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Decision-Making in Family Dyads in the Context of Advanced Cancer

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Dedication

"Decision-Making in Family Dyads in the Context of Advanced Cancer"
is dedicated to my parents and my sisters who inspired this study, and to the participants who made the study a reality.

I have appreciated the ongoing support provided by my husband and children, and would like to thank my thesis supervisor, and thesis committee members for their expert guidance.

Abstract

An individual with advanced cancer moves through his or her illness trajectory engaged in an ongoing process of negotiation with the health care system, caregivers, and family members. The ability to maintain control is a key principle upheld in western society, but it may be difficult to do so if cognitive or physical decline occurs during the palliative phase of advanced cancer. Cognitive decline in progressive dementias such as Alzheimer's disease or AIDS Dementia Complex is often gradual, allowing such individuals and their family members time to reassign responsibilities for illness management that protect the sense of control of the ill family member. When the onset of cognitive decline occurs more quickly, as is often the case in advanced cancer, ill individuals and their family members may not have the luxury of time to incorporate a transition in responsibilities for illness management into their collective decision-making process, leading to a sense on the part of the person with advanced cancer that he or she has lost control. Current understanding of this transition is limited, and thus the qualitative, grounded theory study, "Decision-Making in Family Dyads in the Context of Advanced Cancer" was conducted. Advanced cancer patients (n = 5), family caregivers (n = 3), and bereaved caregivers (n = 9) from palliative home care settings in Ontario were recruited for the study. Purposive and theoretical sampling of participants occurred until saturation was reached. Data collection, coding, and analysis occurred simultaneously. Results indicated that family caregivers who tried to fulfill their dying family member's wishes often did so at the expense of their own health or finances. The core category *Covering* captured the strategies caregivers used to enable their family members to

die in the manner of his or her choosing. The basic social process *Dancing on the Stairs* chronicled the stages of the patient-caregiver relationship as they navigated through the grey areas of decision-making in their final months together. The findings may assist health care personnel striving to help individuals with advanced cancer and their family caregivers maintain a sense of control during the palliative phase of an illness.

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CHAPTER ONE

Statement of Problem

As a former clinical nurse specialist in palliative and hospice care, I have worked with individuals who were in the palliative phase of their illness but who were determined to maintain control over their illness, including the dying process. Assisting patients to achieve this goal required a balance between the use of professional expertise and maintenance of patient autonomy. Many issues arose, but clinical observations suggested that they could usually be managed through open communication, negotiation, the use of ethical decision-making frameworks, and the advice of experts in the field. These approaches were not effective, however, when my parents were faced with similar issues at the end of their lives. At that point my family and I entered into a grey area of uncertainty.

My parents were becoming incapable of caring for themselves and decisions had to be made regarding institutional care. At age 70, they toured various retirement facilities and pronounced them all inadequate, opting to remain in their home. They did not want to be in an institution and exhorted their three daughters to "always keep us together, no matter what." Now both on the verge of their 80th birthdays, they had been married for 50 years, had no physical infirmities, but were exhibiting signs of dementia. They could no longer prepare meals, do laundry, bathe, or take care of financial matters on their own.

My eldest sister had been designated as my parents' power of attorney. In an attempt to activate her power of attorney and begin to make legal decisions for my parents she accompanied them to a physician to confirm their deteriorating cognitive status. Strangely, in a doctor's office my parents seemed perfectly fine, they seemed aware and competent, and the physician did not see a problem. When he refused to conduct mental status tests and maintained an autocratic stance toward my sister, she left feeling foolish.

It wasn't long before my parents could no longer be left on their own, but they would not move in with their children, and rejected any caregiver that we tried to provide. Their physician still refused to declare them incompetent. We could not negotiate with my father, who was fiercely independent and refused to compromise. We had to wait for further deterioration of my parents' cognitive status before assistance could be sought. As her siblings did not live in the same community as our parents, my sister assumed my parents' daily care, along with the responsibilities of her own immediate family and her job. Decisions needed to be made, but my parents were unable to make them or to transfer responsibility for them to my sisters and me. Western countries value individual autonomy and our legal and health care system reflect these values, and my parents likely thought that they were simply doing what was expected of them by society (Northcott & Wilson, 2001). As a health care professional I had watched many families deal with similar issues but now these issues had become real in a new way within my own family.

While my professional experience told me that my family's problem was not unique, my family and I had not fully discussed my parents' wishes for this time in their lives and thus we were not adequately prepared. Since their own parents had died at relatively early ages of cancer or heart disease, my parents had not expected to survive until the age of 80. Therefore, they had not explored the ramifications of a longer life and the decisions that would ensue.

My clinical experience at the time was in HIV/AIDS supportive and palliative care where the focus was on relatively young people managing an illness in a manner which preserved quality of life and control within a “life-until-death” approach. One of the issues faced by this population was the potential of acquiring AIDS Dementia Complex. Its gradual onset and slow, progressive clinical course were similar to the dementia seen in my parents. Although the management issues related to dementia could be difficult, the changes were gradual. Both my own family and the families of my patients used this time to figure out how to manage the declining cognitive status of our loved ones. As a result of these experiences, I became interested in decision-making at the end of life in situations where declining cognitive or physical status happens more quickly or in an unpredictable manner. Advanced cancer patients in the palliative phase of their illness are one such population. These changes place family caregivers in difficult situations in which they must move quickly to new roles and responsibilities that require them to make an increasing number of decisions for their ill family member, while also supporting their family member’s desires to maintain control over health-related decisions whenever possible.

In this dissertation, I examine the process by which individuals with advanced cancer and their family caregivers made decisions regarding care during the palliative phase of illness, when their ill family member’s cognitive and physical status was declining, and the person was unable to participate in decision-making in his or her usual manner. I also explore how families and their ill family member balanced issues related to control and autonomy. This population was selected because I expected the above process to be more readily apparent and because, given my professional qualifications, it was one to which I had access. In this chapter, I outline the historical context of palliative care, and some of the issues that frame my research question.

The History of Palliative Care

Individuals with advanced cancer in the palliative phase of illness and their family caregivers make decisions regarding care within the context of the society in which they live. Historically in the western world, care of the ill and dying was delegated to informal caregivers in the home or to members of religious orders. However, as the use of antibiotics, advanced medical techniques, and public health campaigns increased longevity, care of the dying shifted increasingly to health care providers (Northcott & Wilson, 2001). Palliative care was born out of this professionalization and is, therefore, a fairly recent construct. "Hospice, or palliative care, has emerged as a specialized field only within the past 30 years. In the United States, Canada, and Britain, hospice care is often used interchangeably with the term palliative care" (Barnard, Towers, Boston, & Lambrinidou, 2000, p. 2). While it initially addressed only care for individuals who were dying, it is currently understood more broadly to include supportive care and symptom management in the context of illness. It is important, therefore, to understand the origins of the terms *hospice* and *palliative* care as they figure prominently in the development of the modern hospice-palliative care philosophy.

Dame Cicely Saunders founded the modern *hospice* movement in the 1960s, profoundly influencing the development of palliative care in the western world. She opened St. Christopher Hospice in 1967, the first modern hospice in Britain. The hospice operated according to the tenets of Dame Saunders' hospice philosophy of care, which stipulated that an emphasis should be placed on the relief of pain and suffering. Care was to be provided by an interdisciplinary team, and although the patient and family (as defined by the patient) formed the unit of care, patient control over decisions was maintained for as long as possible (Kuebler, Berry, & Heidrich, 2002; Meghani, 2004; Saunders, 1991). This philosophy formed the basis of integrated holistic, bio-psycho-social, and spiritual palliative care, delivered in an interdisciplinary model. This new model of care delivery ran counter to the prevailing norms of health care provision. In the new interdisciplinary model, the authoritarian stance of the health care professional was subsumed by the patient's needs. All health care professionals caring for the patient worked together collaboratively, rather than in the traditional hierarchal format where only the physician made key decisions. This interdisciplinary model of care became a key component of the modern hospice-palliative care philosophy.

Dame Saunders' influence spread beyond Britain. As an invited speaker, she introduced her hospice philosophy to the United States in 1966, which prompted Florence Wald, then Dean of Yale University's School of Nursing, to resign her position and dedicate her time to the development of hospice care in the United States. Hospice care initially began with a home care model in the United States but remained institutionally based in Britain. In 1975, St. Luke's Hospice became the first hospice in the United States to be incorporated into an existing medical center. This model subsequently became the template for other American hospices (Kuebler et al., 2002; Meghani, 2004).

The advent of *palliative* care occurred in Canada in 1975 when the term was used by Balfour Mount to describe a hospital-based palliative care service at the Royal

Victoria Hospital in Montreal (Kuebler et al., 2002). Palliative care in Canada was defined as an extension of the hospice approach that included services available in the hospital setting. Palliative care offered an improvement in the quality rather than the quantity of one's life, by emphasizing supportive (comfort-oriented) rather than curative care (Northcott & Wilson, 2001).

Palliative care originally followed the cancer illness trajectory, with palliation only offered in the last months or year of life. However, since the 1980s with improved treatments for cancer and other terminal illnesses, life expectancies increased, and this necessitated a revised view of palliative care. As a result, in 1995, the joint National Hospice and Palliative Care Organization (NHPCO) in the United States issued palliative care guidelines for noncancer illnesses such as dementia, AIDS, amyotrophic lateral sclerosis, and organ failure (NHPCO, 2003). Canada released similar guidelines shortly thereafter.

Since 2002, when the World Health Organization (WHO) updated their definition of palliative care, there has been a general understanding in western countries including Canada that palliative care is no longer offered only during the end-of-life stage of a terminal illness. Instead, palliative care should be offered when necessary to relieve suffering at any point in the disease trajectory, and in conjunction with curative treatment if desired (Choi & Billings, 2002; Pieper & Dacher, 2004; WHO, 2002).

Palliative care has evolved to the point where it is delivered in many different venues. In Canada, there are now palliative care programs in acute care hospitals, as well as in long-term care facilities, and in one or two freestanding hospices in Toronto and Vancouver. It is also anticipated that palliative care programs in long-term care facilities will increase in response to American and Canadian statistics which indicate that the majority of those who die in these countries are the elderly (Meghani, 2004; Northcott & Wilson, 2001; Stamler & Yiu, 2005).

Recently, in the United States and in Canada there has also been a movement toward a “life-within-illness” paradigm of palliative care, which can best be achieved within a community-based nursing model (Pieper & Dacher, 2004). The basic tenets of this movement are that the patient lives until death (rather than dying until death) in the locale of one’s choice, which is generally his or her home. In some settings, community-based programs provide home care nursing and ancillary services, including respite or day care. Community-based palliative care is considered to be the future path of palliative care. It is “efficient, effective, and mandatory for the care of dying patients” (Stamler & Yiu, 2005, p. 326).

Organizations in Canada, the United States, and Britain may continue to use the individual terms *hospice* or *palliative care* to describe their functions. However, their programs are now guided by a unified philosophy of hospice and palliative care irrespective of the terms used to describe them (AAHPM, 2003; CHPCA, 2002). The evolution of palliative care has, therefore, culminated in a combined model of hospice-palliative care, thereby standardizing these major concepts across most western nations.

Current Issues in Palliative Care

Dying and Death

Elisabeth Kübler-Ross, a Swiss psychiatrist who moved to the United States in 1958, revolutionized the way that the western world views the dying process. She realized that her dying patients typically went through various nonsequential stages in their journey toward death. These stages included denial, anger, bargaining, depression, and acceptance. Her book, *On Death and Dying* (1969), has become a classic in the palliative care literature. She gave a voice to dying individuals and provided comfort by describing the dying process. Sadly, as she herself lay dying, she experienced less than ideal care, finding that nurses often spent more time working on their computers than being with their patients. She cautioned health care professionals not to revert back to a time when dying individuals were ignored in rooms far from the nurse's station and exhorted them to maintain the progress that she had worked to achieve (Rosa, 1997).

Interdisciplinary Care

Since the 1960s, health care provision in western countries, including Canada, has evolved from a physician-led approach, to multidisciplinary teams in which each member of the team takes responsibility for part of a patient's care plan. The present ideal of care is an interdisciplinary model where team members "are more aware of the overall plan [and] work collaboratively with each other" (Kuebler et al., 2002, p. 9), often blending their roles as they care for patients and their families. As a result, nurses have become more actively involved in palliative care. However, there are still traditional forces within the health care environment that attempt to relegate nurses to a subservient role, such that the physician retains ultimate authority, and a hierarchal structure is preserved (Sheer, 1996). Vachon (2001) notes that both physicians and nurses experience similar emotions while working with the dying, therefore, functioning as a team and offering each other support throughout the process benefits patient and caregiver alike.

If true interdisciplinary collaboration is to be achieved, it is also important to understand the perspectives of others within the interdisciplinary team.

Misunderstandings or conflicts may occur due to differing perceptions of ethical issues within the team. Oberle and Hughes (2001) found that many health care professionals experienced ethical problems around decision-making during the palliative phase of a patient's illness. These ethical problems stemmed from witnessing suffering, which engendered a moral obligation to reduce that suffering. Uncertainty about the best course of action became a source of moral distress for members of the health care team. The authors recommended that health care providers not rely solely upon medical ethics when dealing with difficult ethical decisions, but also include relational ethics in their repertoire. The concept of relational ethics is based on being present in every encounter with patients and with those in the health care environment, and on making a conscious choice to ethically engage on a day-to-day basis with others in the context of a relationship. As Bergum (2004) reminds us, the health care environment is not "out there" (p. 489). "It is each of us … we are the health care system" (p. 489).

Communication

Communication, a key aspect of the patient-health care provider relationship, continues to evolve according to changing patient needs in palliative care. In the past, health care personnel often evaded the truth about impending death or were asked to avoid disclosure by family members. Even when the health care provider believed that the truth was being conveyed to the patient, it may have been couched in vague terminology that the patient was unable to decipher (Glaser & Strauss, 1965). Current standards of palliative care stipulate that such covert communication is not in the best interest of the patient because it interferes with the patient's ability to make decisions pertaining to the end of his or her life. Palliative care health care practitioners are now expected to communicate directly and honestly with patients when addressing their concerns (Johnston & Abraham, 2000).

The patient-health care provider relationship is maintained by communication on a variety of levels and begins with the ability to communicate effectively within the interdisciplinary team. This includes verbal communication skills as well as an understanding of the group dynamics that facilitate team functioning (CHPCA, 2002). A communication skill set includes not only direct communication with the patient, but also encompasses the ability to attend to a patient's unspoken needs and to recognize when suffering occurs.

Communication is also facilitated by the use of tools such as quality-of-life (QOL) measures. These measures can assist palliative care practitioners to improve their communication regarding symptom control and patient care. Quality-of-life measures have been used to identify differences in patient and nurse perceptions. In one such study, nurses were surprised at how much their perception of a patient's QOL differed from that of the patient (Hill, 2002). Since the goal of palliative care is to achieve the best quality-of-life for patients and their families, these measures can enhance patient-health care provider communication and subsequently, client control of the dying process (Friedman & Bono-Snell, 2004).

Education for Health Care Professionals

The development of palliative care has been facilitated by changes in medical and nursing education programs, which emphasize the development of excellent communication skills in an interdisciplinary context to a much greater degree than in the past (Fineberg, Wenger, & Forrow, 2004). In addition, for those who are actively practicing in palliative care, there has been an expansion in end-of-life continuing education programs that incorporate communication components (University of Toronto, 1997). Research into these educational programs is ongoing. One such study began with the premise that students cannot understand the hidden norms of palliative care practice if they are also concerned about clinical skill acquisition. The study paired case study discussion with participant observation in a palliative care setting for a two-week period. The observation period allowed students to focus on the psychosocial and contextual factors that influence palliative care in an effort to develop their humanistic and self-reflective skills. Students were satisfied with the experience and further study was recommended (Fins et al., 2003). Research and education programs such as those described above are building blocks in the continuing effort to attain excellence in the quality of palliative care.

Societal Influences

Changing societal attitudes toward dying and death continue to affect the landscape of palliative care. Increases in longevity due to health care improvements since the 19th century have decreased individuals' fears of death due to injury or infectious disease. However, there has been a corresponding increase in concerns about chronic illness and the effects of aging (Northcott & Wilson, 2001). Such concerns have brought about new fears regarding the delay of death due to life-sustaining medical technology. This shift has likely influenced patient concern about controlling the dying process. Many patients now wish for a "good death," which they define as relatively brief and occurring in the place and manner of their own choosing (Clarke, 2003).

A Good Death

Walters (2004) states that we are no longer "helpless in the face of death … the key difference between the pre and postmodern concepts of a good death is the element of control that medical science has brought us" (p. 406). This may encompass control over the symptoms that make the dying process unbearable or, for some, control over the timing of their death, as advocated by the right-to-die movement (Walters, 2004).

