Working in palliative care] makes me think, "What is it that I *do* believe in?" I don't know why, but every now and then, I'll just need to think about the afterlife or what happens. I haven't come to any strong conclusions. But it just brings it up again and again, maybe a little more frequent than it had in the past.

It is through Karen's story that I heard of hope. Through experiencing what she called the "beautiful death" of a young patient, Karen stated she found hope. I pursued this discussion further and asked Karen what it meant to find hope:

> Hope. It's a very strange thing to say, but of all my experiences, she was my experience of hope. It's because she was so beautiful in her dying. I was there once when the doctor came in to ask her a bunch of questions, and she asked him how he was. She talked about the Decadron[5] and how it was a good-bad drug. She was very real. She had lost an awful lot, and she knew that. She knew how lousy she felt, but at the same time, she totally appreciated people. She was living ... somehow ... to an extent that is really to be admired, right up to the end. To see something so devastating and something so beautiful at once, in the same person, at the same event, that's why it gives me hope. ... Gives me hope that something so awful isn't necessarily so awful.

Herth (1993), in her study of the meaning of hope for family caregivers of the terminally ill, defined hope as a "dynamic inner power" (p. 538). I was reminded of this definition as Karen spoke with such admiration for a patient who appeared to possess great inner strength.

Though Doyle (1998) indicated hope is the underpinning of palliative care occupational therapy, it was only Karen who wove this ideal into her story. Doyle explained that hope is unique to each patient and is usually difficult to articulate. For Doyle, hope is defined as "a quality of personhood — of being loved, and valued despite, but not because of, all that is happening" (p. 817). In other words, hope for the terminally ill patient is related to a unique, valued state of being, not cure or recovery.

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[5] Decadron is a trademark for a glucocorticoid, an analgesic medication widely used to manage cancer pain.

Using this description, hope is linked to the palliative care goals of maximizing quality of life and dignity.

In considering Doyle's (1998) description of hope, I suspected other participants had also experienced hope as they relayed stories of memorable clients. Still, participants chose to view these experiences as satisfying. Hope was not mentioned. In an effort to remain true to the participants' stories, I chose not to ask specifically if their experiences could be explored in relation to hope. I wanted participants to explore their experiences in whichever manner they chose, using examples and concepts that were relevant to them.

Fear of the Unknown

Seven participants expressed initial apprehension at accepting a position in palliative care. What lay in the days ahead? How would they cope with the grief and loss surrounding them? Would they feel overwhelmed by the tasks required of them? Not knowing what they would encounter in their professional practice as palliative care occupational therapists evoked a sense of fear. However, with time and experience most participants reported their fear of the unknown was alleviated, as evident in the words of Ketya and Mickey:

> Sometimes, you know, you're afraid of the unknown, and once it's there, it's not so frightening anymore. ... Initially, I thought it would be frightening, it would be very difficult, I wouldn't be able to handle it. Now that I'm there, I don't know why I would have thought that in the first place.

> Before I got onto the unit ... I was very uptight about death and dying. Trying to deny it in some ways. ... But, just experiencing the process. Seeing people dying, going through the whole process with the family and the staff, listening to the families and the advice ... [shrugged]

The participants who discussed their fears about working in palliative care stated that these fears had been alleviated to a large degree for their professional sense of self. On a personal level, however, Megan was the one participant who shared her continuing fear of death, of what would happen after the body stopped functioning:

> I've always been scared to die, personally. ... I've talked to a lot of people, and they say to me, "I'm not scared to die, I'm scared of the dying process ... the pain." *I'm* scared to die. I'm not scared of the pain — I'm scared to die! ... I'm a very spiritual person, by the way. I believe in God, I believe in Heaven, but I'm still scared to die! ... Death is so permanent ... it's so definite: that's it, it's over, it's gone. I find that very scary.

As Megan's story demonstrated, professional exposure to death may not alleviate personal fear.

Personal Thoughts on Death and Dying

Facing death on a regular basis as a professional forces a person to confront personal thoughts on issues relating to death and dying (Petrosino, 1984; Robbins & Moscrop, 1995). Death and dying issues do not necessarily revolve around the fear which has been discussed above. Each participant expressed personal ideas and concerns about death and dying. For example, Karen entertained thoughts related to her own mortality by wondering how she would react if she were diagnosed with a terminal illness:

> You begin thinking about your own mortality, your own situation. ... I start thinking about what kind of funeral I would have.

Joan and Ziggy reported not only thinking about their own mortality, but going so far as making plans for their deaths and discussing these plans with their families:

> I might take [death] home and say to my husband, "Would you want to be buried or would you want to be cremated?" And then you start thinking about things like, "Would you want your ashes scattered or would you want to be in a box somewhere?" You know? It's okay if you start talking about stuff like that. I think you think more about your own mortality, and sometimes, I even think, "Yeah, I'm in my 40s. I could only have 20 years left to live, and that 20 years doesn't seem very long." So you start counting out the years you have left and what you want to do.
>
> Since I've been working in palliative care, my thoughts on death and dying have changed a lot. Not that [I] dwell on them, but it's something that [my family] talks about at home — not trying to be morbid — but just the reality that [death] is going to happen. Our wills are up-to-date.

Participants discussed an increased comfort with their thoughts on death. Mickey stated death was simply a "natural part of life." Joan indicated that since beginning her work in palliative care, she was more comfortable thinking and talking about death:

> [There is] an openness, or thinking about [death], without having to think, "Oh, never think that! That is a terrible thought." You *can* think that, knowing that it's not terrible to think about possibilities, especially when you are around it all the time. You can't help but think, "What if that was my kid?" Or, "If I died, what would happen to my kids? [Did I] leave them enough to remember me?"

Betty remarked that along with feeling more comfortable about death and dying, there is, for her, distress as well. Betty had not experienced any personal loss since she had begun her practice as a palliative care occupational therapist. She indicated that the knowledge of the dying process could comfort her in a time of personal loss, providing her with a "sense of direction." On the other hand, to know what the possibilities were, including the horrible pain and suffering which might lie ahead for a loved one who is dying, could cause her distress.

What is Important in Life

Davies and Oberle (1990) defined spirituality as reflection on what is important in one's life. All participants strongly articulated that their professional practice had taught them to appreciate life, to live for the moment. Rasmussen et al. (1995) stated that nurses who work with the dying learn to value each day and to live life to the fullest. These very sentiments resonated through all of the participants' stories.

Each participant, through their professional practice, had learned to value their personal existence. Many participants stated that their professional practice had made them realize the finiteness of life itself. Such realization comes through in the words of Karen and Joan:

> Life is very brief, we're here to live it, we're not here to accomplish this and this and this, in which case there's only satisfaction at the end of the accomplishment. But we're here to live it every day, and whether it's over in one year or another or another, is not the most important thing.
>
> Live more day to day with the idea that you can die anytime, or something could happen. You could get sick. There's a chance of that. Just be aware — "Yeah, that's a possibility."

The uncertainty of life's course which is so evident in palliative care practice had helped Joan to consider the practical realities of her own life. She described a frequent contemplation about balancing her present wishes with future plans:

> It hits me when I'm with somebody who doesn't have a long time to live. ... My husband and I talk, "Should we be spending all our money, or making sure we have tons in the bank for when we're older, or making sure we have fun?" ... Working with people in palliative care, you [realize that you] never know what can happen and what life can bring. So, we try to balance it and try to have fun. But we make sure we are also saving for the future.