Dying is not necessarily a "single moment in time" (Proulx & Jacelon, 2004, p. 116) but a process. When the process is prolonged it can be said to be a "bad death," as was found in a qualitative study involving 26 men who had terminal heart disease or cancer. Eleven of the participants believed that prolonged dying would be associated with pain, suffering, and increased burden of care for the patient's family and would, therefore, be a bad death. Conversely a good death would be quick and painless (Vig & Pearlman, 2004).

Other studies have found variations on the aforementioned themes. The primary concerns about dying in one study were "freedom from unpleasant symptoms, choice over timing of death, and choice over place of death" (Clarke, 2003, p. 180). In another study, a prolonged death was defined as death associated with mental and physical anguish, or one that was inconsistent with the patient's wishes. The authors stated that a good death involved the provision of high quality care, which could only be achieved by engaging in effective communication with patients, their families, and health care providers (Tong et al., 2003).

Kaufmann (2000) proposed that the elements of a bad death in the elderly were similar to those experienced by younger age groups and included "suffering, loneliness, and lack of autonomy … due to invasive treatments" (p. 1). The author stated that assisting the elderly with the dying journey was difficult because it assumed that all involved knew exactly what the components of a good death would be for that person. To make the process easier, Carr (2003) recommended the use of living wills or advance directives to guide family members in honouring the wishes of the dying person.

Other research has examined the meaning of the dying process and found that as the patient neared death, he or she was no longer viewed by others as a functional human being. This social death, however, may prepare the family for the actual biological death. Those involved considered the journey to be more difficult if the patient remained conscious and appeared to be suffering (Johnson, Cook, Giacomini, & Williams 2000).

A patient, believing that a faster death would result in a good or a better death, may attempt to hasten the dying process. The Oregon Death with Dignity Act allows such patients to "choose to die while still in full control of cognitive and bodily functions and before they become a burden to others" (Proulx & Jacelon, 2004, p.117). Twelve participants in Winland-Brown's (2001) phenomenological study also saw assisted suicide as a viable option to achieve a good death.

John Masson (2002) added a discussion about how to negotiate a good death. He stated that the term good death was too limited and did not capture the complexities of the dying process, and that the "the concept of a 'good enough' death may be more appropriate" (p. 207). Hopkinson and Hallett (2002) concurred, and maintained that a universal definition of a good death was too reductionist. In their phenomenological study of 28 hospital nurses' understanding of a good death, they found that "a common element of caring for a dying person was not a good death, but a personal ideal that had both similarities with and differences from the ideal of others" (p. 538). The authors also stated that the professional ideal of a good death may serve to maintain "the control and management of death in institutions" (p. 533). Not wishing to dismiss professional expertise, they advocated for the use of such expertise to "enable the dying person to realize their own personally ideal death" (p. 539). Proulx and Jacelon (2004) expressed a similar concern, indicating that dying patients may succumb to societal pressure to be good patients in an effort not to burden others with their care. This may cause them to "lose the opportunity for the experience of dying with dignity" (p. 117).

Client Control

A basic tenet of palliative care is maintaining the dignity of the individual. The palliative client retains dignity by making his or her own decisions and by controlling the dying process (Tang, 2003). "The concept of taking charge assumes that dying people play an active role in control, which may range from their assuming total control to deciding to delegate total control to others"(Carter, MacLeod, Brander, & McPherson, 2004, p. 618).

In a study of newly diagnosed breast cancer patients, the authors found that the amount of control desired by the patients varied considerably (Beaver, Luker, Owens, Degner, & Sloan, 1996). Taking charge may not be an immediate concern when patients are initially diagnosed; they may not be prepared to cope at that time with all facets of the decision-making process.

The health care literature also uses the term *empowerment* when referring to patient control of health care decisions. Hewitt-Taylor (2004) stated that patient empowerment included the right to choose to delegate decisions to others, but also found that patient control could be affected by the balance of power that existed in the health care system. “Increased decision-making by patients will challenge the control and authority of healthcare professions” (Hewitt-Taylor, 2004, p. 34). This implies that although patient empowerment is encouraged, not all health care professionals will be able to adapt to this type of decision-making. Exercise of power can be indirect or unconscious; particularly when a health care professional feels that he or she possesses expert knowledge and thus knows better.

The movement for increased patient autonomy and control in western countries poses challenges for the palliative care practitioner. “The traditional model, where professional ‘experts’ prescribed treatment for ‘compliant patients,’ is no longer considered best practice” (Durbach & Kerzner, 2004, p. 26). The current ideal in client-centered care is to enact a *power with* rather than *power over* stance with the client. While this has become one of the cornerstones of palliative care practice, it is not always implemented. Not all health care professionals are able to adapt to this ideal. Bottorff et al. (2000) found that while some health care providers indicated that they were “committed to patient agency to some degree, the strength of their commitment varied” (p. 148). Adherence to palliative care standards that focus on the *power with* stance in the patient-health care provider relationship may assist the palliative care practitioner to maintain his or her commitment to the facilitation of patient control, particularly when used in conjunction with discipline-specific professional standards or best practice guidelines, such as those developed in nursing (CNO, 2002; RNAO, 2002).

Cognitive decline affects decision-making capacity and patient control, but age can also be a factor that affects patient autonomy. Wolinsky, Wyrwich, Babu, Kroenke, and Tierney (2003) found that although mental well-being is a predictor of patient control, age is also correlated with an individual's sense of control. Sense of control was measured at baseline and at each of six bimonthly follow-up interviews among 1,662 patients at two medical centers. Significant changes related to age were observed over a one-year period. The authors stated that "compelling evidence is found for statistically significant associations between age and the sense of control at baseline, and between age and changes in the sense of control over time" (p. 212).

Delegation

Facilitating patient control of the dying process has been the main theme in the development of palliative care since the 1960s. However, control may not be consistently implemented when it occurs by indirect means such as delegation. As the terminal illness advances, the patient may use delegation as a coping mechanism, which could be misinterpreted by caregivers as an abdication of control (Carter et al., 2004). However, palliative cancer patients, who have used delegation to maintain control, indicate that since it is deliberately initiated, delegation should not be perceived by the caregiver as relinquishment of control (Olson, Morse, Smith, Mayan, & Hammond, 2001).

An advance directive or living will is a formal mechanism that allows the patient to maintain control of his or her medical or legal affairs even though he or she is no longer competent to do so. "The ethical principles underlying decision making by proxy are preservation of patient autonomy or self-determination, and promotion of patient welfare" (Robinson, 2001, p. 75). Clinical ethics have a long history and are well documented in nursing and medical literature. They are based on the philosophies of Immanuel Kant and John Stuart Mill. Autonomy according to Kant should be governed by rational choice. Mill believed that one has the right to self-determination as long as no harm is done to others. Kantian autonomy supports patient-provider collaboration and partnership. Millean autonomy supports consumer choice (Davis, Davis, Smith, & Cooper, 2003).

While it is recommended that advance directives be initiated when a patient is still capable of making decisions, such as prior to, or at the time of, a terminal diagnosis, the death denying undercurrent in western society may, however, prevent this from happening. In the absence of an advance directive, health care providers may defer decisions to family members, which can be highly stressful for families who are not prepared for this added responsibility (Hayes, 2003; Northcott & Wilson, 2001; Panke & Volicer, 2002).

Control over Time of Death

The ultimate aspect of client control over the dying process is the wish to exert control over the timing of one's death. The client may wish to discuss assisted suicide with the health care provider without a clear understanding of its legal implications. Many health care providers feel that client initiation of this topic is actually an expression of concern regarding fears of a prolonged death with poor pain and symptom control. In the past, such fears may have been valid, since concerns about criminal prosecution and censure by licensing authorities often led physicians and family caregivers to withhold strong pain relief in the belief that such measures would hasten death and lead to criminal prosecution (Northcott & Wilson, 2001). These concerns have been somewhat alleviated by the publication of various position statements, particularly those of the Canadian Palliative Care Association (1997), which maintain that although death may be precipitated by comfort measures, alleviation of suffering is the most important consideration.

At the present time, assisted suicide is a legal choice only in selected jurisdictions. It remains a criminal offence in Canada and is legal only in Belgium, Holland, and the state of Oregon in the United States. Assisted suicide is a controversial issue, which was illustrated recently by an unsuccessful attempt in Oregon to overturn the legislation (Freeman, 2006). It remains to be seen how future developments in the law related to this issue will affect the basic tenets of palliative care in the western world.

Control over Place of Death

Client concerns such as where to die and when, are issues that affect client choice and ultimately also control over the dying process. In Canada, there has been a shift away from hospitals as places of death since 1994 (Wilson et al., 2001). In a meta-synthesis of related literature, the authors reported that clients, if given a choice, preferred to die at home and that there was evidence of benefit for home care (Higginson et al., 2003). A phenomenological study conducted with six cancer patients and their partners found that all participants were satisfied to be in their own homes with family and friends. Nevertheless, all felt anxious about pain and were fearful that hospitalization would be necessary if pain could not be controlled. While these patients felt somewhat powerless due to uncertainty about the disease process and an inability to influence their life situation, being in their own home enhanced their sense of independence and subsequently their feeling of control over the dying process (Appelin & Bertero, 2004).

Unfortunately for palliative care patients in Canada, advances in the field have not always been consistently implemented. The “Senate Report on End-of-Life Care” revealed that only five percent of dying Canadians will receive supportive, interdisciplinary palliative care in the place of their choice (CHPCA, 2002). Health care restructuring has reduced the number of palliative care beds and health care funding is directed mainly to the hospital sector. Home care programs are therefore under-funded, hampering the future direction of palliative care (Stamler & Yiu, 2005). This situation is mirrored in the United States, with even more dire consequences, since this country does not have a nationally funded health care insurance program (Meghani, 2004).

A patient's preference for home care may be further threatened if the burden of care for family caregivers is high, as is the case when the patient's cognitive and physical abilities decline quickly. The family may have to cope with high financial, emotional, and physical burdens, and may lack the necessary skills or resources to manage in these complex situations (Stamler & Yiu, 2005). In addition, the traditional caregivers in the home, who have predominately been women, may be in the workforce due to economic factors and thus be unavailable to care for dying family members at home. Families might then be required to search for private nursing care, only to find that the majority of Canadian nurses are employed in the better funded hospital sector (Wilson et al., 2002).

Family caregivers, who manage to maintain the palliative client in the home for at least part if not all of the palliative period, despite the disadvantages mentioned above, may be overwhelmed by care demands if ongoing support is not provided. Wennman-Larsen and Tishelman (2002) found that support for caregivers was essential if the developments in palliative care since the 1960s are to be sustained. The investigators found that participants had no one to whom they could express concerns regarding the burden of providing care. The researchers concluded that home care could be a positive alternative to hospital care only if each individual caregiver's expectations for support were addressed by the palliative care team.

My clinical experience suggests that caregiver burden is partly a function of the increased responsibility for decision-making that caregivers assume as the ill family member's cognitive and physical abilities decline. If we knew more about how families made decisions at this important time, and about the impact of changing decision-making responsibilities on caregiver burden, we may be able to reduce the burden by providing more targeted support related to decision-making for the family dyad in the home. The focus of this dissertation is on the decision-making process. Future studies will examine the links between the family dyad decision-making process and caregiver burden.

Research Question

The research question in this study was "What is the process by which individuals with advanced cancer and their family caregivers make decisions regarding care when cognitive and physical abilities begin to decline during the palliative phase of illness? I was particularly interested in:

1. How the family decision-making process changed in the context of lost cognitive and physical abilities when the individual was no longer able to participate the way they had before they became ill.
2. How the family decision-making process was influenced by a broader social context that values control.

This dissertation is comprised of five additional chapters. Chapter Two provides a review of relevant literature regarding the concepts of transition, uncertainty, and decision-making. The methodology, including further explication of the research question, data collection, and data analysis will occur in Chapter Three. The results of the study are reported in Chapter Four. Chapter Five contains a discussion of the study. Recommendations for education, future research directions, and policy change are made in Chapter Six.

Definitions

For the purposes of this dissertation, the following definitions will be used:

1. *Palliative care*:

   > Health care for individuals and families who are living with a life-threatening illness that is usually at an advanced stage. The goal of palliative care is comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. (CHPCA, 2002, p. 1)

   The participants in this study were no longer receiving treatment intended to cure their illness, but were receiving treatment intended to relieve the symptoms of their illness. Participants may receive palliative care for varying periods of time, depending primarily on the aggressiveness of their illness. The period during which a person receives palliative care ends with their death.

2. *Advanced Cancer*: Cancer that has been determined to be metastatic and thus no longer curable.
3. *Family*: Any person whom the individual with advanced cancer considers to be "family". The term does not necessarily assume a biological or legal connection.
4. *Family Caregiver*: A family (see definition above) member who lives in the household of an individual with advanced cancer, or if not living in the household

has a close connection with the individual and is the primary provider of the individual's informal care in the home. In this study *caregiver* will be used to denote *family caregiver*.

5. *Family Dyad*: This term describes the relationship between the individual with advanced cancer and his or her family caregiver.

CHAPTER TWO

Dissertation Concepts: Literature Review

Glaser (1978) noted that normally researchers using grounded theory are already experts in the area of study and thus an extensive literature review is not conducted until after data are collected and analyzed. This approach makes it easier for the researcher to remain undistracted by current writing while analyzing the data. Subsequent grounded theory researchers have stated, however, that in the case of graduate students it is important for them to do a literature review early in their work to ensure that they understand and can articulate the concepts that frame their study (Morse & Richards, 2002).

In this chapter, I have outlined literature pertaining to transition, uncertainty, and decision-making, as these concepts underpin the research question in my view. The literature has, however, been delimited and does not extensively review the decision-making literature with respect to patient-health care provider interactions or that of family dyads coping with dementia.

Transition

Selder (1989) connected the concepts of transition and uncertainty in her early work in life transition theory. She stated that transitions are precipitated when one's "current reality is disrupted. The disruption … can originate in a crucial event or from a determined decision" (Selder, 1989, p. 437). Uncertainty, according to Selder is ubiquitous in the lived experience; however, we remain unaware of it if our reality is constructed so that uncertainty recedes from our consciousness. When a disruption occurs, uncertainty comes to the forefront of one’s awareness once again. One’s sense of safety may, therefore, be compromised, and disorientation occurs.

These two concepts were further explicated as separate entities in the literature by Mishel (1999) and Meleis, Sawyer, Im, Messias, and Schumacher (2000), and were united again in a concept analysis conducted by Wilkins and Woodgate (2006).

My starting point in this thesis, based on the literature review which follows, was that transition is a process marked by a heightened sense of uncertainty, followed by a resolution of some kind. The final transition of one’s life begins when one realizes that life may be drawing to a close and ends with death. This transition may be shared with those within one’s family but it is likely experienced differently by each person in the family. The decisions that must be made during this transition are ideally made with two goals in mind: to gain mastery over uncertainty and thus resolution of uncertainty, and to maintain the individual’s autonomy. Some decisions may address both goals well, while others may address only one goal. It is conceivable that some decisions may not accomplish either goal and could indeed increase uncertainty and decrease the patient’s autonomy.

Meleis and Trangenstein (1994) proposed that the discipline of nursing adopt the concept of transition as an organizing framework, stating that “facilitating transitions is a focus for the discipline of nursing” (p. 255). While recognized as an important concept in nursing, transition has not been accepted as an overarching framework for nursing. Nevertheless, the concept does add to the lexicon of theoretical concepts that contribute to an understanding of nursing and consequently to the development of the discipline.

Meleis, in partnership with other nurse researchers, has honed the concept of transition for the nursing discipline. Chick and Meleis (1986) identified this concept as a nursing concern and defined it as “a passage from one life phase, condition, or status to another” (p. 237). Schumacher and Meleis (1994) conducted a review of the nursing literature from 1986 to 1992, and found that nurses address a variety of transitions in their scope of practice. These transitions may be developmental or situational and may occur in relation to either health or illness. The review also delineated the three indicators of a successful transition as: emotional well-being, mastery, and well-being of relationships. The authors contended that while disciplines other than nursing utilize the concept, only nurses, in the context of their scope of practice, facilitate transitions toward health and a sense of well-being.

It is important to differentiate the concept of transition from that of change. Transition implies an internal process that occurs over time and that has a “sense of flow and movement” (Meleis & Trangenstein, 1994, p. 257). Change, however, is an abrupt, external process that substitutes one item for another and is not considered descriptive of the transitions that occur in an illness state such as cancer (Meleis & Trangenstein, 1994).

In 2000, Meleis, Sawyer, Im, Messias, and Schumacher detailed five qualitative studies that further developed the concept of transition. Based on this work the authors expanded the theoretical framework of transitions to include: types and patterns of transitions, properties of the transition experience, transition conditions (i.e., facilitators and inhibitors), process indicators, outcome indicators, and nursing therapeutics (Meleis et al., 2000).