For Ziggy, facing the uncertainty of life was a reminder to live her life according to her own aspirations. She encouraged me to do the same: to dream, to reach for those dreams, and not to wait for a more opportune time which may never come to pass:

> Live your life to your fullest ... Set goals for yourself and make yourself reach those goals. I don't have real high aspirations at the moment in terms of career, but certainly just for day-to-day things that need to be done, get them done, don't procrastinate. Cause you just never know! How many [patients] say, "You know, 6 weeks ago, I was shoveling, mowing my lawn, whatever, and look at me now." You just never know when [illness] is going to come about.

Ketya spoke of enjoying life, of "not getting hung up on material issues and decreasing debt load." She stated that working in palliative care had not brought forth a realization she should enjoy life; rather, her work had simply reinforced her long-standing belief that each day is a gift to savour. Betty's palliative care practice had prompted her to enjoy life more which for her meant no longer worrying about trivial matters, life's little mishaps like a broken down car:

> I think before [I worked in palliative care], I might have dwelled a little bit longer on the little things. I might have thought of them a bit more before they would not bother me any more. ... I dwelled on [things] for a little longer before I let [them] go.

The discussions in Chapters 4 through to 7 have focused on the interplay between the occupational therapist participants' personal and professional lives. What the participants encountered as professionals influenced them in very personal ways ranging from feeling emotions, to considering their own belief systems, to planning for their own deaths. When I asked participants which of the impacts of working in palliative care were "professionally-related" and which were "personally-related," puzzled looks crossed their faces. Inevitably, the answer was, "I can't really be sure." In a related discussion, the following chapter examines aspects of personal growth, professional growth, and the interplay between them.

Chapter 8

PERSONAL-PROFESSIONAL GROWTH

Our life experiences contribute to our development as persons. Professional experiences are no exception. When discussing personal growth, the participants had difficulty differentiating personal growth from professional development. Participants all identified ways in which their personal lives were enriched by their professional practice in palliative care. The skills and knowledge about caring for the dying that participants gained as professionals translated into benefits in the participants' personal lives. In turn, these benefits as personal growth spilled back into their professional lives. I will discuss personal and professional growth together in keeping with the preference of the participants.

Appreciating Self

In speaking with participants, I came to understand that an occupational therapist, in caring for the dying patient and family, is afforded the opportunity to gain a deeper understanding of him or herself. Working in palliative care not only made Karen more aware of her personal strengths, but provided her the confidence to trust in her strengths and to trust in herself:

> I'm discovering that I have a lot of confidence ... I recognize that I have more strength than I thought I did. ... I do feel like I could work in almost any environment now and it wouldn't unnerve me.

> [Working in palliative care] has made me aware of what's inside me, my own criticisms, the struggles that are really from inside me, they're not coming from outside. In [the palliative care] environment, I think I've been able to work through them, and I'm a lot more trusting of myself.

Ketya and Ann, through their work in palliative care, were able to confront their own personal losses and learn from their own history. Ketya indicated that working in palliative care had made her "appreciate life in terms of what [she] has gone through, what [her] personal experiences have been." She further indicated that because of her palliative care experience, she had been able to discuss with someone close to her the loss of a parent which occurred many years earlier. Ann's personal loss was more recent. Less than one year ago, her mother died of cancer. Her professional practice also helped her to better understand this personal loss:

> I lost my mother to cancer. ... I came back to work and the first few days were a little tough, partly because you're telling the story to your colleagues and answering questions. But then, things were back to normal, and I thought, "Oh, this is not too bad. It's going better than I expected." Then, 6 or 8 weeks later, I was looking after an older woman, I think she was 80 something, and her daughter who'd come in from out of town, walked in. Something about her mannerism, her appearance, or something, reminded me of my mother. I was struggling with the lump in my throat. And you think, "This is kind of weird." You use all your coping skills to deal with that emotion, stay on the path, finish the job, sort it out later, but it still hits you. You realize that you're still fragile, I guess.

Like Thibeault (1997), Ann had discovered her vulnerability. The blending of Ann's personal and professional lives had not only helped illuminate a hidden aspect of her self, but allowed Ann to acknowledge, to appreciate, and to accept this aspect of herself, this fragility.

Ziggy had developed a unique personal self-awareness which I had not found reported in any previous literature. She related that she had a fascination with funerals and with the manner in which different cultures say good-bye to their loved ones. Ziggy's experience attending funerals of past patients helped her define her personal wishes:

> You get to go to funerals! That's interesting … that people say good-bye to their loved ones in different ways, to the point of not even having a funeral — which to me, I never thought of. Different ways that people respond to a person dying in their home. Some people want the body out right away. Other people will take their time and wash the body and dress them up in the clothes that they want to be buried in. The ritual around the dead, that has opened my eyes. I never thought of it before. ... I just find it interesting! I just never thought about funerals, or how you would conduct a funeral. When I do go to a funeral, I'll collect [programmes]. Some of the programmes are really interesting, and I thought, "Oh, I'll collect those, and when my time comes, I'll [choose] … which one I like the best and organize it that way!" Some of them are really neat, the songs that they pick or the poems that they pick. Just thought-provoking, and I think, "Oh, yeah, that would fit with me." Save me some ground work when it comes time to funerals!

Ziggy had gained a unique knowledge in her professional practice which she was able to put to use in her personal life.

Appreciating Others

Participants indicated that they not only became aware of their own characteristics through their professional practice, but of the unique characteristics of those people they encountered as well. Kubler-Ross (1969) suggested that being "a therapist to a dying patient makes us aware of the uniqueness of each individual in this vast sea of humanity" (p. 276). After years of general practice as an occupational therapist, Karen realized that she was beginning to classify people according to diagnosis and removing a sense of their individuality. Once she began to practice in the palliative care setting, Karen's way of looking at other people began to change:

> Even when I was a student in rheumatology: "This person has an arthritic personality." I don't really know if that exists, but I was thinking along those lines and thought that with experience, you could pick out people and classify them. But after working in palliative care ... I seem to have much more appreciation for the uniqueness of people and the uniqueness of how they suffer, how they deal with what's before them. ... It's very hard, really, to classify people. I appreciate that. ... I'd like to think I'm more accepting. Even if somebody's coping isn't really healthy and is keeping people away, that's how it is and this is *their* dying. I can't judge whether it's inferior or superior or anything like that.

Betty described many past clients as simply "amazing." To Ziggy they were "kind and genuine." Joan's admiration for other people and the strengths they possess was reflected in the following story:

> I have a lady that is unbelievable ... her condition! ... But, she is totally independent with her wheelchair and getting around the house. Cancer is in her heels, so it limits her in so many ways. ... But, she's just been able to put things [in order] and organize things. If I come up with an idea she will either think it's great, or tell me where I could have done better. ... She is just an amazing person, just such a positive attitude, not going to let [the disease] get to her, [she] just overcomes everything. She has been a real pleasure to visit. She always makes me think. ... I can't believe how some people can get through as much as is happening to her.

Through direct contact with patients facing adversity and death, participants gained an appreciation for a person's ability to face such adversity.

Ziggy claimed that her professional practice had helped her to accept the strength of others and the help they offered her in times of need. She learned "not to think that you have to do it all on your own." In addition, she became more aware of the needs of people around her in times of crisis, people with whom she has social relationships. The developmental nature of this personal growth is evident in the way she spoke about this awareness:

> Being more sensitive to the needs of friends and family, especially in times of family members' deaths. Just extending a supportive word or extending myself in some other way to acknowledge their situation. It's just being ... more aware that people have these needs in those times. When you're young, you just never thought of those things, I never did. ... I think it's a matter of working in palliative care, 'cause ... I was never exposed to anything like this when I was younger or growing up.

Kubler-Ross observed a connection between palliative care practice and the awareness of the uniqueness of individuals as far back as 1969, a connection that appeared to be a part of the palliative care occupational therapy practice experiences of the participants in this study.

Appreciating Culture

Canada is a multi-cultural country. People of various cultures, races, and beliefs reside within close proximity. The participants indicated they gained an appreciation for the cultures of other people, the ways different people approach both life and death. Mickey reported "people come from different areas of the world ... everybody brings their own unique sense of life." Ann told me a story of a cultural experience which, for her, was very profound. She related the story of a client whom her palliative care team was able to care for in the context of his culture. In respecting cultural diversity and working within thc boundaries of a culture other than her own, Ann gained a sense of pride and accomplishment:

> This man was from North Vietnam, and had been brought over a year or two previously by family members. He got quite ill fairly suddenly. He'd been taken into hospital and treated in hospital for 6 to 8 weeks. The family had been told he wasn't going to get better; he was going to die. They panicked. Culturally they couldn't allow him to die in hospital. The Buddhists believe that their soul, or whatever they equate to the soul, goes back down into the earth to come back out of the earth a few hours or so later to be reincarnated. So, they wanted him to basically die on the ground[6]. It was February ... and there were at least 3 or 4 feet of snow on the ground. The family was talking about needing to take [the patient] home to be on the ground — was sort of the message I got initially as an O.T. from the nurse, saying this man's coming out of hospital, he's dying, he may not live very long, and we have to figure out some way to accommodate him. I went to the patient's home, and there was lots of good space in the home. We could have put in a hospital bed for the time that he had left, but they didn't want that; that wasn't going to serve their needs. We ended up organizing a bed on the floor, in the basement — because they considered that to be the best possible compromise — with little space heaters around, because the basement wasn't as warm as the upstairs. And that's where he died. It meant that all the basic things like bed baths and transferring were really one of a kind. And he died on the floor in the basement. The Buddhist priest came and chanted his soul off to wherever they believed it was going ... [tearful] ... I've always felt that I did a really good job there ... We were committed to trying to meet that man's needs on his terms.

Cultural issues were not discussed by many participants, but for Mickey and Ann, working with persons of different cultures provided personal-professional learning. Both participants agreed that learning to appreciate culture was beneficial to their professional practice and was valuable on a personal level.

Appreciating Suffering

Twycross and Lichter (1998) pointed out that suffering has many forms, be they physical, psychological, social, or spiritual, and that even mild symptoms can cause considerable suffering. There is much suffering in palliative care as patients deteriorate

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[6] The Buddhist practice described was the understanding of one particular patient and family. Such a belief and practice may or may not be subscribed to by other Buddhists.

and eventually die. Family members and staff grieve and experience loss. Contrary to what Vachon (1978) suggested, the suffering described by Mickey and Joan was not an unpleasant experience. Rather, their experiences became opportunities for them to appreciate what human suffering entails:

> I really admire [client's name] strength and courage. She has never complained much about her pain, which can be excruciating. Sometimes, when I have problems, I think of the problems she has endured. All of my problems become like a drop of water in the ocean.
>
> [I have seen] how other people can cope with a devastating diagnosis and handle it. You know how [people] say, "I never could do that." Well, I know you can. You can probably do whatever you are faced with because [terminal patients] do not want to be faced with [suffering] anymore than anyone else does. To learn how they do that with some grace, or they scream, or whatever they need to do — well, it has been a privilege, actually, to work with people that have gone through some of those things.

For some caregivers, observing the suffering of others brings out an empathetic response. Ferrell (1998) noted that observing the suffering of the patient leads to a greater degree of suffering for the caregiver. Although study participants did not identify an increase in their own suffering, they clearly did show empathy for their dying patients. Empathy, according to Twycross and Lichter (1998) is essential for one to have in order to help to ease a patient's suffering, hence essential to palliative care practice.

Family Relationships

As a result of their experiences with palliative care occupational therapy, 3 participants described the changes in the way they perceived their relationships with their families. For instance, following her scare with a possible diagnosis of cancer and knowing all that involved from her professional practice, Joan made a conscious effort to place her family, her husband, and her marriage "before work." For Betty, it was a loss of tolerance for unjustified complaints of others. Instead of being swayed by the self-defeating thoughts of a loved one, Betty consciously made an effort to challenge and change such thinking:

> For example, I might say, "Well, let's go out to the mall and have a coffee." She might say, "Oh, I really can't walk very well. I can't walk very long." She doesn't use a wheelchair, she doesn't use a walker. There is nothing wrong with her, but she just thinks that she can't walk. Well ... I'm not very sympathetic to that because she doesn't have a problem. She doesn't use a wheelchair, she doesn't use a walker. She just says she's tired, but I don't even think she is. I'll call her on it whereas before, I wouldn't call her on it. I probably would have just said, "Well, we'll just go for a short little walk." But now I would say, "You're not using a wheelchair, you're not using a walker, you're not this, you're not that. I think you're doing pretty good and let's go."

Through her exposure to multiple patient deaths, Ketya not only came to terms with her personal losses, but came to discuss these losses openly with those closest to her. In particular, communication between Ketya and her significant other flourished as they both began talking about the deaths of their parents. Karen identified overall changes in the way she approached her relationships, in this case with her mother:

> I know that my relationships have improved ... I can see definite signs of that. For example, I went on a holiday with my mother, and I'm very in tune to when [she is] not listening to me and [she] does not have the same communication skills. Although we communicate ... I noticed that, of course, [she] does not have the same skills as the people I work with or the people I live with, who happen to be fabulous at it as well. I think I have a little bit more insight and I'm a little more patient, and slowly, [the communication] is coming along. ... Acceptance, greater appreciation, compassion, a little more understanding ... Which I guess translates into better communication. Annoyances don't come out as much. ... They don't bother me as much. ... I'm probably more sensitive to picking up unspoken stuff.

Vachon (1983) encouraged staff caring for terminally ill patients to have well-integrated social support systems. The study participants not only identified strong social supports, some identified growth and improvement in these relationships as a result of their work with the dying.

Clinical Skill and Knowledge

Mickey discussed learning about different clinical assessments and treatment modalities used in palliative care. Other participants focused on interaction skills, those which the occupational therapist uses in his or her interaction with patients and families. Thibeault (1997) said that caring for the dying helps a professional to develop listening skills. For Karen, this was particularly evident when she spoke about her approach to assessing patients in palliative care:

> I saw that after I was working in palliative care, what I would do is not go in [to an initial interview with a patient] and try right off the bat to get as much information for my assessment form as I could. I would go in, sit down, start talking and really try to listen to where this person was at, what was most on their mind. ... It takes time to listen. You need to give the other person time to feel comfortable enough to say the things that are more personal to them. Sometimes I will spend a long time with one person or one person and their family. I see that as listening, rather than if I were to cut them off and say, "I can only spend half an hour with you. I've got to see all these other people." I don't think that would be listening.