The authors stated that transition implies a process that takes place over time, rather than a singular event or a series of events. An event or a series of events may trigger a transition, and multiple transitions may occur simultaneously. It behooves nurses, therefore, to be cognizant of "the patterns of all significant transitions in an individual or family's life rather than focusing only on one specific type of transition" (Meleis et al., 2000, p. 18). The authors found that transitions, while complex, did have interrelated core properties such as awareness, engagement, change and difference, time span, and critical points and events. They cautioned, however, that a person could be in transition without recognizing what was occurring at the time. Awareness could come after the transition had transpired or be recognized by a health care provider rather than the person experiencing the transition (e.g., menopause). They also noted that it was difficult to engage in the process of transition if one was not aware of an event with the potential to trigger a transition (e.g., early stages of pregnancy).

A number of conditions that may assist with or deter the transition were also identified. The meaning that one ascribes to the transition may dictate how the transition occurs and in some cases ascribing no meaning may be facilitative. In societies where menopause is considered uneventful, the transition may occur seamlessly, whereas a life stage that is perceived negatively may have a correspondingly difficult transition.

Cultural beliefs may stigmatize a life event, forcing those who become engaged in a transition to hide its occurrence. Preparation for a transition can facilitate the process; this is particularly so when one is preparing for motherhood. Availability and knowledge of community resources and support may also facilitate or inhibit a transitional process (Meleis et al., 2000). Process indicators that move one toward a healthy transition include: feeling connected; interacting; being situated in terms of time, space, and relationships; and developing confidence and coping (Meleis et al., 2000). These indicators are factors that can be facilitated through early assessment and intervention by nurses.

While acknowledging that change and transition differ, Meleis et al. (2000) indicated that change may also be a component of transition. After a person has experienced a life transition, a change from one's previous condition is perceived and the difference is acknowledged. Level of comfort with the change or mastery of the change may, however, take time to occur and in some cases may not be achievable. Mastery, one of the two outcome indicators identified within the five studies, allows one to manage in a new situation. The second outcome indicator, a reformulated or fluid identity, is indicative of the settling-in experience that occurs after a successful transition.

Further Research

At least one other conceptualization of transition has been developed. Kralik, Koch, and Eastwood (2003) based their work on a conceptualization developed by Kralik (2002) through her work on chronic illness. In Kralik's conceptualization of transition, women who experience chronic illness move between states of *extraordinariness* and *ordinariness*. The authors used this conceptualization in a participatory action study of sexual self-identity in women living with multiple sclerosis. Inquiry in the study centered on the issue of self-identity and observation to identify the transitions. Selected aspects of the transitions experienced by the participants were similar to those of the participants in the studies using the conceptualization developed by Meleis and colleagues described above. Movement was evident in all studies, as was the meaning of the event and the support received. Mastery of the transition was not necessarily achievable in the study by Kralik et al., since loss of control was a prevalent theme. However, a settling-in experience did occur for some participants as they adjusted to their new condition. Change from extraordinariness to ordinariness did occur for study participants when they were able to incorporate their disability into the schema of their new self-identity.

In a phenomenological hermeneutic study, 30 women were interviewed regarding the lived experience of receiving notification of an abnormal Pap-smear result after a mass screening program in Sweden (Forss, Tishelman, Widmark, & Sachs, 2004). The study, while purporting to be about transition, did not address knowledge regarding the concept. Transition literature was not cited, and parallels that could have been drawn were nonexistent. Sadly, this was a missed opportunity, as most of the elements pertaining to transition were present. The authors acknowledged that there was a before-and-after condition that the participants experienced; however, this was not explored.

Duggleby and Berry (2005) examined the transitions and shifting goals of care that palliative patients and their families may experience. They stated that the WHO (2002) definition of palliative care implies that transitions are innate in the trajectory of a palliative illness. Examples of such transitions “include transitions from cure to comfort care, transitions related to loss, changes in care settings, and psychosocial and spiritual transitions” (Duggleby & Berry, 2005, p. 425). The authors provided a case study that was a compilation of a number of patient cases. The intent of the case study was to illustrate how nurses could facilitate and support palliative care patients and their families during the transitional process. The authors concluded that transitions in palliative care should not be rushed, but instead, must be undertaken according to patients’ own needs and timing. Ideally, the patient and family should be in control of the process and their wishes should not be challenged. Duggleby and Berry stated that the nursing role was to be supportive and serve as a guide throughout the process. In this article, the conclusions were reminiscent of the philosophy of hospice and palliative care, in that the patient and family formed the unit of care and were supported to remain in control of the palliative care process. Elements of mastery and settling in were apparent in the case study but were not delineated as pertaining to specific transitional states.

Hutchinson (2005) also described the transitional components of a chronic illness but did not delve into the nature of such transitions. He described the transitions that occur in the lives of patients with end stage renal disease (ESRD), and comprehensively detailed 15 such states in a table. The author concluded his discussion by stating that "although there is good reason to believe that patients with ESRD experience adjustment crises at major transition points in the course of their disease, we need to know a lot more about this phenomenon" (Hutchinson, 2005, p. 275).

Davies (2005) brings us back to the actual concept of transition in her study about nursing transitions and relatives' experiences of nursing home entry. The purpose of the paper was to explore Meleis' mid-range theory of transition as it related to the topic of the study. The author concluded that "all domains of the theory of nursing transition were supported by the data generated within the study" (Davis, 2005. p. 658).

The author did, however, find that the theory seemed to be incomplete and suggested that it required further exploration. She indicated that the theory was unable to represent the "interactive and dynamic nature of relationships between formal and informal caregivers in the nursing home context" (Davis, 2005, p. 658).

Redefining the Concept of Transition

Wilkins and Woodgate (2006) conducted a concept analysis of transition in the context of siblings of children with cancer, utilizing Walker and Advant's (1995) method of concept analysis. The authors acknowledged Meleis et al.'s (2000) work regarding the concept and explored the concept from the perspective of pediatric oncology, specifically with regard to the sibling experience. Also crediting Meleis and Trangenstein's (1994) work, the authors built upon the original definition of transition by redefining it as "a process that involves movement from a state of equilibrium to a state of disequilibrium and to a new state of equilibrium" (Wilson & Woodgate, 2006, p. 263).

The authors' analysis brought the concept of uncertainty together with the concept of transition once again by stating that, "because disequilibrium experienced in transitions is characterized by uncertainty, it follows that documenting an individual's degree of certainty would be a good indicator of whether a person is in transition" (Wilkins & Woodgate, 2006, p. 262). They recommended the use of Mishel's (1999) Uncertainty in Illness Scale for this purpose.

Building on the literature review conducted by Schumacher and Meleis (1994), Kralik, Visentin, and Van Loon (2006) conducted a meta-analysis and an additional review of the literature from 1994 to 2004. The authors confirmed that the concept of transition was a central concept in nursing, and recommended further research in this area.

As was also noted by Davies (2005), Kralik et al. (2006) stated that new methodologies must extend beyond singular approaches and singular events and that comparative and cross-sectional longitudinal inquiry of transition was now required. The authors also identified the following gaps in the literature: inquiry regarding why some people experience transition while others do not, identification of the structures and processes of transition, examination of the gendered and cultural experiences of the concept, and the influence of age and other intrapersonal factors. The authors concluded that:

> Transition processes occur when life's circumstances or relationships change. Transition entails change and adaptation…but not all change results in transition….common to these experiences, is the dislocation, disorientation, and disruption caused to the person's life and the need for them to locate new ways of living. (Kralik et al., 2006, p. 323)

Transition theory may be useful in understanding the changes in roles and responsibilities related to the ongoing management of advanced cancer. In turn, this dissertation study may advance the existing hypotheses regarding transition by exploring how transitions are affected when they need to be made quickly and in the context of rapid cognitive and physical decline.

Uncertainty

My starting point with respect to the definition of uncertainty in the context of palliative care is most closely associated with the work of Morse and Penrod (1999), who said that a core attribute of uncertainty was the requirement to tolerate an uncomfortable present because of an inability to move toward a future goal. My position is different from the work of Morse and Penrod, however, in that uncertainty in the palliative phase of an illness is not associated with the inability to move toward a future goal, but rather a wish to forestall the resolution of the transition at hand, which is death. The management of uncertainty requires the ability to think clearly and concentrate and is often compromised by cognitive or physical decline. Thus, as cognitive or physical decline become more pronounced, uncertainty may increase, and the ability to play an active role in the final transition of one's life may be compromised. Uncertainty is experienced by both the individual and his or her family members, but factors that contribute to uncertainty for the individual and the family members may be different. Thus, uncertainty may be at the root of tensions within the family of a terminally ill individual.

Parsons (1980) began the discussion of uncertainty by stating that "exposure to uncertainty is perhaps the most negative aspect of human life" (p. 145). Selder (1989) suggested that this negative aspect was rooted in the inherent disconnection from one's usual relationships and Weitz (1989) indicated that uncertainty existed when one was unable to predict the outcome of one's behaviour.

Mishel (1990) maintained that uncertainty was a neutral cognitive state, neither positive nor negative, until the person determined the implications of the condition; once appraised the individual then perceived the event as an opportunity or a danger. This idea was supported by the work of Gauthier (2001), who studied uncertainty in the context of terminally ill adults who received hospice care in their homes. Those who were able to engage uncertainty were able to manage it while continuing to make health and personal decisions. Nevertheless, Neville (2003) noted:

> Few individuals tolerate uncertainty well. Uncertainty in illness is generally perceived as a significant stressor, and most people seek ways to reduce uncertainty or to learn methods to cope with uncertainty, either alone or through social resources or health providers. (p. 207)

In a phenomenological study of the lived experience of having cancer Halldorsdottir and Hamrin (1996), found that all participants experienced uncertainty and lack of control in all the stages of cancer. “Getting rid of uncertainty means that sometimes the diagnosis of cancer is welcomed after a long period of uncertainty” (p. 31).

Literature pertaining to Alzheimer’s disease and AIDS Dementia Complex supports the notion that uncertainty is heightened as cognitive capacity declines (Gregory & Gibbs, 2002). In these patient populations, the stage of dementia may last for several years, and individuals in this state, “can be considered to be dying” (Blasi, Hurley, & Volicer, 2002, p. 58).

Initially experiencing uncertainty, dementia patients progress along a continuum that results in loss of control and autonomy in their daily lives, a process that is distressing to the individual and to his or her family. A participant in a grounded theory study of early onset Alzheimer’s dementia stated, “I have lost my ability to be a coparent to my children and a decision-making partner. It’s almost like I have become the third child” (Harris, Keedy, & Cert, 2004, p. 124). Another participant stated, “Every day I ask myself how long this will carry on. He’s been in the home for four years now and I want to get on with my life” (p. 122). The nature of advanced cancer, however, means that the loss of cognitive and physical function happens more quickly, thereby increasing uncertainty, and making adjustment more difficult.

Cognitive capacity affects patient choice and the degree of control that a palliative patient can maintain. Cognitive capacity as defined by Mishel (1988) is a person’s information processing ability. This ability can become impaired during illness due to physiological, psychological, and environmental stimuli. When cognitive capacity is reduced, an individual often has difficulty perceiving congruence between expectations and experience, resulting in uncertainty.

Investigators who studied patients with HIV/AIDS and Down Syndrome found that uncertainty was also experienced among family members. Uncertainty was increased for patients and their family members when healthcare workers provided unclear explanations or were perceived as unable to assist with the intricacies of the illness (Tomey & Alligood, 2002). This lack of information made it difficult for families to form a *cognitive schema* that would help them to understand the illness (a cognitive schema is the subjective interpretation of illness, treatment, and hospitalization).

Uncertainty is appraised by the patient as being either a danger or an opportunity. If perceived as harmful, coping strategies to reduce the uncertainty are implemented. If perceived as an opportunity, coping strategies to maintain uncertainty are sought and, if they are effective, adaptation occurs (Mishel, 1988). “The relationships between illness events, uncertainty, appraisal, coping, and adaptation are linear and unidirectional, moving from situations promoting uncertainty towards adaptation” (Tomey & Alligood, 2002, p. 565). The individual may, however, fluctuate repeatedly between the two polarities during the course of an illness (Mishel, 1990).

Uncertainty in Illness

Mishel began her research into uncertainty in illness by drawing on existing research (primarily from the psychology discipline). This research characterized uncertainty as a cognitive state resulting from insufficient cues from which to form a cognitive schema. Mishel attributed the underlying stress, appraisal, coping, and adaptation framework of her theory to the work of psychologists Lazarus and Folkman (1984). After an analysis of coping in 100 middle-aged participants, the psychologists concluded that taking action in stressful conditions is a powerful coping tool, and that the context of an event and how it is appraised are the most important factors when choosing a type of coping behaviour. Mishel applied this psychological framework to uncertainty as a stressor in the context of illness, thereby making her theory of Uncertainty in Illness meaningful to the nursing discipline.

Mishel investigated the role of uncertainty “as a significant variable influencing patient’s experiences in illness, treatment, and hospitalization” (Mishel, 1981, p. 258). She identified that considerable nursing research had been conducted with the intent of reducing a patient’s stress during hospitalization, but stated that identification of the processes and conditions that produce different stress reactions had not been explored. Mishel found the literature lacking in the investigation of uncertainty as a perceptual variable, which influences the appraisal of illness related events. Evidence to date; 1980, was largely anecdotal. There was no conceptualization in the literature of uncertainty in illness and no instruments had been developed to measure the concept. This led to a series of studies to define the concept of uncertainty in illness and the development of the Mishel Uncertainty in Illness Scale, a 30-item scale based on uncertainty in symptomology, diagnosis, treatment, relationship with caregivers, and planning for the future.

To clarify the antecedents of uncertainty in illness, Mishel (1988) studied 61 women with gynecological cancer. She found that social support, credible authority, and event familiarity had the greatest influence on lowering the level of uncertainty. Event familiarity and credible authority were primarily effective in reducing the complexity that surrounds treatment. Social support decreased the level of ambiguity about the illness.

Morse, Mitcham, Hupcey, and Tason (1996b) delineated a method to determine the level of maturity of a concept, which Penrod (2001) used to analyze the concept of uncertainty across disciplines. She reported that "in nursing, uncertainty in the experience of illness is broader and tends toward maturity, with evidence of evolving theoretical frameworks" (p. 240), indicating that Mishel's work regarding concept development has achieved noteworthy status in the nursing literature.

After nearly a decade of research with acute care clients, Mishel realized that all patients did not progress in a linear fashion to the adaptation stage as indicated in her theory. She discovered contrary findings when working with patients who had a chronic illness. The theory was strongly supported by patients who were experiencing a "downward illness trajectory" (Mishel, 1990, p. 256) but not when patients were living with the continual uncertainty of a chronic illness or an illness with a treatable acute phase and a possible eventual recurrence.

This lead Mishel to re-examine the concept of uncertainty; by using critical social theory, she found that her original theory supported a mechanistic view of society that valued predictability, control, and mastery of the environment. In this view, there is an expectation that cause and effect can be determined, and that success is judged by the degree to which this goal can be achieved (Mishel, 1990). Having examined western cultural attitudes toward the experience of uncertainty, Mishel concluded that the original theory reflected a cultural bias whereby preference for certainty and an orientation to achieve equilibrium were valued. In addition, the original version of the theory could not account for the evolution of a patient's appraisal of uncertainty over time.

Reconceptualization.

Incorporating the concepts of chaos theory into the Uncertainty of Illness Theory allowed Mishel to address the aspects of the theory that required modification (Mishel, 1990). This was particularly useful because it shifted the view from the traditional focus of science on stability and order, to a new view in which disorder, diversity, and nonlinear relationships were important (Hayles, 1990).

According to the reconceptualization of the theory, patients develop a new view of life based on an exchange between themselves and the external environment, which also includes input from social resources and health care providers. This new view includes the development of probabilistic thinking and the acceptance of the nature of uncertainty as the natural rhythm of life. To maintain this worldview it is helpful if health care providers also hold a probabilistic, rather than a mechanistic, world view (Mishel, 1990). Mishel confirmed her reconceptualization of uncertainty theory in a series of qualitative studies (1997, 1999). In her reconceptualization of uncertainty theory, Mishel offers a more multidimensional and complex view of humanity, a more realistic vantage point from which to consider transitions related to declines in cognitive and physical status during the palliative phase of illness.

Decision-Making

My starting point in this thesis was that the ability to make decisions is an ongoing process, and is crucial to the reduction of uncertainty and maintenance of control during the final transition of one's life. Ideally, both the patient and the family are involved in key decisions, but this may not always be possible, particularly if patients experience a significant decline in their cognitive or physical status, which often happens as they move closer to their time of death. Decisions made jointly by the patient and family, may be less likely to result in conflict within the family, and thus, are more likely to decrease uncertainty.