Ziggy explained how she had learned to be more sensitive to the needs and feelings of people around her, in both her personal and professional lives in general. She described how she now approaches patients in the palliative care setting, showing this sensitivity through her words:

> I wouldn't go in on my first interview and say, "I hear you have cancer!" I break the ice, and kind of get a feel for the individual and the family. There might be some general chit-chat. It gives me time to assess the situation, assess the personality of the client, and it tells me how open [and forward] I can be with these people, or if I have to use more tact. I often don't even ask [the patient] what is wrong with them, 'cause I have all that information from my medical charts. ... Eventually it will come out. I wait for them to use different words. Like some people won't use the word "cancer"; others will. Some people will just say, "I have lung cancer," where others would say, "I have a bit of pain in my lung"; they don't refer to it as cancer. I pick up cues from my clients, and that's what I'm being sensitive to. I sort of follow the flow of how they want to deal with this.

Listening for and responding to the cues provided by patients was Ziggy's way of tuning in to that patient and the particular needs that only become apparent when one is oriented to finding them. For Ketya, sensitivity was translated into having self-control and knowing her personal and professional boundaries. She indicated that she learned to control her tears when someone touched her heart and emotions. She stated that she was careful to display her emotions only if she interpreted the situation as being an appropriate outlet. How she assessed a situation was simply an inner feeling or sense which she was not able to articulate.

Betty and Karen reported transferring skills and knowledge gained in palliative care to other occupational therapy environments such as long-term care and psychiatry. In addition, Karen had taken her acquired palliative care skill and knowledge to the public realm. In an effort to educate the public about the value of palliative care and the value of suffering, Karen had taken on the challenge to promote the personal benefits of occupational therapy in the lives of others:

> [By] promoting [palliative care] in a way that [demonstrates how] it has decreased my fear, perhaps it could decrease other people's fear. When they are more aware of the resources that are there to help them when they need help, maybe they will be less fearful. When the time comes that they need help, they will get it.

Karen also spoke of the value of theory for promoting occupational therapy as a profession. The utility of various models of occupational therapy to guide practice had become more meaningful to her, something that will be addressed more fully when I discuss the implications of this study for occupational therapy theory.

Discussions of personal-professional growth were key in helping me understand the personal-professional connection of palliative care occupational therapy. Whether a participant described appreciating self, others, culture, or suffering, changes in family relationships, or clinical skill and knowledge, all of the stories told of personal growth related to professional experience. The boundary between participants' personal and professional lives appeared to be permeable, effects spilling back and forth. The stories relayed, along with the inability of participants to separate their personal and professional lives, made me think that a separation would really be forced and artificial. What became important to the study were not only specific impacts of working in palliative care on occupational therapists, but the interplay of these impacts — the interplay between personal and professional experiences.

Chapter 9

IMPLICATIONS AND CONCLUSION

Implications for Occupational Therapy Practice in Palliative Care

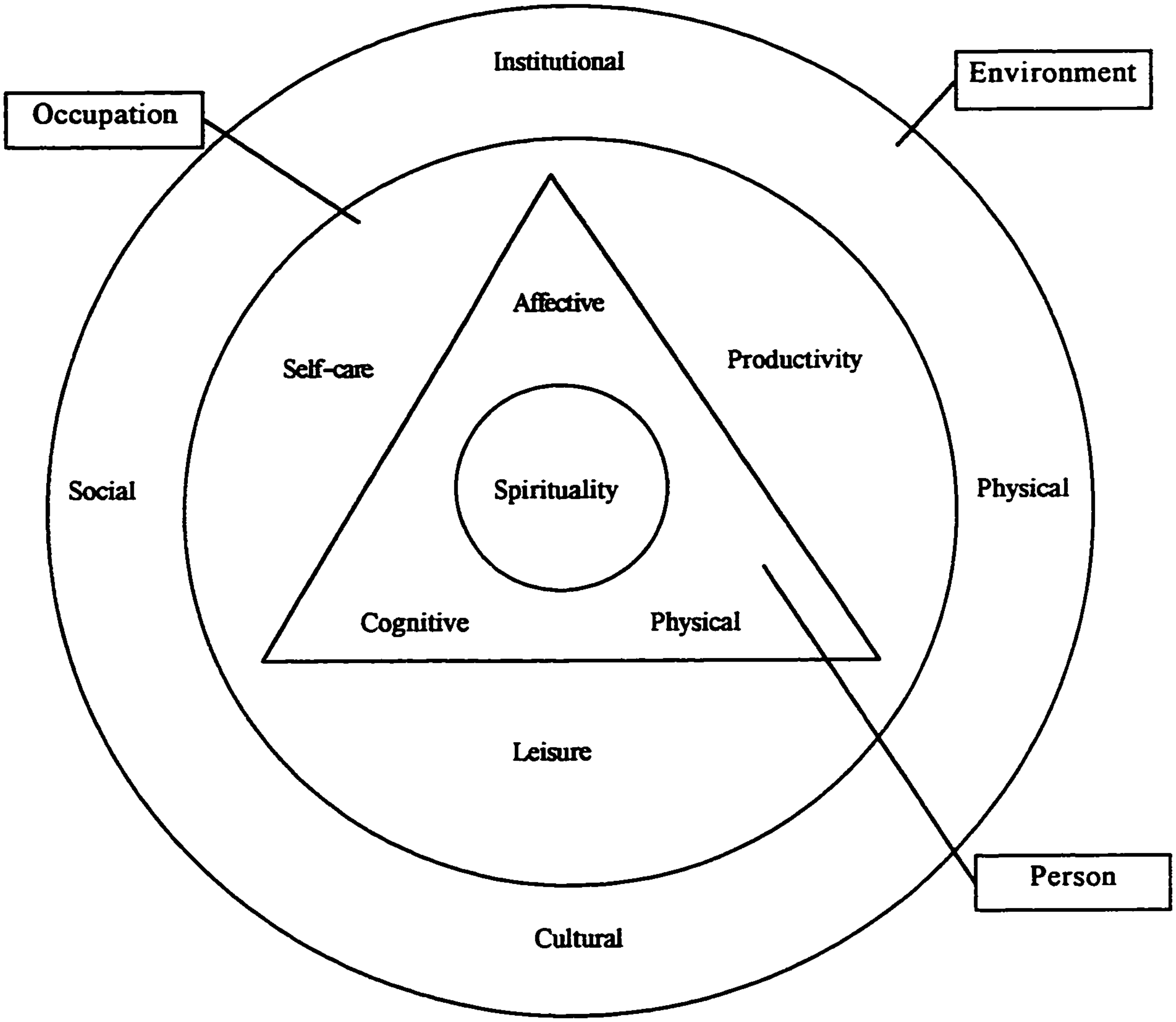
I undertook the present study to develop a better understanding of the personal-professional connections in palliative care occupational therapy. The spectrum of the unique experiences that can evolve out of palliative care occupational therapy are best suited to qualitative methods. From the beginning, my intention had been for present and future occupational therapists as well as other palliative care professionals to consider and gain insight about personal-professional connections within their practice. It is a valuable endeavour to try to understand the uniqueness of each person's experience, to recognize the variations of personal experiences within the setting and their relationships to professional practice. An occupational therapist working in palliative care who experiences satisfaction along with grief, frustration, and a realization of their spirituality can be reassured that they are not alone, that other therapists can empathize. In short, working in palliative care is both a professional and personal investment.