Informed decision-making underpins ethical medical and nursing practice. It implies that the patient is fully informed regarding all aspects of his or her illness and can, therefore, participate autonomously in their own care. The precursor to informed decision-making, informed consent; continues to be utilized in health care terminology. However, this term has legal rather than ethical connotations and generally means that the patient's role is to agree with a physician's treatment decision rather than to share in the decision-making process (Kottow, 2004).

To determine the extent to which palliative care patients were informed about all of their care options Gattellair, Voigt, Butow, Martin, and Tattersall (2002) analyzed the content of the interactions between 118 cancer patients and their oncologists. The authors state that patients may comply with anticancer therapies without completely understanding how these therapies pertain to their individual medical conditions. The pursuit of unnecessary treatment is particularly questionable when a patient's life span is measured and it is, therefore, important that patients be fully informed. Overall the study found that rather than encouraging participation, doctors more commonly provided information to their patients. However, the physicians responded to patient cues and were more likely to encourage participation when patient's clearly asked for or sought information. Physicians also provided more information when a patient was newly diagnosed and encouraged participation when metastases had occurred. The authors concluded that encouragement to participate, therefore, depended largely upon the patient and his or her disease factors.

Weissman (2004) expanded upon the work of Gatteliar et al., stating that the palliative patient would benefit during a life-threatening crisis from the time the physician had taken to explore all curative and palliative care options prior to the emergency situation. The health care provider could accomplish this by "providing honest and timely prognostic information, making clear recommendations, facilitating patient-family discussions, and affirming patient choices" (Weissman, 2004, p.1738). Decision-making is, therefore, an ongoing process that requires the health care practitioner to explore all options with the patient.

A review article of decision-making literature found that most patients wished for full information, and two-thirds wanted to participate actively in decision-making. Higher educational level, younger age, and female gender predicted active involvement in decisions. Patients diagnosed with breast cancer were more likely to participate actively in treatment decisions than those who had prostate cancer. Interventions such as decision aids, information sheets, and audio taping of consultations were recommended to increase patient participation in decision-making (Gaston & Mitchell, 2005).

The patient's family also plays a role in treatment decisions, and in physician and hospital selection. In a descriptive, qualitative study conducted with 37 patients who had lung cancer and their caregivers, Zhang and Simonoff (2003) found that more than half of the families studied disagreed with each other about routine treatment decisions, discontinuation of treatment, and use of hospice care. Knowledge of family disagreements can, therefore, assist health care practitioners to integrate both family and patient care expectations into the decision-making process. This can only occur, however, if the health care provider has taken the time to work with the patient and his or her family to elicit these issues.

The ability to make decisions is a core component of autonomy. "By definition, autonomous individuals are fully capable of making their own decisions…assessing capacity is difficult, in part, because decision-making capacity is not an all-or-nothing ability; it occurs on a continuum" (Collopy & Boyles, 1991, p. 2). Many factors influence the ability to make decisions. Some of these factors are modifiable, while others are not. For example, patients who cannot make decisions due to the sedating effects of their medication, may make capable decisions if their medication is reduced (Tonelli, 2005). The capacity of individuals with extensive brain metastases, on the other hand, is not as amenable to clinical intervention.

Advance directives have been recommended as a way to continue to honour the patient's wishes once his or her decision-making capacity has diminished. In this way, everyone has a clear idea of the patient's wishes and the patient's care can proceed. Advance directives are treatment decisions made "in anticipation of some future time when the patient will be mentally incompetent or otherwise incapacitated to the extent that he or she cannot make or participate in such decisions" (Jordens, Little, Kerridge & McPhee, 2005, p. 563). Lo and Steinbrook (2004) contend, however, that efforts to promote advance directives during the past 25 years have been ineffective and health provider interventions to increase their use have been unsuccessful.

One reason for minimal adoption of advance directives may be the heavy emphasis on the legal aspects of the documents and insufficient attention to discussion and clear communication with caregivers and family members. Laws requiring directives to be witnessed or notarized may deter patients from completing them. Patients are also encouraged to delineate their care instructions for various end-of-life scenarios; however, every eventuality cannot be predicted. The patient may, therefore, not complete the document, or, if completed, the document may not be comprehensive, leaving proxy decision-makers in limbo (Lo & Steinbeck, 2004).

Drought and Koenig (2002) contend that patient choice regarding decision-making is an illusion that is promoted in the palliative care literature, stating that "there is little or no empirical evidence to support the autonomy paradigm of patient 'choice' in end-of-life care decision-making" (p. 114). The authors state that patient choice is based on three inaccurate assumptions. First, that the timing of one's death can be predicted; second, that there are choices available for the patient to consider; third, that all patients can ponder their own mortality in a manner that leads to rational decision-making. Rather, choice is often constrained by unexpected occurrences in the illness trajectory, the limits of one's physiology or available resources, and the patient's inability to engage with the dying process. This ideology is based upon patient's rights movements that occurred in western countries during the 1960s and 1970s. Such rights have now been enshrined in our health care systems and have become difficult to dispute. The authors, citing the ethnographic studies that they have conducted into this matter, further contend that the choices offered to a palliative patient are presented as choices between life and death. The cultural norms of western society obligate the patient to choose life, and, therefore, the complicated treatments that are offered to preserve that life. The reality of terminal illness, however, is that death will come shortly whether one chooses it or not. The challenge for health care providers is to help patients understand the limitations of the choices they are offered and to support them regardless of the treatment decisions they make.

Autonomy

Autonomy, beneficence, nonmalfeasance, and justice are the core principles of biomedical ethics that health care providers strive to uphold in health care and home care settings (Storch, 2004). Autonomy is the principle cited by palliative care patients and their health care providers as essential to maintaining control of the illness process. The principle of autonomy upholds a patient's right to make choices for themselves. While individual autonomy is an ethical principle that is prized in western society, it may be lost when safety considerations become a concern. In long-term care settings, safety may be given priority over autonomy and the rules and regulations of the organization may limit patient choice. "In addition, the social context of long-term care settings means that one resident's needs must be balanced with the needs of other residents" (Hickman, 2004, p. 14).

Caregivers may hasten a patient's loss of autonomy by their lack of awareness of an individual's abilities. In a qualitative study, Gregory and Gibbs (2002) explored the experience of participants diagnosed with AIDS Dementia Complex (ADC) and their perceptions of, and insights into, their loss of function. They found that major discrepancies emerged between the participants and their health care providers regarding the need for assistance and support with activities of daily living. Patient autonomy can be maintained if, as the authors recommend, caregivers are aware of the degree of insight that ADC patients have retained.

Other caregivers may take extra care to maintain the perception of autonomy by preserving the individual's self-esteem, as was found in a grounded theory study where patterns of spousal care-giving in elderly dementia care were observed. Responsibilities and decisions which had formerly been shared equally were gradually assumed during the course of the illness and resided solely now with the care-giving partner (Jansson, Nordberg, & Grafstrom, 2001). Although the care-giving spouses were engaged in demanding and time consuming care, they cared about their partners as well as for them. The partners with dementia could no longer conduct a continuous conversation, but some of the spouses habitually spoke to their partners, even if the partners did not respond. One characteristic of spousal caregivers was their ability to "enter into their partner's feelings and illness. They enhanced their spouse's self-esteem thereby protecting their identity" (Jansson et al., 2001, p. 808).

Good care.

The concept of *good care* can also contribute to a patient's sense of autonomy. End-stage cancer patients reported feeling that good care was received when events moved along in the right direction. Good care included the categories of safety, participation, and trust. All three categories must be present for the perception of good care to exist. In the absence of even one category, patients felt worried, felt that they were not receiving good care, and perceived that events affecting their care had either stopped or were moving in the wrong direction. "If patients are to feel safe, they need to participate in their care, and this participation creates a feeling of trust, which in turn, creates a feeling of safety" (Harstade & Andershed, 2004, p. 33). Interestingly, participants in this study indicated that the best site for receiving good care was a hospital setting. They perceived that a hospital setting could provide safety. They also did not want to disturb the lives of their families or burden them with their care.

Trust.

As noted previously, a feeling of trust is necessary for patients to feel safe and to participate autonomously in their own care. According to Austin (2005), every relationship involves trust, notable either by its existence or by its absence. Trust is essential to the human experience and forms the manner in which one relates to the world. Austin also states that trust is difficult to define; however, it is a substantial or *thick concept* and such concepts can "give us insight into how to live, how to make sense of what we are doing and how to act and behave toward others … [and] can give us greater insight into nursing practice" (Austin, 2005, p. 318).

Patients are dependent upon health care organizations for their care, either in hospital or in the community. However, health care organizations in western countries are experiencing challenges and uncertainty regarding funding, appropriate patient care delivery, and adequate staffing. Trust has, therefore, become an issue not only in the nurse-patient relationship but also in regard to nursing leadership and management. Rogers (2005) posits that nurses do not trust that nursing leaders will do what is right for appropriate patient care and that conflict has become the norm in health care organizations. "Trust is not an acquired trait; it is an expectation resulting from an interactive process of human concern and caring" (Rogers, 2005, p. 311). Bruhn (2005) adds a physician voice to the issue, stating that "the principle of trust is not outdated … a relationship of trust is built on the style and quality of verbal and nonverbal communication" (p. 312).

As the concepts delineated above illustrate, the path to control over the dying process is not straightforward. Throughout his or her illness trajectory an individual experiences a number of transitions, hovering between care-related choices and an uncertain future. Choice is often dictated by treatment options, one's physiology, or family member wishes. Decision-making may be delegated to others due to cognitive or physical decline, necessitating that one place his or her trust in advance care directives, family caregivers, or health care providers. The responsibility to aid the patient in this journey toward a good death may fall to family caregivers who will require the ongoing support of the palliative care team to sustain them throughout the process.

For the purposes of this dissertation study, it was assumed that control over the dying process is important to an individual with advanced cancer during the palliative phase of illness, because it helps them to attain the ultimate goal of a *good death*. Whether this goal is created by the health care environment that surrounds the individual or by society's dictates regarding dying and death, a good death motivates the individual and his or her caregivers. Ultimately then, the individual will attempt to maintain control when decisions regarding his or her care need to be made, as they expect this to result in a good death. As noted in Chapter One, the concept of a *good enough death* has been introduced more recently. The challenge for health care professionals is to help family dyads find the balance between their ideal goals regarding death and those that are good enough from their perspective.

Uncertainty is the antecedent of decision-making. Whether this uncertainty is stressful depends on how it is perceived by the individual (i.e., positively or negatively). If negative, the individual will try to reduce the stress and may make the decision quickly or engage others to assist with the decision-making process. Such an individual may be perceived by others as being in control of the decision-making process and, ultimately, of the illness trajectory. Conversely, if uncertainty is perceived as neutral or positive, the individual may prolong the decision until more facts have been gathered, and may feel that engaging others in the process is unnecessary. Such an individual may be perceived to be procrastinating, and not as being in command of the decision-making process, and, therefore, not in control.

The way decisions are made for an individual whose cognitive or physical abilities have declined has an impact on the sense of uncertainty and control of both the ill individual and the person to whom they have given the authority to make decisions on their behalf. If the ill individual has delegated decision-making to others and has left information about their wishes, the ill individual may feel less uncertainty and more control than those who have not delegated this responsibility to others and left no information regarding their wishes. The person or persons to whom the responsibility for making decisions was given may feel increased uncertainty, given the newness of their responsibility, but ideally will try to make decisions in a way that honours the intentions of their family member. For example they may say, “he always made decisions quickly and remained in control of the illness, therefore, to maintain this control we will also make decisions in this manner.” Although potential sources of tension and conflict between the ill individual and his or her family caregiver exist, clear plans that lay out decisions ahead of time, as much as possible, help to alleviate uncertainty and maintain the ill individual's control over important decisions even as death approaches.

A lack of delegation with respect to decision-making in the face of declining cognitive or physical abilities may occur for many reasons, such as the lack of a family member willing to accept decision-making responsibility, the unwillingness of the ill family member to relinquish responsibility, or the rapidity of the individual's decline. Under these conditions, tensions between the ill individual, his or her family caregiver, and the health care team regarding important care-related decisions are more likely, adding to the sense of uncertainty and loss of control.

The decisions that must be made at the end of life are a core component of the final transitions in life. If the decisions are in keeping with the wishes of the ill individual, and he or she has the time or ability for reflection, a sense of mastery, as discussed by Mishel (1997, 1999) may occur and be perceived as a part of a good death. A good death indicates resolution of the final transitions, and can be identified in the ill individual and his or her family caregiver by their sense of being changed in some way.

The literature indicates, however, that transitional states may not always be recognized by the individual until they are completed, and in palliative patients, the completion of these final transitions is synonymous with death. If decision-making is difficult, and the burden of care for family members is high, the individual may be in a constant state of flux and unable to appreciate that he or she is in transition. At the end-stage of life, this individual may not have the luxury of time and may need the assistance of others to recognize and acknowledge this transitional state.

To summarize, very little is known about how ill individuals and their family care givers make care-related decisions during the palliative phase of illness. There is some literature that supports higher patient satisfaction with health care decision-making if patients have a *power with* relationship with health care personnel. There is no literature, however, on how family dyads manage decision-making or on their joint satisfaction with the outcome. As shown in the diagram in Figure 1, these decisions could be expected to influence transitions at the end of life, and thus, may reduce some of the uncertainty inherent in palliative care, increase control, and result in a good, or a good enough, death (see Figure 1).

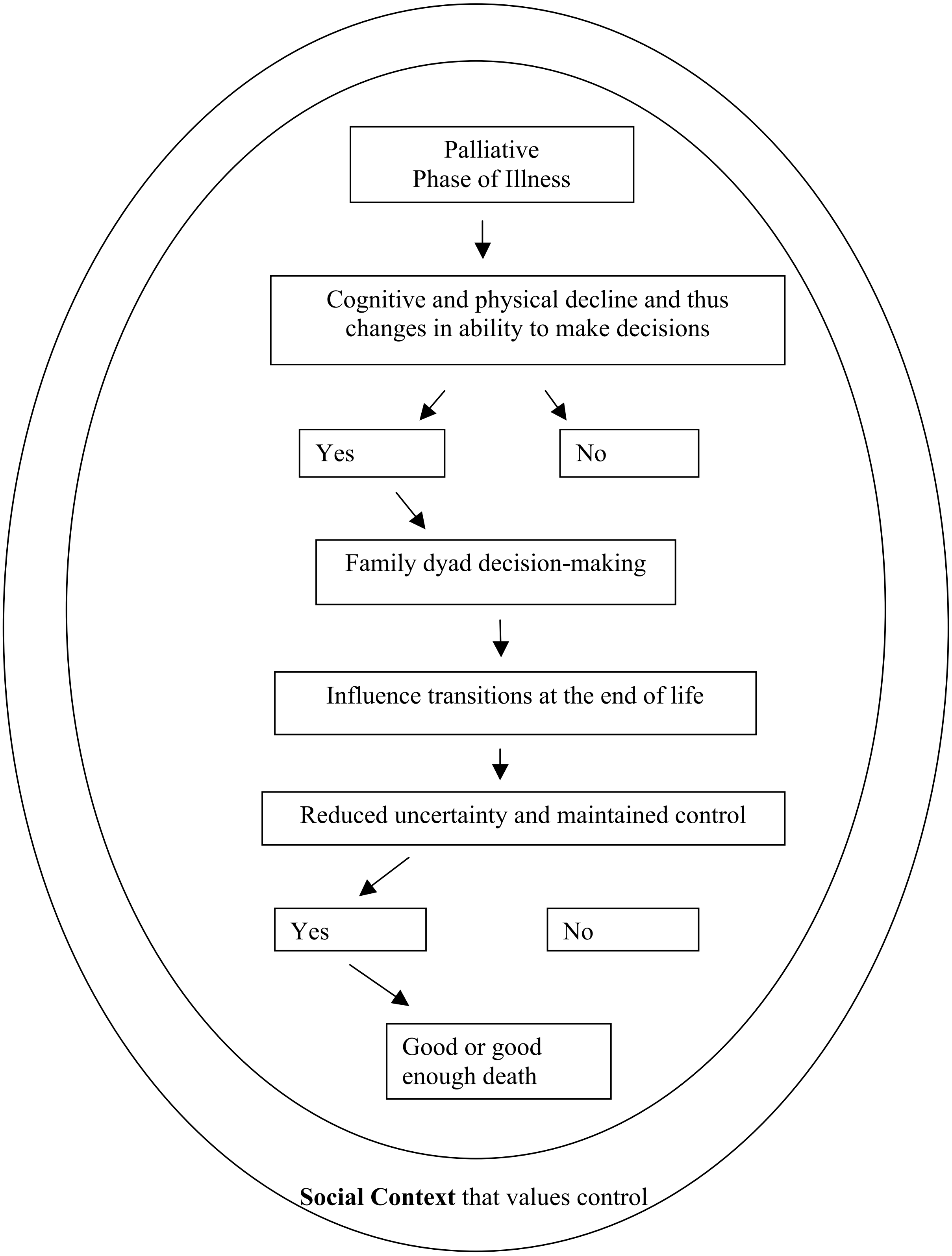

Figure 1. Cognitive and physical decline and family dyad decision-making

CHAPTER THREE

Method

The dissertation study "Decision-Making in Family Dyads in the Context of Advanced Cancer" was conducted using qualitative inquiry. Palliative care has been extensively studied, as have issues pertaining to the field, such as caregiver burden and maintenance of patient autonomy. The process by which individuals with advanced cancer in the palliative phase of their illness and their family caregivers manage decisions that must be made when the ill individual experiences periods of cognitive or physical decline has not been extensively researched, and thus, an inductive approach was selected. Grounded theory was the qualitative approach chosen for this study, as it is the most appropriate method for research questions that focus on a process. Grounded theory provides a mechanism by which one may examine the social construction of reality and the inherent stages and related processes (Morse & Richards, 2002).