Implications for Occupational Therapy Theory

Professional knowledge and skill have both a theoretical and a practical base. Where theory serves as a guide to practice, experience in turn makes that theory workable. A conceptual model is defined as "an abstract representation of practice ... consisting of a frame of reference and an organized system of assumptions, concepts, goals, assessment instruments, intervention strategies, deductions, and intervention principles" (Schwartzberg, 1988, p. 383). Currently, there are many models of practice in occupational therapy including the Model of Human Occupation (Kielhofner, 1985), the Occupational Behaviour Model (Reilly, 1962), and the Canadian Model of Occupational Performance (CMOP) (Canadian Association of Occupational Therapists, 1997). Law and McColl (1989) found that only a moderate number (65.8%) of Canadian occupational therapists actually used theory to guide clinical practice. In spite of this, the majority of Canadian occupational therapists (91%) felt that theory was useful to practice (Law & McColl). The CMOP, the most widely used model in Canada, will be the focus of my discussion.

There has been a change in focus over the last 20 years with health promotion and client empowerment becoming a focus of health care delivery (Canadian Association of Occupational Therapists, 1997). In 1983, the Canadian Association Of Occupational Therapists (CAOT) developed a model of practice to provide direction for occupational therapy client-centred practice. This model was revised in 1997 and has become a standard in Canadian occupational therapy practice. The CMOP presents a view of person as an integrated whole, stressing the dynamic interaction between person, environment, and occupation (Canadian Association Of Occupational Therapists). *Person* encompasses an individual's physical, cognitive, and affective being. *Occupation* includes the activities of self-care, productivity, and leisure. *Environment* includes physical, institutional, cultural, and social environments. At the centre of these three lies an individual's spirituality (see Figure 1). There is an interdependence between person,

Figure 1. The Canadian Model of Occupational Performance



Note. Adapted from three-dimensional to two-dimensional from *Enabling occupation: An occupational therapy perspective* (p. 32) by Canadian Association of Occupational Therapists, 1997, Toronto, Ontario: CAOT Publications ACE. Copyright 1997 by the Canadian Association of Occupational Therapists.

environment, and occupation such that "change in any aspect of the Model would affect all other aspects" (p. 33).

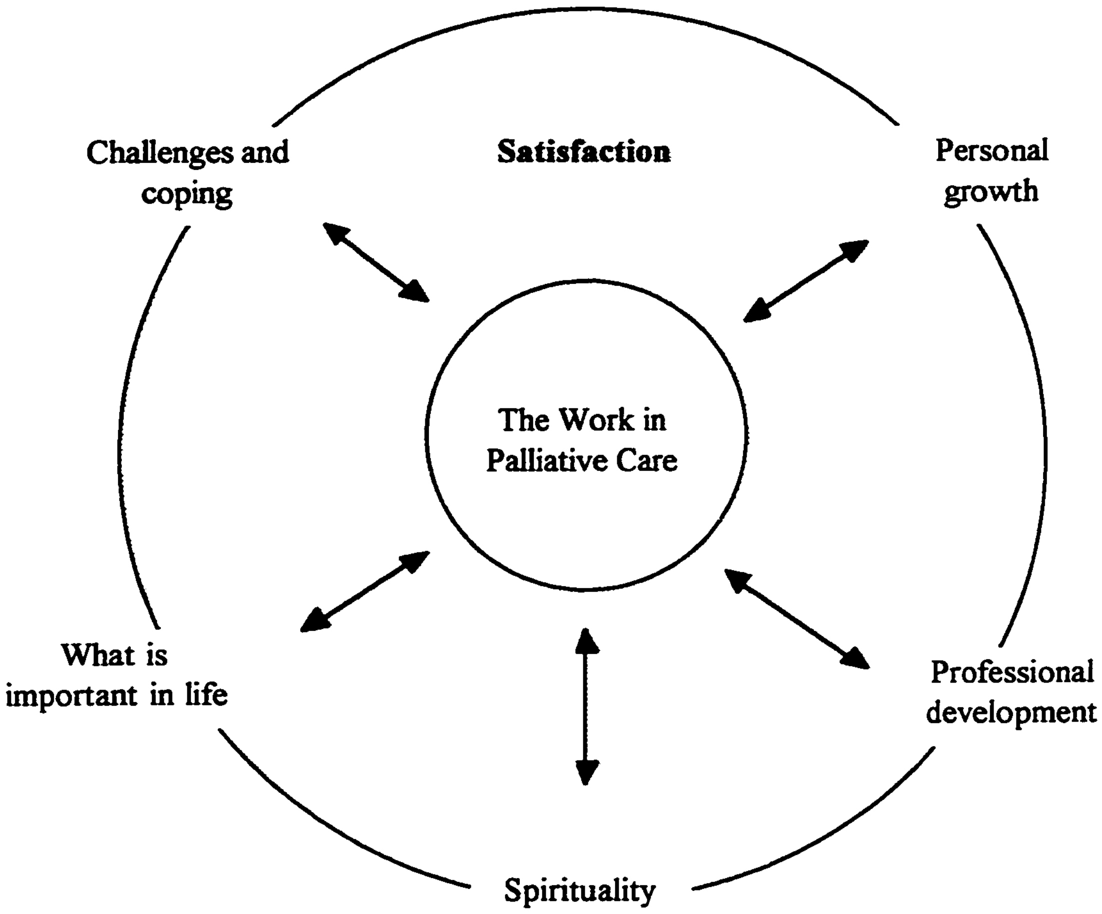
The CMOP was originally conceptualized as a model of occupational therapy practice; however, the authors further state "the implication is that the Canadian Model of Occupational Performance presents a view of humanity and the environment which is applicable to occupational therapists as well as to clients" (Canadian Association Of Occupational Therapists, 1997, p. 5). Furthermore, "occupational therapists are encouraged to apply theory in everyday practice and to use their experience of everyday practice to advance theory" (p. 3). I took these two pieces of advice to heart. I had hoped to be able to explore participant data and experience as they related to the CMOP.

As it happened, I found a striking resemblance to the CMOP in the blending of participant personal and professional experiences. While the connection between the participants' productivity and their person was apparent to me as a researcher, the similarity between participant notions of a model that guided their practice and the CMOP was less evident. I was excited when Karen introduced the CMOP as the specific model for which she had gained appreciation. I was curious about the CMOP and how relevant it was in practice. It was as if she had read my mind. Karen claimed that the model represented her *self* in terms of spirituality being at the centre surrounded by all other aspects of her self and the environment. However, when we tried to put her personal-professional connection in palliative care into the various components of the model, Karen indicated that the present study had a different focus for her. "I don't think work is the centre of my life. ... But, when we are looking at my work in palliative care, we are putting *that* in the centre and we are looking at *it*, we are examining *it*." With this, Karen drew my attention to a diagram she had drawn earlier to represent the ways in which working in palliative care had touched Karen's life (see Figure 2).

Karen identified those impacts of her work in palliative care which she felt were most salient to her personal-professional connection. Similar to the CMOP, there existed an interdependence, with each aspect of Karen's experience interacting with the others. From this interplay arose satisfaction, the key to Karen's personal-professional connection. Though the CMOP was visually similar to Karen's diagram, the two differed in content. The labels Karen used were very specific to her personal-professional connection in palliative care occupational therapy, whereas she indicated the CMOP labels were too global and vague in order to be useful in generating understanding of her experience.

When I asked the other participants to consider the fit between their personal sense of palliative care occupational therapy and the CMOP, they could not do it. The model did not adequately represent their experiences. While each participant was able to find some meaning in the CMOP, with only one exception, all of them were more comfortable with their own configuration of personal-professional connections in palliative care occupational therapy. As such, the individual variations in occupational therapy experiences in palliative care were not easily illustrated by the CMOP.

Figure 2. Karen's diagram



As Karen demonstrated, a universal model does not always work for a specific case where context and circumstances unique to the individual may be difficult to accommodate. Schon (1983) suggested that applying theory to practice is problematic when theory has been generated within context-free situations and hence ignores the context of the practice situation. Schwartzberg (1988) and Feaver and Creek (1993) would concur, suggesting occupational therapy, due to its diversity and contextual nature, cannot be represented by a single, all-encompassing model. Occupational therapy "cannot be encapsulated in a structure or process such as a model provides" (Feaver & Creek, p. 62); rather, a therapist needs to understand and apply a model only as is appropriate. Occupational therapy models can be said to represent a global view of the profession without considering the personal frame of reference of the individual occupational therapist. Kortman (1995) suggested that a therapist's "personal model" (p. 534), which is the individual therapist's interpretation of the global model, is more important than the global professional model. While the professional model is more abstract, the personal model is more practical (Kortman). Through reflection, each participant in this study was able to discuss his or her unique personal-professional connection, in a sense, his or her unique personal model of palliative care occupational therapy which developed as a result of his or her individual experience. These personal-professional connections were creative configurations which most participants found to be more practical than a general model such as the CMOP.

Such consideration of these creative configurations can only happen through reflection. Reflection-on-practice, as described by Schon (1983, 1987), occurs when the practitioner actively considers aspects of practice at times other than the moment of action. Reflection in this way brings about a greater understanding of practice. According to Clarke, James and Kelly's (1996) model of reflection, the outcome of reflection-on-practice is fundamental to growth and transformation of the individual. Furthermore, reflection is a way to make sense of the reality of one's professional life (Clarke et al., 1996). Clarke et al. suggest deep reflection is difficult to achieve on one's own. Participation in this study provided participants with the opportunity for reflection and enabled these occupational therapists to explore their practice and to enhance their understanding of themselves.

Recommendations for Future Research

As I conducted these interviews with the 8 participants and enjoyed listening to their unique and fascinating stories, I realized I was only beginning my research career. There is still much to be investigated. I heard suggestions that working in palliative care has not only different impacts on different people, but that these impacts may change with time and experience. A longitudinal study would be advantageous to investigate the themes I have explored in this study as time progresses. Does a person's personal-professional connection modify and change with the passage of time and the acquiring of new experiences? Is there a sequence to learning to cope with grief? Are some coping strategies more useful to palliative care professionals as they progress throughout their career?

Participants often referred to the context of palliative care — the intensity and the urgency, the continual exposure to death and grief. Each of these characteristics of palliative care is worthy of further investigation. What experiences affect the occupational therapist's intensity and duration of grief and their ability to cope and manage it? How do personal experiences with losses enhance or hinder one's work in palliative care?

The contribution of working environments to the personal-professional connection needs to be investigated. I was unable to disclose characteristics of the palliative care environments in which the participants worked in order to protect their anonymity. The small community of palliative care professionals from which the participants came prevented discussing circumstances that might influence participant perspectives. Nevertheless, a future study could be undertaken to examine the impact of the environmental milieu on the personal-professional connection of palliative care occupational therapists. Related environmental milieus could also be examined. How does an intensive care environment or a psychiatric environment contribute to an occupational therapist's personal-professional connection?

Palliative care practice, while not exclusive to oncology, in this study generally focused on the care of terminal cancer patients. The definition of terminal illness could be expanded to include illnesses which are not physical in nature, such as Alzheimer's

Disease. Leukemia and many other childhood diseases could also be considered terminal. Would an exploration with occupational therapists working with these patient populations yield similar personal-professional connections?

Though the present study was conducted with palliative care occupational therapists, it is reasonable to assume that other palliative care providers experience their own personal-professional connections (Martin & Berchulc, 1987; Rasmussen et al., 1995; Vachon, 1978, 1983, 1987, 1998). What might these connections be? An interdisciplinary comparison of personal-professional connections may illuminate common as well as unique connections, not only within, but between, disciplines.

The illustration of personal-professional connections in this study may challenge traditional notions of professional behaviour and the expectation to keep personal separate from professional. From the discussions presented in this thesis, it appears that the separation of personal and professional may be a pretense. A future study may ask what defines professional behaviour? Could professional behaviour include an element of personal sharing?

Conclusion

This exploration has demonstrated that there are connections between the personal and professional lives of palliative care occupational therapists. The boundary between one's personal and professional lives appears to be permeable, with professional practice having personal impacts, and vice versa. In general, an occupational therapist experiences satisfaction, hardships and difficulties, coping, spirituality, and personal-professional growth when working in palliative care. In particular, an occupational therapist experiences these effects in a very personal manner. Each participant created a unique personal-professional connection in exploring their individual palliative care experience. Other practicing occupational therapists, future occupational therapists, and other palliative care professionals reading this study may see similarities in their experiences to the connections of these 8 participants. Differences also are to be expected as each professional creates his or her own personal-professional connection.

Epilogue

In completing this study I was awakened to a new understanding about myself. I had been able to identify eight personal-professional connections in palliative care occupational therapy and I realized that my own is a ninth personal-professional connection. Throughout the study, I was approached by a number of colleagues and friends inquiring how I was progressing. Each time I was struck by how easily I was beginning to form answers to my original question about the impacts of working in palliative care on occupational therapists. More important to me, I was beginning to express the interplay between the personal and professional lives of the participants.

With my newly acquired research skills and my growing enthusiasm for qualitative research, I now sit and contemplate my next project. Meanwhile, I leave this study to you the reader. In faith I leave you to the stories of Ann, Betty, Joan, Karen, Ketya, Megan, Mickey, and Ziggy, that you may gain understanding of the many personal-professional connections of palliative care occupational therapists, that you may recognize your own personal-professional connection, whatever it may be.

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Appendix A

PARTICIPANT CONSENT FORM

Title of Study: A Qualitative Study of the Impact of Working in Palliative Care on Occupational Therapists

Research Investigator: Cassie Jacknicke BScOT, OT(c) Phone: (403) 439 4277
MScOT Student, University of Alberta
Co-Supervisor: Lili Liu, PhD, U of A Phone: (403) 492 5108
Co-Supervisor: Jeanette Boman, PhD, U of A Phone: (403) 492 0066

Please tick or check (or) one line in response to each of the following questions:

	Yes	No
Do you understand that you have been asked to participate in a research study?	________	________
Have you read the Information Sheet and the Invitation to Participate?	________	________
Do you understand the risks and benefits of taking part in this study?	________	________
Have you had an opportunity to ask questions and discuss the study?	________	________
Do you understand that you are participating voluntarily and are free to withdraw from the study at any time without having to give reason and without consequence?	________	________
Has the issue of confidentiality been described to you?	________	________
Do you understand who will have access to the information you provide?	________	________
Do you understand the information you provide will be used in the process of completing a Master's degree in Occupational Therapy, including publication of possible findings?	________	________

I agree to take part in this study, including the audio-taping of the interview(s) conducted for the purpose of the study. Yes _____ No _____

____
Signature of Participant

____
Printed Name

____
Date

*Two copies of this form are provided for your completion and signature. One copy, along with the Information Sheet and Invitation to Participate should be kept by you, and the other Consent Form should be returned in the envelope provided to the researcher **Cassie Jacknicke**, Occupational Therapy, 2-64 Corbett Hall, University of Alberta, Edmonton, Alberta, T6G 2G4).

APPENDIX B

A Qualitative Study of The Impact of Working in Palliative Care on Occupational Therapists

INFORMATION SHEET

Thank you for your interest in this research study. I value the contribution you can make to my study.