Grounded Theory

Grounded theory, developed by Glaser and Strauss (1967) originated from symbolic interactionisim, which takes the perspective that people behave and interact based on how they interpret or give meaning to specific symbols in their lives (Morse & Field, 1995). Therefore, grounded theory is developed from data that originate in natural settings and the researcher becomes an instrument for theory development.

The major goal of grounded theory is to form a theory that encompasses and explains as much behavioural variation as possible. Data collection, sampling, and analysis occur simultaneously. In this way the researcher moves forward in tandem with the emerging theory, collecting subsequent data and theoretically sampling according to the needs of the developing theory. If the theory does not fit the data, the theory is modified or discarded. This process results in a theory that is grounded in the data (Glaser & Strauss, 1967). To do this well, the researcher must have theoretical sensitivity or the ability to distinguish between meaningful and irrelevant data (Glaser, 1978). The final result of the method is *thick* description of the area of inquiry and a middle range theory that is flexible and applicable to the participants in the area of study (Morse & Field, 1995).

Subsequent researchers have developed their own versions of grounded theory, and Glaser and Strauss themselves eventually diverged onto different methodological paths. I followed the original method described by Glaser and Strauss (1967) and the additional works of Glaser (1978, 1992).

Setting and Sample

In qualitative research, it is imperative that the study be conducted in a setting where the phenomenon can be observed to its fullest extent. This study required data from both individuals with advanced cancer in the palliative phase of their illness and their family caregivers. Advanced cancer patients and their family caregivers were initially recruited through the nurses in the palliative care division of a Community Care Access Center (CCAC) and physicians from a home-visiting palliative care centre; both in a large urban city in Ontario. Additional caregivers were subsequently recruited through an advertisement placed in a free community newspaper and a letter sent out by the educator of a local hospice.

Sampling Approach

Initially I began sampling using a purposive approach, which involved selecting participants who were experts based on their experience with respect to the phenomenon of interest (e.g., patients with advanced cancer and the family members they identified as their primary care givers). As data were collected and interpretations generated, I moved to a theoretical sampling approach and selected participants who were either patients with advanced cancer or family members from other families who identified themselves as primary care givers.

As the study progressed and I was unable to saturate the categories with additional participant interviews (some individuals had died and others were too tired or too busy for another interview), I went back over my data and was able to saturate the categories with the data I had already collected; according to Glaser (1978) this is another form of theoretical sampling. I also sought negative cases by attempting to recruit families in which there was conflict and those who lived outside of urban areas (Glaser & Strauss, 1967).

Sample size.

The estimated sample size was six to nine family dyads in which an adult family member (at least 18 years old) had advanced cancer and was receiving palliative care, and there was at least one supportive adult caregiver. A sample of this size was expected to be sufficiently large to obtain saturation (Morse & Field, 1995). The final sample size was 17 participants. The sample is described in more detail in the results section of Chapter Four of this dissertation.

Eligibility Criteria

The first set of participants to be recruited for this study were family caregivers whose ill family member met the following criteria: had advanced cancer, was in the palliative phase of his or her illness, and had experienced cognitive or physical changes that affected their ability to make decisions about their care. Initially I had planned to interview primary family caregivers from each of the following groups, for a total of six to nine families:

a) Families in which the ill family member is still able to make most decisions about their care
b) Families in which the ill family member is occasionally unable to make decisions about their care, and
c) Families in which the ill family member is not able to make decisions about their care

No family dyads volunteered for the study. Thus, I interviewed ill family members and family caregivers from unrelated households. As the study developed, I also interviewed family caregivers of individuals who had died but who had experienced cognitive or physical decline during the palliative phase of their illness.

Exclusion Criteria

Individuals unable to speak and read English were excluded from this study. Individuals with advanced cancer in the palliative phase of their illness who were in a condition of complete cognitive decline and unable to sign a consent form were not interviewed or observed.

Recruitment

Based on initial discussions with various agencies, I planned to access participants through the home care nurses employed by the CCAC, but eventually also recruited through home-visiting physicians from a local palliative care centre. The nurses and physicians were informed about the study at an information session. They were asked to give the attached information letter (see Appendix A) to family caregivers or patients who met the above criteria and who were interested in hearing more about the study. The nurses and physicians provided me with their contact information, and I phoned and arranged to meet with them to answer any questions. Those interested in taking part were asked to sign a written consent form (see Appendix A).

Data Collection

I conducted all interviews using an unstructured, open-ended format to encourage participants to tell their stories in their own words and in as much detail as they wished (see Appendix B for interview approach). Participants were interviewed individually (e.g., not in the presence of other family members in the home) and verbal prompts were used to clarify issues.

All patient and family caregiver interviews were conducted in person, at the home of study participants. Bereaved caregiver interviews were conducted at the participant's home or in the investigator's office, depending upon the preference of the participant. Each interview was planned for one to two hours but often lasted for three. Follow-up interviews lasting for one to two hours were also conducted in person.

All interviews were audio taped. A master tape has been preserved in a locked filing cabinet in the investigator's office. A copy was made for transcription purposes and transported to the investigator's home in a locked brief case and stored in a locked filing cabinet when not in use. The audio tapes were transcribed to facilitate analysis.

Data Analysis

Data collection and data analysis took place simultaneously using the constant comparative approach typical of grounded theory (Glaser & Strauss, 1967). Initially, the patient interviews were analyzed as a group. This approach was also used to analyze the interviews for the two caregiver groups (nonbereaved and bereaved). As the study progressed, the results from these three groups were compared to explore the decision-making process further. Interviews were analyzed line-by-line to identify *in vivo* or open codes. Coding is important because it assists the researcher to think about the data in a more abstract fashion. As the study progressed, these codes were grouped into categories and the location of the category within each participant's story was established. Data segments were compared both within and across participants in each of the above groups. Glaser (1978, 1992) suggests the use of theoretical codes to enhance this process. Thus, as I became familiar with the data I began to identify theoretical codes based on my emerging theory, and used these new codes to elaborate or modify the properties of my categories. As new theoretical codes were identified I reviewed all previous interviews line-by-line until all data were reviewed in relation to the new theoretical code (Charmaz, 2003).

It must be emphasized that the coding process is not linear, and that the researcher shifts between *in vivo* and theoretical coding. During this process, one large category that is central to the research and that links the codes from the participants gradually emerged and was selected as the core category (Glaser, 1978). From this point onward, the focus of the study became narrower, and both the sampling strategy and the coding became more theoretical in order to tease out the relationships between the concepts included in the core category. As data saturation approached, I deliberately sought negative cases in order to extend the emerging theory in directions that were not initially apparent. The end result of this step was the identification of a basic social process (Glaser, 1992).

To explore the codes and look at the data in new ways, I also prepared memos and diagrams. Diagrams facilitate visualization of the conceptual relationships occurring among the categories, and memo writing assists one to maintain focus. These devices also serve as a bridge between coding and the completed analysis. Since memos are dated, they are a way of regularly recording one's changing thoughts about the emerging theory. I also kept a diary in which I logged the day-to-day activities of my study as well as my personal thoughts and feelings about the study. This diary was particularly critical since I am a distance PhD student working in a clinical area that included difficult emotional encounters. The diary also served as a reminder for topics that I planned to discuss with my supervisory committee.

Rigour

Rigour was maintained using verification processes outlined by Morse, Barrett, Mayan, Olson, and Spiers (2002), and the steps for evaluating grounded theory described by Glaser (1978, 1992). Ultimately it is the investigator's responsibility to engage in research that is valuable, reflects the voices of the participants, is rigorous, and clarifies or addresses a question of significance to one's discipline. To do so, the investigator should maintain methodological congruence by ensuring that verification strategies are woven throughout a qualitative study. Thus, qualitative researchers move “back and forth between design and implementation to ensure congruence among question formulation, literature, recruitment, data collection strategies, and analysis” (Morse et al., 2002, p. 5). In this way, the investigator maintains rigour by identifying and correcting threats to validity as they occur, such as a mismatch between question and method, or failure to obtain data saturation. For example, the code *hope* initially showed promise as a major category for the study. However, it did not fit the data and was not included in further analysis.

In addition, internal validity can be ensured by making sure that the data support the conclusions. External validity speaks to the generalizability of the findings and is known in qualitative research as *fit*. Thus, the researcher must examine the similarities between the emerging results of his or her study, and the descriptions of the phenomenon in other settings. The focus here is on the generalizability of the description of the phenomenon rather than on the impact of the phenomenon on a population.

According to Glaser (1978, 1992), the results of a grounded theory study can be evaluated by assessing four components. He noted that the categories within the theory must directly relate or *fit* the data. The theory should *work,* meaning that what was taking place in the data can be explained by the theory. The theory must also have *relevance* or *grab,* since it has been allowed to emerge from the data rather than the preconceived ideas held by the researcher. Lastly, the theory must be *modifiable,* which allows it to adapt to changing circumstances.

The result of a grounded theory study is distinctive to the method; stages and phases of the research problem are identifiable, action is indicated by the use of gerunds (i.e., labels ending in "ing"), and a core category, a basic social process, or a basic social psychological process, tie the theory together. The result of a grounded theory study is an abstract middle range theory that tells a story about some topic; in this study, the story is about decision-making in family dyads.

Ethical Issues

Permission to conduct the study was received from the Research Ethics Boards of the University of Alberta, Edmonton and Ryerson University, Toronto, Ontario. Further permission was obtained from a Community Care Access Centre, a physician home-visiting palliative care centre, and a hospice, that were all located in a large urban city in Ontario. The following were the main ethical considerations in this study: a) sampling a vulnerable population, and b) the potential experience of emotional distress when recounting the events of one's illness.

Participants recruited for the study were required to sign and understand a consent form written in the English language (see Appendix A). They were also informed that in a qualitative study where the nature of data collection may change, the researcher may utilize a process consent, which allows the consent to be renegotiated as necessary (Loiselle, Profetto-McGrath, Polit, & Beck, 2004).

An information letter informed participants of the risks and benefits associated with the study and advised them that they may withdraw from the study at any time. Participants were also encouraged to utilize the phone number or e-mail address provided in the letter to contact the investigator for further information pertaining to the study (see Appendix A).

Reassurance of anonymity was also provided. Anonymity was maintained by removing all identifying information from the transcripts. Any part of the study that is published will have participant's names and identifying factors removed. The transcription service used by the investigator was reputable and transcribers all signed confidentiality agreements with the transcription agency.

All audio tapes were kept in a locked office. All transcripts were identified only by a participant number, and the informed consent forms were stored separately from the data in a locked filing cabinet.

Physical risks to participants were not expected. It was anticipated, however, that participants may experience fatigue during the interview and thus should be informed that the interview could proceed at a slower pace or could continue at a later time. This approach was communicated to participants. It was also anticipated that participants may experience emotional distress when recounting the events of their own or their family members' illnesses, in which case I had planned to end the interview and refer them to their physician or home care nurse for follow up. Morse and Field (1995) note, however, that relating one's story may actually be therapeutic for the participant and may be perceived as a benefit of participating in the research process. Participants seemed to pace themselves during the interviews and preferred to take breaks rather than scheduling additional data collection sessions. Although many participants cried as they recounted their story, only one person required follow-up.

Dissemination Strategies

The results of this study are reported in the remaining chapters of this dissertation. Following the thesis defense, three papers will be drafted for submission to appropriate peer reviewed palliative care journals. At present, these papers are expected to include one paper based on the literature review, one paper discussing the study findings, and one regarding the ethical and legal issues that pertain to decision-making. Abstracts for conference presentations will be submitted to appropriate peer reviewed conferences. The organizations where I conducted the study will receive a research report and interested participants will be given a two-page summary.

It is also my intention to synthesize the key components of this study into a brief document that is focused upon recommendations pertaining to policy and education for participating sites. This is an important aspect of dissemination that will hopefully engender further discussion and promote partnerships for future research endeavors with a Community Care Access Centre.

CHAPTER FOUR

Results

The major findings of the study "Decision-Making in Family Dyads in the Context of Advanced Cancer" are the core category *Covering* and the basic social process *Dancing on the Stairs.* In this chapter, a description of the participants who volunteered to be in the study will precede a report of the study findings.

Participants

Participant recruitment occurred through the palliative care nurses at a Community Care Access Centre and home-visiting physicians at a palliative care centre in a large urban city in Ontario. Recruitment was a slow process, due to the complexities of the illness, and the care-giving process at this end-stage of the cancer trajectory. An alternative strategy was, therefore, also implemented; bereaved caregivers were recruited from an advertisement placed in a free community paper and a letter mailed directly to bereaved caregivers by the educator of a local hospice. Both the advertisement and the letter were targeted to English speaking adults who were the family caregivers of an adult who had died of cancer at least three months previously. This time frame was consistent with the waiting period stipulated by bereavement support groups (see Appendix C).

Seventeen participants were recruited for the study. Eight participants were from families coping with advanced cancer. Of these, five were patients and three were caregivers, none of the participants were from the same family. In addition, nine caregivers whose family member had died prior to the start of this study were also interviewed.

Of the five patients, four were female ranging in age from 61 to 70 years. The male patient was 50 years old. The participants who were caring for a family member were a sister, a daughter, and a sister-in-law. They varied in age from 57 to 77 years, their family members who were living with advanced cancer were aged 78 to 82 years. The bereaved caregivers included daughters, sisters, sons, same sex partners, and spouses in an age range from 30 to 75 years. Their deceased family members had ranged in age from 39 to 84 years. As indicated in the definitions section of Chapter One, the participants in this study were all part of a family dyad as either a patient or a primary caregiver.

Covering

The core category that emerged from the data was *covering.* I chose to call this category *covering* because it describes the central objective of the caregiver. Participants stated that if a peaceful death occurred, and a patient's care was appropriately *managed,* then all of the patient's needs had been covered.

> He died knowing that he did everything he could, he fought a good fight. He died with dignity and with honour and that up until the last three weeks he didn't really have any pain. He died the way he wanted to die, on his terms, in his home … and even at the last day, smiling and chuckling and reaching out to let me know that I'm going to be okay. So I think that he was content to go at that time. He was ready. Like he had prepared himself and was ready and he just wanted to get the hell out of here.

Covering made it possible to look back on the death of a family member without regret. According to the dictionary, *cover* has several related meanings that are relevant to this study, including: to place something upon or over, to protect or conceal, or to shield from harm or loss (Canadian Oxford Dictionary, 1998).

Covering requires the right combination of people (caregiver, family members, friends, and members of the health care team) and things (medication). For one caregiver an entire battalion of friends and family kept vigil with the patient, moving a queen size bed beside the patient's hospital bed so that they could be nearby, *covering* the patient's needs. This vigilance paid off for one family. The caregiver was so exhausted that she didn't hear the patient even though she was sleeping beside her, but another family member did. The patient had cried out, and this was her last utterance. The family was able to say good-bye, even calling a brother who was not present to say his final good-bye on the telephone.

Covering does not necessarily require a good relationship between the caregiver and others who assist with *covering.* For example, one participant, who was somewhat estranged from her mother and sister, was amazed that they offered to help her near the end stage when it was difficult for her to carry on.

One caregiver noted that assistance with *covering* provided by family and friends helped the caregiver cope with the patient's horrible death, since it was not covered by adequate pain medication. Her friends were there to support her through the patient's last pain-filled moments.

The location of *covering* varied. Pain that could not be managed at home was most commonly the cause of admission to a palliative care unit. In cases where this was recognized by a nurse or a doctor, the caregiver was encouraged to transfer the patient.

The patients themselves often encouraged such a transfer, *covering* this responsibility for the caregiver.

Some things made it difficult for *covering* to happen. For example, sooner or later the caregiver needed help. If family and friends did not offer assistance, it became impossible for the caregiver to cover the various issues that required attention. This lack of *covering* was associated with profound regret following the death of a loved one.

Provision of support by health care personnel played a key role in the ability of the caregiver to cover the needs of their family member. Caregivers who had health care personnel that they trusted felt more confident about their own abilities to cover the patient's needs. Health care personnel who did not adequately *step up* and provide appropriate *service* to the dyad interfered with management of the patient's care, denying the dyad full coverage for their needs. Lack of appropriate support by health care personnel made it impossible for the caregiver to cover all of the patient's needs.

Lack of support for caregivers seemed to be associated with a lack of communication and co-ordination of services among health care personnel. Not listening or spending adequate time with the patient to understand their needs was deemed the most important cause of lack of support, and a primary contributor to caregiver concern and anxiety, and to their inability to cope. Lack of support was also partly due to a lack of flexibility in providing for the family's care needs. For example, personal support workers and hospice volunteers are only permitted to offer care that supports the patient, but not the caregiver. Oftentimes, the caregiver is burdened by household chores that pile up but support staff are not allowed to assist with these chores. As one caregiver said:

The whole situation doesn't make any sense … if you went to the store for me

> that would be more help than saying – here, why don’t you go to the store. Well I don’t want to go to the store. I’d like to take my husband for a walk but unfortunately I’ve got eight loads of laundry to do so I can’t leave.

Support staff who stepped out of their roles were valued by the caregivers. For example, one staff person helped a caregiver to pack her belongings during the last days of her husband’s life when they were forced to move from their home due to financial reasons. The support staff assisted the couple with their move by giving them the help that they needed to carry on.

Physicians who permitted the caregiver to phone them during the night if the patient was expected to die were also appreciated by the caregivers. In a situation where the patient had died a horrible death, the doctor had forgotten to tell the caregiver to phone him during the night. He realized that he had not covered the patient’s death and apologized later, saying that he should have done so even if it went against the rules.

In an effort to cover all their care-giving duties, some caregivers resorted to subterfuge to obtain the best possible care for their family member. One caregiver felt forced to cover up the stage of his family member’s illness to acquire treatment for him in another country. Treatment had been denied to his family member in Canada and he had been told to make him “comfortable”. The family member was 84 years old and the caregiver felt that he had been dismissed by his Canadian physician due to his age. Another caregiver covered up the location of the family dyad’s rural residence to access better care at an urban hospital. These activities were seen as necessary actions, an extreme form of advocacy that benefitted the patient as long as others were “not harmed,” and were considered acceptable behaviour that “I would do again”. Small increments of time were gained - time that was precious to these caregivers, since it extended their family members' life by "months".

Overall, caregivers were not pleased with the hospital-based Canadian health care system, deeming it too fractured to cover the needs of palliative care patients. This put extra responsibility on the caregiver. One family dyad living in a rural area could not receive palliative care in the home. They were forced to drive to the city for care and had to endure repeated hospital admissions where they had to advocate strongly for the patient's needs. Caregivers were, however, extremely pleased with the palliative care offered by doctors and nurses who visited them at home. This support was consistently said to be excellent by caregivers who lived in the city.

Dancing on the Stairs

Dancing on the Stairs was the basic social process embedded within *covering* that described the nature of the family dyad's decision-making process in this study. The intricacies of the family dyad relationship are so delicately balanced that both members of the dyad move in tandem with the other as if engaged in a dance. This was illustrated by a caregiver's description of assisting her brother on a stairway. She explained that unless they co-ordinated their movements, they would both be at risk of falling down the stairs. *Dancing on the Stairs* explained the relationships between the majority of the categories developed during the analysis and it characterizes the intimate patient-caregiver partnership as they move together to the tunes and rhythms of the cancer trajectory. The basic social process, *Dancing on the Stairs,* is comprised of five stages: *Inviting the Dancers, Finding the Tune, Managing the Steps, Finishing the Dance*, and *Leaving the Dance* (see Figure 2).

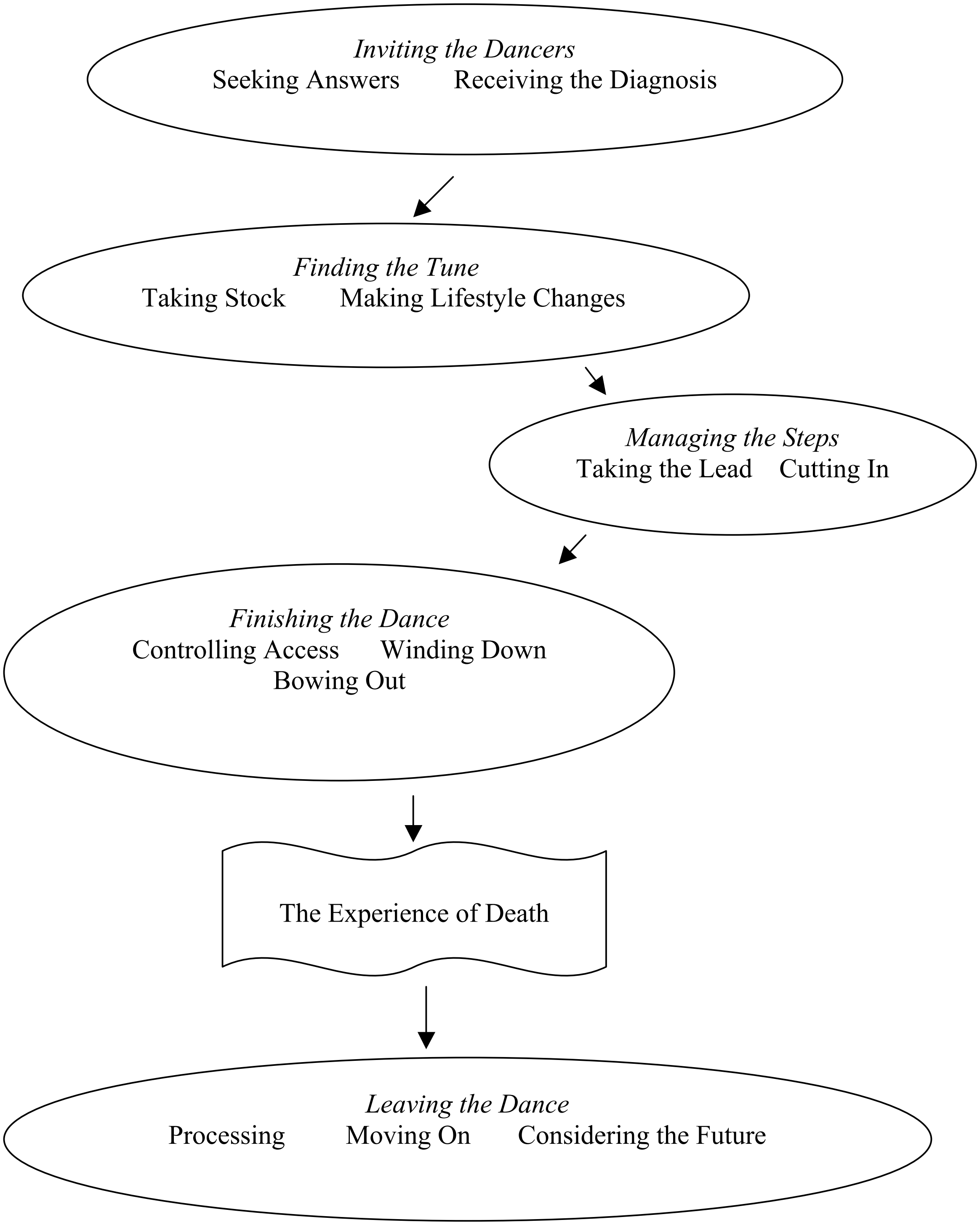

Figure 2. Dancing on the Stairs

Inviting the Dancers

Cancer's invitation to dance to its rhythms was presented differently to each patient. It came as a surprise to some, "all of this came out of nowhere, and out of the blue, totally unexpected … I didn't have any symptoms. I know people do have symptoms, but in my case it was quite silent", and was overt and rebuffed by others, "she was obviously ill for a while and ignored it, the hacking cough, the wheezing". In other cases, the invitation remained hidden and was discovered when the cancer was quite advanced, in spite of symptoms such as, "a weird sort of chest pain", "pains in her side", or a feeling that "something is wrong with me". In these situations a diagnosis remained elusive and was delayed until metastases occurred. As one caregiver lamented "she was bleeding like a stuck pig … she might have lived longer if they had diagnosed her". *Inviting the Dancers* had two phases: *Seeking answers* and *Receiving the diagnosis.*

Seeking answers.

In an attempt to understand the patient's vague symptoms, the caregiver often pushed the patient to "go further" in *seeking answers.* Intuitive knowledge of the patient as not being the type to complain, worry about strange pains, or have a feeling that something was wrong, spurred the caregiver on to advocate for the patient. This occurred in spite of some patients' reluctance to pursue the issue, particularly if the definitive test was unpalatable, such as a colonoscopy. Persistence paid off in some circumstances as more tests were done and a diagnosis was eventually delivered. For others, however, the health care system blocked their attempts at *seeking answers.* Patients were told that they were too young or did not fit the profile for a particular type of cancer. Eventually, as symptoms worsened or patients switched to a different physician, the appropriate testing was conducted and a diagnosis was received.

Receiving the diagnosis.

Patients were extremely forgiving of a delayed diagnosis. They accepted that their type of cancer may have been difficult to diagnose. As one patient quipped, "it was an honest mistake but they could have been a bit swifter". She then quickly moved on to deal with decisions regarding treatment options. Caregivers moved on as well, however, after the patient died they expressed anger at the health care system for not listening to the patient's story and felt robbed of time with their loved ones. In all cases, once the diagnosis was received the patient and caregiver moved quickly into *finding the tune* that needed to be played to deal with this event in their lives.

Finding the Tune

Following the diagnosis, the patient and caregiver danced to a whirlwind of tunes orchestrated by the cancer specialists. "It was like having your world flipped completely upside down". Not all of these tunes fit together very well. As a result, this time was arduous and was depicted by patients as, "not a pleasant experience", "pretty shattering", "terrible", "horrifying", "very shocking", "quite devastating", and "like a nightmare". One caregiver related the following account of these initial events:

> When he was discharged from the hospital, he wasn't given any information, any contacts, any support, nothing. He was just discharged from the hospital and we pretty much had to figure everything out for ourselves. And it was a real learning experience. It was hard, too, because when he was diagnosed, when they found the tumour, they didn't tell him right away that it was

> terminal, but they told me, and I found that very upsetting because at first I didn't know they hadn't told him.

Stunned by the illness, patients made their initial decisions regarding treatment options with their oncologists, also making decisions regarding which treatments, if any, they would undertake. As one patient stated, "they advised me - and any big medications were from the specialist, like my tumour medication and all that". Another patient indicated that it seemed to be an expectation of the physician that his or her advice be followed. "Generally if a doctor recommended that something be done then it was done. I didn't question it. I did once, and he was very annoyed that I questioned things". A caregiver concurred:

> The oncologist that we saw did not want us to get second opinions, did not want to give us any referrals, and we really had to fight for every single thing, every single step of the way throughout the whole illness. It's very frustrating. There's something wrong with the system, because when you are at that point, it's so hard to pick yourself up and dust yourself off and fight for yourself.

The caregivers were equally devastated by the diagnosis and assumed the supporting role of chauffeur, chef, and appointment secretary to the patient in an effort to bring together the tunes, some of which were discordant, from various members of the health care team. A participant who co-ordinated care for a relative said, "She's got a complicated medical history to start with so checking up on medical appointments with the specialists, and making connections with the hospital is part of it, and also kind of keeping track, because she sometimes forgets, or, you know, needs assistance getting to appointments". *Finding the Tune* had two phases: *Taking stock* and *Making lifestyle changes.*

Taking stock.

As the patient and caregiver adapted to the diagnosis they began to *take stock* of their situation. Adjustments occurred. As one patient said, "at first I didn't know how to handle the situation or what it's all about. But now … I can manage everything and I know what to expect and how things will work out". Alternative treatments were also explored (and in most cases rejected) as one caregiver explained to his mother:

> I understand the hope that this gives you. I totally do, and I'm sorry to say this, but if this was a real cure then we would know. We would be able to go to McDonalds and get a "happy meal" and the cure at the same time.

Experimental treatments and medication not available in Canada were also pursued, which one family turned into a family event. The patient, her sister, and parents took a brief trip to another country and compared the excursion to a "cross-border shopping trip". Another caregiver took a family member overseas to obtain the chemotherapy that a Canadian physician "had refused him here".

Making lifestyle changes.

As the patient and caregiver came to understand potential options, lifestyle changes were implemented to facilitate the selected approach. As one caregiver said:

> We were willing to try anything and everything. He saw a naturopath. He tried Chinese medicine, meditation. We changed our diet. I did everything with him because I wanted to save his life and I was convinced that if I tried hard enough that I'd be able to do it.

Other dyads curtailed activities that they had enjoyed such as vacationing in another country to remain closer to their home, “until I was diagnosed with cancer we had a place for twenty-five years and we went back after Christmas and sold it”.

As a result of the lifestyle changes selected, the dominant *tune* for the dance changed from time to time in ways that were not predictable. *Making lifestyle changes* helped patients move into the next stage in *Dancing on the Stairs,* which was *Managing the Steps.*

Managing the Steps

In a dance there are moments when the partners are entwined and when they separate. Moments when they are barely touching or when they turn their backs to each other and twirl away, always remaining within reach to execute the next step in the dance. This is a process that is born out of the dancers’ intimate knowledge of each other. The frequent changes in the tune of the cancer dance meant that the dancers - the patient and the caregiver - had to work hard to ensure that their steps fit together. Switching between tunes meant that the steps of the dance were complicated and had to be managed.

Nevertheless, the caregiver intuitively knew how to manage his or her role to facilitate the dance for the patient. In some cases, it was a role that they had played before as caregivers to others, such as siblings or parents. While in other cases, it was a new role. Whatever the situation, this role was more complex and difficult than any they had previously faced. They felt unprepared and alone in handling the issues that confronted them, but they persevered. There was no other choice.

Initially, as noted above, the caregiver followed the direction that the patient took to cope with the illness; after all, it was the patient’s illness. The caregiver would arrange whatever the patient needed to cope in the situation. If the patient wished to be surrounded by family and friends, the caregiver arranged it. If the patient wished to be alone with the caregiver, then so be it! If a move would improve access to treatment then a move was arranged. And if the diagnosis was not to be revealed to others, then the caregiver respected this wish.

Vigilance was also a constant companion to the caregiver. To anticipate the patient’s needs, the caregiver was required to be attentive. Relationships with others suffered. Monitoring access to the patient did not endear the caregiver to family and friends, however, the caregiver had no time to worry about this and carried on in a direction that they perceived to be the correct course of action for the patient. A caregiver’s long-standing friendships were sometimes severed due to conflicting agendas over the patient’s needs. The caregivers, however, expressed only minimal regrets for this loss, recognizing that the patient’s needs must come first, and if others did not step up to assist, then the dyad must carry on without them. Attention to unspoken fears also occurred. Would the patient take his or her own life if left alone with medication, or if left unattended for long periods throughout the day? Would unintentional accidents occur due to impaired cognition?

Such vigilance eventually took a toll on the caregiver. As the cancer advanced, the caregiver was required to manage more of the activities of daily life for the patient, and sleep for the caregiver became elusive. The caregiver “took over” these activities but managed them in a manner that was consistent with the patient’s wishes. As the patient reached a threshold that signaled this loss of independence, he or she objected to the obvious signs of this loss. For most, the objections were about things like the use of adult diapers or assistive devices such as commode chairs that would make toileting easier. The caregiver was, therefore, forced to wake numerous times throughout the night to escort the patient to the bathroom or to change the bed linens. Sleep became a prized commodity and was snatched between such care-giving duties. When exhaustion overtook the caregiver, accidents occurred. For example, in an attempt to reach the bathroom on his own, a patient fell and was unable to wake the caregiver. The patient waited in a pool of excrement until the caregiver woke.

These accidents signaled a change in the patient-caregiver relationship. The caregiver became more domineering, chastising, or at times downright angry. They were at the limit of their tolerance and had given all that they could give. Yet they carried on. Regrets about this stage of the family dyad relationship were expressed once the patient had died, but the caregiver acknowledged that it was a necessary step in the relationship if the patient was to be managed at home. The patient knew the caregiver was simply overcome by the moment. A caregiver advised:

> Don’t be so hard on yourself, because you’re probably doing way more than you realize you are. Even if you get angry sometimes, the person still knows that you love them … and talk to them about it. If you’re angry, explain to them that you’re not angry at them; you’re angry at the situation … it helped him to know that I wasn’t angry at him for being sick. I was just pissed off because I’ve done the laundry already today and now I’ve got to do more, and I don’t want to.