The goals of this study are to:

- explore the impact of working in palliative care on occupational therapists;

- obtain detailed, qualitative information regarding the impact working in palliative care has on an occupational therapist's:
  a) professional practice,
  b) social relationships, and
  c) personal feelings, values, and beliefs about what is important in life;

- develop a clear, comprehensive description of the impact of working in palliative care on occupational therapists;

- utilize the results of the study in the development of a Master's thesis for the purposes of completing a Masters degree in Occupational Therapy;

- disseminate findings through presentations/publications and a Master's thesis submitted to the Faculty of Graduate Studies and Research at the University of Alberta.

To achieve these goals, I am requesting your participation in the study as a key informant knowledgeable about occupational therapy in palliative care. I am asking you to take part in at least 2 to a maximum of 3 or 4 semi-structured, audio-taped interviews which will take about one and one half hours each of your time scheduled at your convenience. You will receive a transcript of the previous (i.e. 1st) interview 2 days prior to a subsequent (i.e. 2nd) interview so that you may familiarize yourself with the data, and clarify or expand on the information in the subsequent interview.

Some Questions You Might Have about the Study

Q. Do I have to participate?

A. No. You may refuse to participate. If you decide to participate, you may withdraw from the study at any time without any consequence.

Q. If I participate, is it necessary that my interview be audio-taped?

A. Yes. Taping of the interview will ensure an accurate record of information received. Tapes will remain confidential and will remain in the researcher's possession for 7 years after which the tapes will be destroyed.

Q. Will my information be kept confidential?

A. The final report of the study will be submitted as an Occupational Therapy Master's thesis to the Department of Occupational Therapy at the University of Alberta.

The identity of interview participants, along with anyone identified during an interview, will not be revealed at any time. Information received will be coded using a pseudonym selected by yourself so as to protect the confidentiality of this information and the your identity. Findings will be analyzed and reported without using the name of the individual respondents. Overall findings and themes will be reported using pseudonyms so that individual respondents cannot be identified. The location of the study will not be revealed in any presentation or publication material. A critical reader, an occupational therapist with palliative care experience, will be employed as to review the final analysis/report to indicate truthfulness in relation to her experience.

Data will be stored using pseudonyms and will remain under lock and key in the researcher's office. The researcher will store data for a minimum of seven years, after which time data will be destroyed. During this seven year period, data will be available to other researchers for purposes of clarification of results and evaluation of the present researcher's thought processes in determining study findings.

Q. What are the risks/benefits of participating in the study?

A. The researcher is bound by the Alberta Association of Registered Occupational Therapists Code of Conduct. You are not obligated to discuss any experience(s) you are uncomfortable revealing.

Participation in the study may raise an awareness for participants, a self-awareness, adverse personal/emotional reactions affecting life-style choices and priorities. This could in turn contribute to a rewarding and meaningful experience for the participant.

Each participant will be provided with a list of general resources including support groups, agencies, organizations, and non-agency services which can be both personally and professionally useful. (This list of resources will be provided to all participants, including those who choose to withdraw from the study.)

Q. Will I be able to learn about the findings of the study?

A. Yes, but results of the study will not be available until the fall of 1998. At that time I intend to present the findings in the form of a Master's thesis. Once the thesis has been defended at the University of Alberta, copies of the completed thesis will be available to participants on request. I also intend to publish the results in a peer-reviewed journal.

If you have any further questions about this study, you may contact **Cassie Jacknicke** at telephone number (403) 439 4277. If she is unavailable, you may leave a message for her and she will get back to you as soon as possible. Her mailing address is 2-64 Corbett Hall, University of Alberta, Edmonton, Alberta, T6G 2G4. You may also contact **Dr. Lili Liu** at telephone number (403) 492 5108.

A FINAL NOTE

Thank you for considering this request. Your help with this important study is essential to its success.

Cassie Jacknicke, BScOT, OT(C)
MScOT Student, Department of Occupational Therapy, University of Alberta

APPENDIX C

Letter of Invitation to Participate

Title of Project: A Qualitative Study of the Impact of Working in Palliative Care on Occupational Therapists

Date _________
Dear _____________,

Thank you for your interest in my research on the impact of working in palliative care on occupational therapists. I value the contribution you can make to my study.

The research model I am using is a qualitative one through which I am seeking comprehensive descriptions of your experience. In this way I hope to explore the impact of working in palliative care for occupational therapists such as yourself.

Through your participation, I hope to understand the impact as it reveals itself in your experience. You will be asked to recall specific events, situations, thoughts and feelings that you experience(d) as an occupational therapist in a palliative care environment. I am seeking comprehensive portrayals of what these experiences are (were) like for you.

All information will remain anonymous and confidential. If you decide to withdraw at any time, your data will be destroyed immediately and there will be no consequence to you.

I value your participation and thank you for your commitment of time and energy.

If you are willing to participate in my study, please initial this document and sign the participation consent form provided. If you have any further questions, please feel free to contact me. I can be reached at (403) 439 4277.

With warm regards and thanks,

Cassie Jacknicke BScOT, OT(c)

att.

____
initial

APPENDIX D

General Resources for Bereavement and Grief

This list has been compiled from information provided by:
The Bereavement Society of Alberta
#302 11456 Jasper Avenue
Edmonton, Alberta
T5K 0M1
phone (403) 482 LOSS (5677)
fax (403) 488 1495

This list is not comprehensive nor does it intentionally leave out names or agencies which may also provide services related to bereavement and grief issues. Inclusion on this list does not imply endorsement by C. Jacknicke, the researcher, or the Bereavement Society of Alberta.

Information updated by C. Jacknicke, December 1997

Reprinted with permission from P. Brindley, President,
The Bereavement Society of Alberta

Support Groups:

AIDS Bereavement Group (AIDS Network)
contact 488 5742

Compassionate Friends Support Group, Edmonton
contact 986 3582

Compassionate Friends of St. Albert
contact Al Holmes
458 8114

Cross Cancer Patient & Family Support Group
contact 432 8545

Leduc Grief Support Group
contact Brian
986 2543

Pastoral Care at the General Hospital
contact 482 8029

Pastoral Care at the Grey Nuns Community Health Centre
contact 450 7029

Pastoral Care at the Misericordia Community Health Centre
contact 930 5877

Pastoral Care at the Royal Alexandra Hospital
contact 477 4119

Pastoral Care at the Sturgeon General Hospital
contact 460 6266

Pastoral Care at the University of Alberta Hospital
contact 492 8447

Agency And Organizational:

Catholic Social Services
8815 99 Street, Edmonton
contact 420 6081

Cornerstone Counselling (one-to-one counselling services)
#302 Plaza 82, 10508 82 Avenue, Edmonton
contact 482 6215

Cross Cancer Institute
11560 University Avenue, Edmonton
contact 432 8545 (pastoral care)

Lousage Institute
#302 Lousage Centre, 10140 117 Street, Edmonton
contact 488 7679

North Land Family Counselling Services
Rm 201 10508 82 Avenue, Edmonton
contact 439 5683

Pastoral Counselling Group
Rm 5R05, Edmonton General Hospital, 11111 Jasper Avenue, Edmonton
contact 482 8998

The Pastoral Institute of Edmonton
#300 10235 124 Street, Edmonton
contact 482 2424

Redemptorist Centre for Growth
10713 85 Avenue, Edmonton
contact 432 1730

The Support Network (Suicide Bereavement Counselling and drop-in one session counselling)
#302 11456 Jasper Avenue, Edmonton
contact 482 0198

YWCA of Edmonton
10242 105 Street, Edmonton
contact 423 9922

Non-Agency:

Rev. Peter Dyck (Family Therapist)
Rm 252B Bonnie Doon Professional Offices, Edmonton
contact 469 6605

Karen Goldstone (Family Therapist)
southside Edmonton location — phone for specific address
contact 914 4564

Jim Henry ("Coupleworks" Psychologist)
#502, 10240 124 Street, Edmonton
contact 413 6071

A. Blair McPherson (M.Ed.)
Rm 204 Capilano Mall, 5004 98 Avenue, Edmonton
contact 440 2954

APPENDIXE

Interview Protocol, Cues and Prompts

The following is a guide for the interviewer when conducting the semi-structured interview for palliative care occupational therapists. The interviewer may vary the order and wording according to the needs of the participant. It is important to maintain a relaxed, conversational tone throughout the discussion.