This caregiver suggested that someone write the book, *Terminal Cancer Care for Dummies*, “because sometimes you just need some black humour to get you through”. *Managing the Steps* had two phases: *Taking the lead* and *Cutting in.*

Taking the lead.

Taking the lead was about trying to understand the patient’s wishes in as much detail as possible, so that even though the patient may not be able to physically do very much on his or her own behalf, the patient’s wishes could still be followed. For example, when the side effects of chemotherapy and radiation became unbearable or simply annoying to the patient as cancer advanced, and the patient indicated that they didn’t want to continue the treatment, the caregiver helped the patient to find a new *tune* that was more consistent with his or her wishes. Other patients continued the health professional *tune*, to the growing frustration of the caregivers. One caregiver noted, “She was going to finish out that chemo … it was all very stressful … she begged for and received chest radiation, which they only did because of her age and her strength”. Following the lead of the patient was often stressful for the caregiver, particularly when he or she didn’t agree with the patient’s choices.

Cutting in.

Caregivers knew when they were having trouble continuing in the dance because they became very tired. They realized that they needed help; as one caregiver stated, “I was trying to keep him home as long as I could and then I kind of thought, ‘I’ve bit off more than I can chew’, because it is getting more difficult”. Some of the caregivers were elderly and physically frail themselves. Others had an illness of their own, such as chronic fatigue syndrome that was exacerbated by their care-giving duties. They realized that they needed support if they wanted to be present for the end of the dance. Thus, they began to look for others who would step up and take over some of their responsibilities. They looked for someone who both could and would *cut in. Cutting in* was facilitated by doctors who visited the home and urged the caregiver to bring in visiting nurses, or volunteers, or to place the patient on the waiting list of a palliative care unit or hospice.

Cutting in was also facilitated by friends and family who stepped up at opportune times to cover the care-giving duties. These respites gave the caregivers the opportunity to rest and gain the energy that they would require at the end of the dance. One participant noted that it was a relief to have assistance, “I was very happy to have her just move in and act for me”.

There were times when, despite the best possible support, *cutting in* was the only alternative open to the caregiver, given the complexities of the health of their loved one. In these cases, *cutting in* was considered a strategy that promoted *covering.* Other participants noted, however, that *cutting in* could have been forestalled if more support had been available. The principal factor that determined whether to look for someone who would or could *cut in* was whether care-giving duties were being covered. If sufficient support was available through health professionals, family and friends, patients were able to remain at home. Sometimes, however, sufficient support was not available, and the patient was transferred to a palliative care facility. This transfer, a type of *cutting in,* was seen as necessary by the caregiver but was distressing to him or her. They viewed it as an indication that they had been unable to adequately *manage the steps* of the dance.

Finishing the Dance

Throughout the last days of the cancer dance, regardless of location, the patient and caregiver were isolated from others in cancer's ballroom. Friends, family, and health care workers swirled around offering support and care, but they were "outside" somehow, and the patient and caregiver remained locked together. This focus on each other was initially characterized by the nature of the patient-caregiver relationship; a partnership born out of intimate knowledge of the other. Words were no longer necessary. This may be because there had been many discussions throughout their time together, and each now knew, intuitively, what the other person thought about various subjects. There was no longer a need to explain. The patient "trusted" that his or her wishes would be carried out. There seemed to be no need for a living will because the caregiver "knows what I would want". Similarly, the patient may have continued with chemotherapy or radiation only because he or she "knows that this is what I would want" explained a caregiver whose husband was elderly and prepared to die. He endured treatment only "because of me" even though "I didn't explicitly ask him too". *Finishing the Dance* had three stages*:* *Controlling access, Winding down,* and *Bowing out.*

Controlling access.

A key feature of *Finishing the Dance* was that the patient and the caregiver controlled entrance. Some people were allowed or even invited in, while others were excluded. As cancer advanced, the dyad became increasingly isolated in their home. This physical manifestation of their isolation was either chosen by the patient and caregiver or imposed by others. One participant said, "I haven't gone out for two years … at first when I came home from the hospital I was weak and I didn't really move around in the apartment much. I don’t think that I said to myself consciously ‘you’re not going to go out anymore’… everyday passed and I didn’t feel like going out so I just stopped”.

Sometimes, to cope with the illness, the patient and caregiver permitted no others inside the cocoon of their home. Their lives became circumscribed by the necessity of remaining available for treatments and doctor’s visits. The caregiver left the home periodically to cope with household chores when a personal support worker arrived, but otherwise, remained isolated with the patient.

Some caregivers described this stage as a honeymoon period that was “bittersweet”. Sweet, because one’s senses were enhanced and details of this time remained vividly etched in the mind’s eye, not forgotten even with the passage of time. Bitter, because “you know it can’t last and it is our last time together.” One patient and caregiver took an actual honeymoon together, not having taken the time for one when they were first married. The caregiver of another patient said that this period was simply a stage in their lives together. It was a natural transition, one that shouldn’t be missed, and she felt “honoured” to have experienced it.

Some patients wanted family and friends inside the cocoon of their home, but their family and friends had fallen away. Some caregivers tried to manage this stage for the patient. For example, those who knew that the patient had been a sociable person arranged for friends to visit. Such visits sometimes occurred at the caregiver’s own expense; they had to put aside their own feelings to allow a family member whose relations with the patient and caregiver were “conflicted” to assume a role in the patient’s care.

Being available to the dyad during this period of isolation did not require physical presence. One caregiver said:

> Call, leave a message, tell them that you're thinking about them, and tell them that you don't need them to call you back and that you just wanted to let them know that you're thinking of them. If they want to call you back that's great. If not, that's totally fine too. And you'll be there for them and if you call once a week and leave that message and the person never calls you back, deal with it. They need you. You don't need them.

When friends and family were absent, a volunteer could sometimes fill the void. Time that hospice volunteers spent with a patient was considered "a gift" by the caregivers. Volunteers played games, worked on puzzles with patients or took them back on a trip through their past. These moments were valued and gave the caregiver a needed respite from the intimacy of the dyad relationship.

Winding down.

As the end of the cancer dance drew near, the patient knew that his or her life was *winding down.* They coped by isolating themselves with their own thoughts and preoccupations while the caregiver and others bustled around them. Sometimes patients restricted their space physically to a particular room, a favorite chair, or a bed. They were "cozy". For caregivers who were not sociable this was a "trying time". They had to endure the intrusion of others into their homes that were helping to cover off care-giving responsibilities. A patient describing her husband said, "it bothers him to have a lot of people around the house, I know it does. I was lucky, I could come up here and shut the door … but he had to direct traffic downstairs".

Some patients further isolated themselves from the caregiver by retreating emotionally within themselves or by asking to be admitted to a palliative care unit. Confused that their close bond had been severed, some caregivers sought an answer. Experienced palliative care personnel and volunteers allayed the caregiver's concerns by explaining that the patient was "preparing to die" and needed to separate from the caregiver to make this ultimate transition. When this transition occurred, the patient became a fragile passenger that needed to be "carried" through to the end of the dance by the caregiver. The caregiver became focused upon this goal, isolating themselves deeper emotionally and physically from the outside world to accomplish their task. They described this as a period of "numbness" that lasted until well after the death of their loved one.

Bowing out.

Winding down was a particularly trying time for caregivers, as they realized that they may not be able to remain in the dance until the end. Some caregivers could see that they could no longer manage the patient's care and would be *bowing out* before the end of the dance. *Bowing out* in this context meant transferring the patient to a palliative care facility. Some elderly partners knew that they would not be able to manage the cognitive or physical changes that often occur as cancer advances and were encouraged by health care personnel to place the patient on a hospice waiting list.

Other caregivers had predetermined a point at which their care giving duties would end and they would bow out. For example, a son or daughter with other responsibilities might decide that admission to a palliative care unit would be required when adult diapers were needed or if care-giving interfered with his or her employment.

A caregiver who worked from her home had tried to look after her mother's physical needs but found it very time consuming and was finding it difficult to meet her work responsibilities. She had found herself dealing with adult diapers intermittently during times of crises in her mother's illness and now said, "I just can't go back to the diapers. That was just such a disaster". She had, therefore, indicated to the CCAC case manager that she would have to place her mother in a care facility if the situation became permanent.

There were some other caregivers, however, who decided that "no matter what" they would keep the patient at home, at considerable cost to their own health. The patients, seeing the toll this placed on the caregivers, decided that "I want to go" and admission to a palliative care unit was arranged. One caregiver later admitted that "he did it for me", knowing that the patient would have preferred to die at home.

For some caregivers *bowing out* meant "letting go" of their family member. They had remained alongside the patient so that both could stay in the cancer dance but they now had to admit that the patient was staying alive "just for me". So they had to relinquish their hold on the patient and allow their family member to *bow out* of the dance. This action was born out of the caregiver's intimate knowledge of the patient and represented the caregiver's final act of *covering*, once again placing the patient's needs above his or her own.

Leaving the Dance

The bereaved caregivers remained in a numb, robot-like state for a time after the patient's death. This condition allowed them to cope with the funeral arrangements and the aftermath of dismantling the patient's estate. Most retreated for a time into the cocoon that had been their home as a family dyad. Surrounding oneself with familiar possessions that represented the dyad relationship offered comfort. *Leaving the Dance* was comprised of three phases: *Processing, Moving on,* and *Considering the future.*

Processing.

Regardless of when they emerged from their self-imposed isolation, all caregivers needed support. They needed to process the experience by talking or writing, either with a friend or a professional. They were driven to do so. Some sought out such support, and others fell into it by happenstance, but all agreed that it was a necessary activity. They expressed concern for bereaved caregivers that did not receive support, citing support group members who terminated their association with the group. They were worried that these caregivers would not be able to "move on".

The process of grieving proved to be one that the caregiver had to manage; it required action, it was not a natural activity that would resolve itself over time. Some sought assistance from those who were able to provide it, either by training or personal experience. Their memories remained vivid and needed to be understood or placed in context. Regrets preoccupied all caregivers and they needed support to overcome them, even if they felt they "had done everything I could do".

Moving on.

Emergence from their isolation was either forced or initiated reluctantly by the bereaved caregivers. Financial considerations such as obtaining or resuming employment (which had been given up to care for the patient) or moving to another home (mortgage or rent was no longer affordable) drove the caregiver back into the wider world. If these conditions did not apply, and one's home and financial status were stable, the caregiver often reluctantly decided that a change of scene would be beneficial. An extended stay with friends or family was arranged which might involve travel to another city or country.

A caregiver who had been isolated for twelve years with her spouse in the vicinity of their home said that she had never travelled in an airplane before. Therefore, she began to take short trips to expand her world. She said that these “baby steps” were necessary to gear one up to “fly” into the wider world saying, “I can fly now”. She redecorated her home and rekindled old friendships. She considered this transition a life stage. It was inevitable that one of them would die and that the other, while remembering, had to move forward in life. This was possible for most bereaved caregivers of retirement age. Those at an earlier stage of their lives experienced more difficulty. For these individuals, their plans as a couple had been cut short. They had not been able to “grow old together” and were, therefore, more resentful of the vagaries of life that they had been forced to endure.

Considering the future.

All bereaved caregivers felt abandoned by the Canadian health care system, even those who felt that they had covered their family member’s needs by caring for him or her at home. They all feared for their own deaths. Who would be there for them as they had “been there” for their family members? They had worked hard to ensure that their family member’s needs had been met, which had required a lot of their time and energy. Other family and friends had stepped up and professional caregivers may have “broken the rules” to assist them. They worried that in a similar situation, with no one to advocate for their needs, that their own deaths would not be covered.

They had believed that Canada’s universal health care system would be there for everyone at the end of their lives; this was not their experience. They had been required to “fill in” for the health care system, and they did not wish to undertake this experience again for another family member, or to have other family members fill in for the health care system on their behalf. They also did not wish admission to a hospital for any reason in the future, citing lack of caring and continuity of care as reasons for their reluctance. They claimed that excellent nurses, doctors, and support personnel were the exception not the rule.

Most advised that further education be provided to health care personnel, and that some sort of manual be written to help family caregivers cope with the dying process of a family member. They understood the financial constraints placed upon the health care system, but they also felt abandoned, there was little after care provided to them. Health care personnel who had been available to them disappeared immediately following the death. Support groups were offered but could not be accessed until three months after the death of their family member. They felt alone.

The negative feelings expressed by the bereaved caregivers regarding Canada’s universal health care system exceeded their bad feelings for family and friends who had “fallen away”. Caregivers accepted that humans were fallible, and although they were hurt and disappointed, they resolved to walk away and develop new relationships. Coverage by the health care system on the other hand had been promised to them “from cradle to grave”, and it was now found to be lacking. These caregivers were not hopeful when considering the future. The possibility that they would not receive the care in their own homes that they themselves had been able to provide to a family member was disheartening to them. It must be noted, however, that such sentiments are the feelings of a self-selected group of participants and cannot be generalized to the wider population.

It is my belief that it was the caregivers' disillusionment with the health care system that drove their willingness to be interviewed for this study. All caregivers expressed the hope that I would "do something" with their experiences that would improve the system for others. Further discussion of these issues will occur in Chapters Five and Six of this study.

Answering the Research Question

The question that guided this study was: "What is the process by which individuals with advanced cancer and their family caregivers make decisions regarding care when cognitive and physical abilities begin to decline during the palliative phase of the individual's illness"? I was interested in:

1. How the family decision-making process changed in the context of lost cognitive and physical abilities when the individual was no longer able to participate the way they had before they became ill.
2. How the family decision-making process was influenced by a broader social context that values control.

The results of this study indicate that the process of decision-making between an individual with advanced cancer and his or her family caregiver is fluid and changes over time. The key feature is a commitment by the caregiver to honour the wishes of the individual and to remain actively engaged with him or her throughout the dying process, regardless of the individual's cognitive or physical capabilities. This commitment occurs in an atmosphere of mutual trust, and thus, serves to maintain the patient's autonomy.

The decision-making process between an individual with advanced cancer and his or her family caregiver requires the element of “good care” such that extended family and friends or health care personnel step up to assist the caregiver in the provision of this care throughout the dying process. The family dyad expects health care professionals to step up by providing information about the ill family member’s health status in a manner that the family dyad can understand, despite its complexity. The family dyad also expects their health care providers to help them manage symptoms related to the disease process. The family dyad’s expectations for extended family members are that they step up by tailoring their assistance to the needs of the family dyad, rather than try to help in ways that are rooted in the family members’ own perspective of the assistance required.

The stages of the basic social process, *Dancing on the Stairs,* help to show how the decision-making process changes as the cognitive and physical abilities of the individual with advanced cancer decline. Initially in a supportive, and then a managing role, the caregiver eventually takes over decision-making completely. During the first two stages of *Dancing on the Stairs* (*Inviting the Dancers* and *Finding the Tune*), the caregiver and the ill family member made most decisions jointly. During *Taking the Lead*, however, the caregiver began to acquire more decision-making responsibility. This is a subtle and often intuitive process that continued to maintain the individual’s autonomy because all decisions were made in concert with what the individual “would have wanted”. The caregiver did not hesitate to make these decisions; doing what is “right” for the patient came from a deep knowledge born out of their relationship. During *Finishing the Dance*, the caregiver made most, if not all, of the necessary decisions, still striving to follow the ill family member’s wishes.

Decision-making in this study was heavily influenced by a social context that values individual control and, as noted earlier, is often death denying. Thus, it is no surprise that family caregivers in this study were committed to maintaining the control or autonomy of their ill family members and to giving the best care that they could in order to stave off death as long as possible.

Given this societal context, there was some tension and conflict between the individual with advanced cancer and his or her family caregiver and between the family dyad and their health care providers, particularly when goals for good care differed. In some cases in this study, such tensions seemed to increase uncertainty for the family dyad.

Interestingly, uncertainty was not only a function of conflict and tension. Even when the family dyad decision-making process proceeded smoothly and supported the individual’s autonomy (i.e., by maintaining control), maintained trust, and promoted good care, uncertainty was a continual presence during the palliative stage of the individual’s life. The ability of the family dyad’s decision-making process to increase or reduce uncertainty had little impact on their ability to achieve a good, or a good enough, death for the ill family member. This finding has implications for how health care personnel think about their role in relation to uncertainty at the end of life. Knowing that, although good care is provided, uncertainty may not be reduced, health care personnel can offer a reassuring presence to their patients. Participants in this study sincerely appreciated health care professionals who remained “with” them in the midst of uncertainty, and provided guidance and support as required. These findings will be discussed further in Chapter Five and related implications will be outlined in Chapter Six of this dissertation.