Introduction

I am conducting interviews with palliative care occupational therapists. I would like to discuss the impact working in palliative care has had on you as a therapist, as a person. I am particularly interested in how your experiences working in palliative care have affected your professional practice, your social relationships, and your personal feelings, values, and beliefs about what is important in life.

Purpose

Through sharing your experiences and descriptions, you will be helping me to develop a clear, comprehensive description of the impact of working in palliative care on occupational therapists. There are no right or wrong opinions. I am interested in hearing each participant's unique perspective.

Recording Sessions

This session will be taped and transcripts will be completed by a hired clerk. All information will remain confidential.

Cues and Prompts

Environment

What is it like to be an occupational therapist caring for the dying?

What is the physical environment you work in like? How does it affect your practice? How does it affect you personally? Can you give me an example?

What is the social environment you work in like? How does it affect your practice? How does it affect you personally? Can you give me an example?

What is the cultural environment you work in like? How does it affect your practice? How does it affect you personally? Can you give me an example?

Occupation

How have your experiences with dying and death influenced your professional practice?
How is it you began to work with people who are dying?
What are your goals as an occupational therapist? How have your own personal beliefs and values influenced these goals? How do these goals fit with your working as an occupational therapist in palliative care?
How does the experience of being a therapist affect your personal response to loss?
What have you have learned as a professional from your terminally ill clients?

Person

How have your social relationships been affected by your work in palliative care?
What are your personal feelings about dying and death?
What is satisfying to you as an occupational therapist working with the dying?
What have you learned personally from your terminally ill clients?

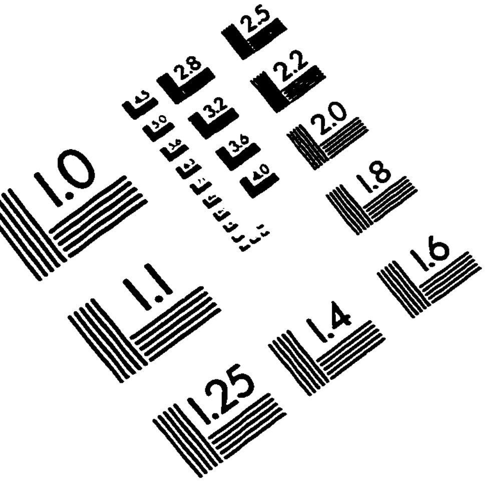
Spirituality

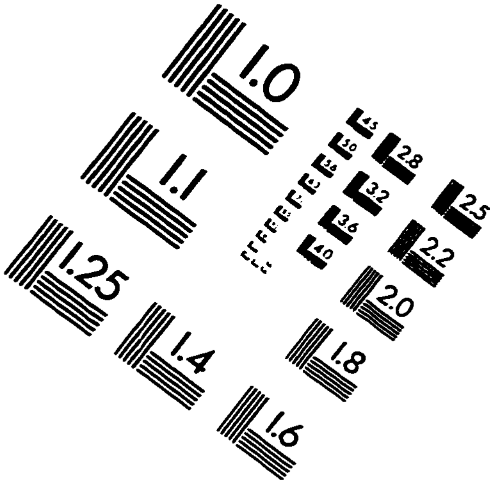
What gives meaning to your everyday life? How does this affect your work as an occupational therapist in a palliative care?
What is it that gives you strength? i.e. poem, music?

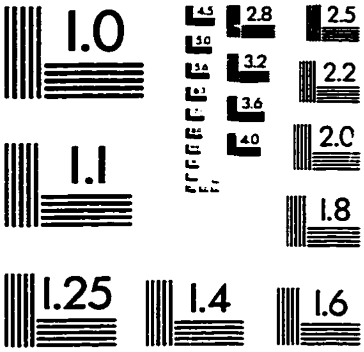
Closure Questions

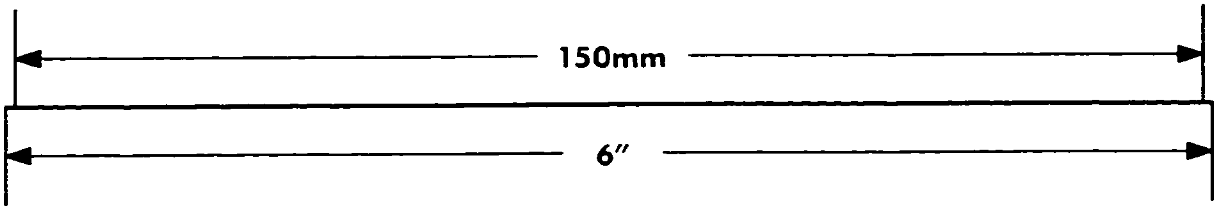
Is there anything more you would like to say about your experiences as an occupational therapist working in palliative care?
Thank you very much for participating. Before we close the interview, is there anything you would like to ask me? (Is there anything else?)
I am turning the tape off now.

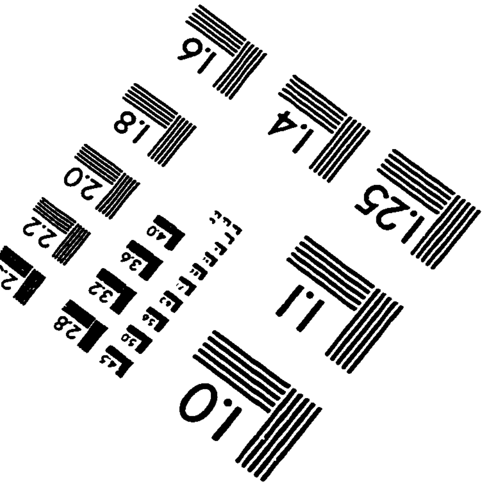
IMAGE EVALUATION
TEST TARGET (QA-3)

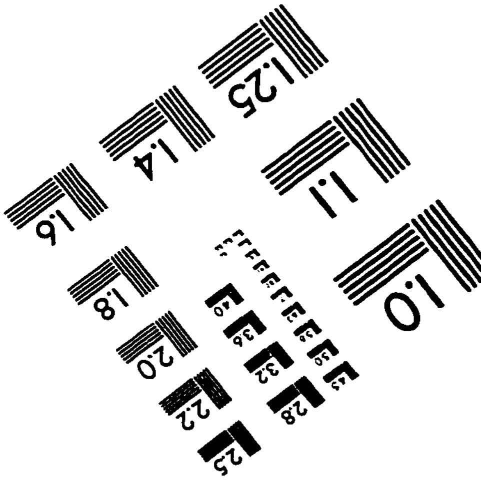












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