CHAPTER FIVE

Discussion

The discussion of this study has been organized into three sections. The first is a reflection on the methods used in the study. Section two, *Study Context,* discusses the social contextual factors that influenced the decision-making process of the patient-caregiver family dyad. Section three, *Study Findings and Literature Intersections,* addresses the issues of transition, uncertainty, and decision-making in relation to the study findings.

Methodological Reflection

Finding the theory in the data requires theoretical sensitivity (Glaser, 1978). Without such sensitivity one would not be able to recognize the relevant issues in the data and would be unable to link them to the emerging theory. Glaser indicated that if one is theoretically sensitive, the theory comes very quickly, and I found this to be true. As my interviews progressed, I found that ideas relevant to my research question came upon me so quickly that I had to frantically write and memo to keep abreast of it all. This required going back over my initial categories to see if the emerging theory *fit* and whether I could construct a *thick* description of the area of interest that incorporated all of the stages and phases inherent in the process. Engaging in these verification strategies throughout the study helped to ensure that the final result was reliable and valid as per the recommendations of Morse and colleagues (Morse et al., 2002).

Basic Social Process

The basic social process, *Dancing on the Stairs,* seems apparent in other difficult events in one's life that need to be managed in the presence of others. I noticed this basic social process in books I read, movies I watched, and stories told to me by those who had encountered difficulties in their lives. A book written by an accomplished woman about a stroke she had experienced in her youth, and how her mother assisted in her recovery, is very similar to the *Dancing on the Stairs* basic social process of this study (Bolte Taylor, 2006).

The "dance" or variation in the basic social process derives from the rich data provided by the participants. They varied in age, gender, marital status, socio-economic background, relationship status to the ill individual, and in their manner of care provision. Their stories, while also varied, maintained the underlying core of honouring their family member and of covering the gaps that they perceived existed in formal health care provision.

Dancing on the Stairs occurred in the context of a relationship, which is consistent with the basic philosophical underpinnings of Grounded Theory and symbolic interactionism. The dance was more complex than it appeared. The actor at each stage changed. The actor in *Inviting the Dancers* for example was the disease itself, while the actors in C*utting In* were family members, friends, and members of the health care team. Ideally, basic social processes extend beyond the context in which they are found, and thus, these components may also be useful in other difficult situations (Glaser, 1992). Health care personnel for example may also use *Dancing on the Stairs* to enhance or bolster their relationships with palliative patients, particularly when no family caregiver is available.

Study Context

My previous experiences in hospice-palliative care and the relevant literature that I reviewed prior to data collection had sensitized me to the substantive area that I planned to explore with this study. Nevertheless, I was unprepared for the feeling that I was “living” inside the literature throughout the data collection phase of the study. For the purposes of this discussion, these issues have been grouped under six headings: *Concerns of the Palliative Care Team*, *Recruitment Issues*, *Nursing Autonomy, Client-Centered Care, Ethics,* and *Assisted Suicide.*

Concerns of the Palliative Care Team

To encourage recruitment for my study, I began attending palliative care case management seminars held monthly at a palliative care centre in the city where the study occurred. As I listened to physicians describe their cases, I felt a sense of déjà vu as they recounted the one step forward three steps back dance that they were all engaged in during the care of their clients. They talked about communication difficulties among the team, referring physicians who disappeared once the case had been handed over to the palliative care team, difficult or delayed diagnosis, complications that made treatment difficult, the expense of medication or medication that was not available in Canada. Of great concern was a patient’s wish to “end it all” prompting a redoubling of their efforts to find a solution to the patients’ problems, which were often the result of uncontrollable pain.

The health care professionals with whom I interacted struggled with the same issues of autonomy and control described by Bottorff et al. (2000) and Durbach and Kerzner (2004). Although they ideally wanted to be present for their patients, they were not always able to do so. Absent family members, a family in conflict, or a family caregiver that interfered with treatment plans presented the most difficulty for the palliative care team. When a family dyad was not functioning to the maximal advantage of the patient, the health care team was not able to provide optimal care. Ironically, the results of this dissertation study indicate that the reverse is also true; the family caregiver cannot provide optimal care if the health-care team does not provide appropriate support.

Recruitment Issues

Referrals to the study were slow. In addition to the issues detailed above that may have affected recruitment, the health care team also found it difficult to refer family dyads to the study that were experiencing conflict within the dyad. In these situations, the health care team's own entry into the home was also tenuous, and they felt that I represented a complicating factor that would not contribute to the patient's care. While I interviewed dyads who had experienced some conflict, I was unable to interview dyads whose relationships were severely conflicted, which is a limitation of this study.

Even in cases where the family dyad was functioning well, nurses in particular had difficulty referring dyads to the study. The nurses felt that their patients were vulnerable and that, at this stage in their lives, they should not be bothered to be in a research study. My explanation of how the study protocols protected the patients (Davis, Davis, Smith, & Cooper, 2003), how the literature indicates that patients often wish to leave a legacy (Duggleby, & Wright, 2004), and that patients should be given the choice to accept or refuse to participate (Dobratz, 2003), did not convince the nurses to refer patients to the study.

My breakthrough in recruitment occurred only after I began attending informal palliative care rounds that both physicians and nurses attended. At these rounds, if the physician agreed that a particular family dyad would be appropriate for the study, then the nurses were also on board with the idea. However, only twice did a nurse actually approach a patient; nurses preferred that the doctor recruit the patient. This process led to the physicians feeling very burdened by study recruitment. They began to ask me if there was not an alternative recruitment method that I could use. I had by this time become very familiar to the palliative care team as I attended their case management rounds quite frequently. The doctors, therefore, suggested that I just phone the patients myself, but I reminded them that such an approach would be contrary to the recruitment protocol outlined in my ethics application. Nevertheless, it was clear that I definitely needed to consider other recruitment approaches. With the support of my supervisory committee, I placed an advertisement in a free community paper and a local hospice sent out letters to bereaved caregivers, inviting caregivers who had already experienced the death of their family member to contact me. These were excellent strategies that enabled me to complete the study.

Nursing Autonomy

The nurses in palliative care were members of interdisciplinary health care teams. As noted by Kuebler et al. (2002), the ideal in such teams is that all members work collaboratively and are aware of the overall plan of care for each patient. I was, therefore, surprised that nurses would not take the initiative to assist with recruitment, preferring to leave this task to their physician counterparts.

The lack of assistance with recruitment for research projects was not an issue that I had encountered in the HIV/AIDS community where I had previously practiced as a clinical nurse specialist. In that community, the nurses were constant advocates for their clients, believing that it was a social justice issue if their clients were not apprised of all issues that might affect their care. As such, they promoted client involvement in research studies as a vehicle that allowed their clients to have a “voice” in their care and an avenue to explore all issues that could potentially affect their well-being, such as giving back to their community by participating in research. As well, these nurses cared for a very politically astute patient community, one that had pushed the boundaries of the traditional patient-health care provider relationship where the health care professional was the expert, to one in which the health care professional was on a more equal footing with the patient. Often, patients were actually more informed than members of their health care team. This may have occurred because of the enormous amount of fear and stigma associated with HIV clients early in the HIV/AIDS pandemic, necessitating that the clients themselves become more educated about their illness and that the nurses who worked with them become more vocal on their behalf.

A comparison of the nurses in palliative care and in HIV/AIDS settings raises questions regarding nursing autonomy. The autonomy of the nurses in HIV/AIDS settings seemed rooted in a client-centered focus and a commitment to a life-within-illness paradigm as described by Pieper and Dracher (2004) in which the terminally ill individual with HIV/AIDS lives until death, and care is provided in a manner that actively engages his or her wishes. Although a basic tenet of palliative care is client control (Tang, 2000), the palliative care nurses' reluctance to assist with recruitment is consistent with the work of Hewitt-Taylor (2004), who noted that not all health care professionals are able to adapt to a work environment in which patients are actively involved in health care decision-making, such as those related to research.

Client-Centered Care

Interestingly, the recipient of care in the HIV/AIDS community was referred to as a *client,* while the recipient of care in the palliative care setting was referred to as a *patient*. It is no accident that I have referred to the participants of this study as patients. This is also the way in which the palliative care team referred to them. The cancer care trajectory is such that a person with cancer is often required to make treatment decisions very quickly and, therefore, may not have the luxury of time to explore all avenues that are open to him or her. As a result, the expertise of the health care team is perpetuated, and the person is placed in the role of a care recipient, and by extension this person becomes a patient. Although individuals receiving care in the hospital setting are often referred to as patients, community-based nurses consider those for whom they provide care to be clients. Thus, it was surprising to find that the palliative care team who provided home care used the term patient rather than client.

The system surrounding access to supportive devices in the home is further evidence of the tension between client-centered care and care which is subject to gate-keeping by experts. One caregiver desperate to acquire a hospital bed for her family member pleaded with the home care worker just to tell her where to buy one. The patient had decubitis ulcers that had tunneled into the muscle and was in excruciating pain. The bed finally arrived a month and a half later, just before the patient died.

Another basic tenet of palliative care is that services should be offered at a time that coincides with the patient and caregiver's needs (Choi & Billings, 2002; Pieper & Dacher, 2004; WHO, 2002). The caregivers in this study reported that the services provided were often insufficient, leaving them exhausted from their care-giving duties. They perceived that the amount of care they received was dependent on the physician's estimate of the amount of time the patient had left to live, and as a result, their support was highest immediately prior to death.

Some may argue that care in the home is truly client-centered since it is provided in consultation with the patient and according to the patient's needs. This study has shown, however, that it is the caregiver who shoulders the burden of care in the home. The home care system does not provide for true palliative care, for the "patient and family" as the unit of care (Kuebler, Berry, & Heidrich, 2002; Meghani, 2004; Saunders, 1991). The patient and their lay caregivers, therefore, remain in a dependent position and are treated as subordinates rather than empowered clients.

Ethics

It seemed that a relational ethic was at play in this study (Bergum, 2004). Health care personnel who did what was best for the family dyad were valued by the caregivers. These health care personnel stepped up and gave the good care that was required, regardless of agency rules or policy. Those who only followed the rules were often perceived by family caregivers to be lacking in "caring and commitment". Here we see the tension between practice guided by a relationship-based ethic and practice guided by rules. Such tension may be a source of moral distress among health care professionals (Oberle & Hughes, 2001). It is not surprising, therefore, that caregivers were reluctant to discuss this topic.

Caregivers noted that they felt as if they were "telling tales" yet they also wanted to improve the health care system for others and they, therefore, decided that these stories should be told. They worried that personnel who "broke the rules" would be fired if their employers knew what they had done and were very careful to insist that I maintain confidentiality. One family caregiver discovered that her dying family member was paying a care provider "outside of the system" in order to obtain extra services and she was considering reporting this to the agency. On the other hand, the relationship was working well. The family member was having her needs met, which relieved the caregiver from a myriad of "small issues" that were difficult to manage. The family caregiver wondered, since the extra payments "worked", if she should "rock the boat". We had a lengthy discussion about the issue and concluded that since the caregiver was uncomfortable with the situation (there was money exchanged) she would speak to the home care nurse involved.

Concerns such as these, if not attended to in a timely fashion, can develop into situations such as the following report in a Globe and Mail newspaper article. A 69 year old male who had a stroke was found by police tied to his bed by a dog leash. The patient in question was reported to have multiple bruising "of various vintages … three broken fingers and a badly swollen arm" (Appleby & Tuscott, Dec. 11, 2009, p. 10), in spite of the oversight of a visiting home care agency that was contracted by a Community Care Access Centre in Ontario to conduct twice-daily visits. The home care workers claimed "that they did not see anything that concerned them [and that] they sponge-bathed [the patient] almost daily" (p. 10). It was later revealed that the workers involved in the situation had not visited the home. Such reports are feared by all home care agencies and by families who cannot themselves take care of their family members in the home. Distinctions between a relational ethic and issues of exploitation need to be explored in further research to ensure that our vulnerable populations are given the best care possible in the home care setting.

Assisted Suicide

The dying husband of a family caregiver in this study had considered assisted suicide. Two of his family members had taken advantage of this option in his country of origin, so he was familiar with the issues surrounding it. He did not move forward with this plan due to his wife's reluctance. She told me that this was a topic that had been discussed between the two of them many times. He was comfortable with the concept because he was from a country that offered this option and he did not have any problems with it. It is possible that he may have pursued this course of action if his pain had been uncontrollable; his death, however, occurred fairly quickly following diagnosis and was relatively pain free.

In a Globe and Mail newspaper article relevant to the above issue, a 67 year old Quebec City man is "pleading for the right to end the agony of cancer and die with dignity through assisted suicide" (Seguin, March 9, 2009, p.6). He has bone pain and feels that his condition is unbearable, noting that he is "at peace with his decision and is not depressed" (p.6). He also wrote a letter to the Quebec Minister of Health and Social Services stating, "I need your help so that I can best terminate my life, to die free with dignity and pride" (p.6). These issues are looming larger in our society because the baby boomer generation has entered their senior years and is known as the generation that advocates vociferously for their needs, generally swaying the status quo to their wishes. A potential example of this is the state of Washington in the United States which has recently become "the second state in the U. S. (after Oregon) to legalize assisted suicide for terminally ill patients" (Stump, 2009, p. 10). The law will take effect in July of 2009 and was voted in by the populace.

Study Findings and Literature Intersections

In Chapter Two I reviewed the literature on transition, uncertainty, and decision-making as it is related to the purpose of my study and research questions. In the discussion that follows, I indicate how my study and this literature intersect, with a focus on similarities and differences. Uncertainty and decision-making are discussed in relation to the four transition stages that are present in my study. I have also included pertinent literature that was reviewed prior to, and subsequent to, the data collection phase of the study.

Transition

The concept of transition in this study was determined in part by the phases of the cancer trajectory and illustrated by the word *go*. Using Meleis et al.'s (2002) conceptual definition, *Dancing on the Stairs,* appears to incorporate four types or patterns of transition (see Table 1).

The properties of the first transition were related to the family dyad's adjustment to their new way of life with one of them "having cancer". The word *go* was used at this stage in the context of "go for testing or go to doctor's appointments". The meaning

Table 1

Family Dyad Transitions at the End of Life

Type of Transition:	Having Cancer	Loss of Capacity	Imminent Death	Bereavement
Properties:	Adjustment to the diagnosis “Go for testing”	Coping with loss of capacity “Hard to go on”	Letting go “Time to go”	Processing loss “Go through”
Facilitators:	Trust and communication within the dyad	Friends, family, and health care providers step up	Information and support from health care personnel about the end of life	Support and/or counselling
Hindrances:	Hiding the diagnosis	Refusal of adaptive devices and isolation from others	Unable to accept that death is imminent	Guilt and/or regret

Continuation of Table 1

Process Indicators:	Frenzy of appointments and lifestyle change	Quiet, living in the moment but still some activity	Focus on being present for the patient	Emotional numbness and "taking care of business"
Outcome Indicators:	Some degree of mastery over cancer and, ultimately, awareness that the patient is palliative	Maintaining patient in location of choice	Peacefulness	Coming to terms with the end of the dyad relationship

ascribed to the illness dictated whether the diagnosis was revealed to others or remained hidden. Some family dyads were able to retain a positive outlook despite having exhausted all available avenues of treatment. Several facilitators were identified. For example, the deep trust within the family dyad made communication possible, even in the face of conflict. Process indicators included changes in life style, such as improved nutrition, and the development of confidence in the dyad's ability to cope with the diagnosis. One outcome indicator was some degree of mastery of the situation.

Of note, the outcome of the first stage is the recognition that treatments intended to cure the cancer are no longer possible and that the patient is now palliative. Caregivers were adamant that health care personnel who did not clearly indicate to the patient that this transition had occurred were negligent in their care. Without this knowledge the patient was unable to complete the first transition. The caregivers also felt forced to remain in this first stage when this happened because they were determined to honour their family member's wishes. Caregivers did not move to the second transition stage until their dying family member was clearly told that treatment aimed at cure was no longer possible. When it was obvious to caregivers that their dying family member did not realize that they were palliative, the caregiver made repeated overtures to the physician to rectify the issue. This situation was most likely to occur when the patient was young (i.e., 30 - 40 years of age), which may have made it difficult for the physician to withdraw curative treatment. In addition, communication with the physician was constrained if the patient had cognitive difficulties, such as a brain tumour that prevented his or her understanding of the prognosis.

The findings of this study support the work of Back et al. (2009), who reported that patients and their families found the transition from active treatment to palliative care distressing and felt abandoned by health care providers. The authors found that this abandonment did not allow for consistency of care and did not permit closure of the therapeutic relationship with the provider of the curative treatment. To ensure that such issues are addressed, the authors recommended that the "professional values" of health care personnel need to be reoriented to include a smoother transition from curative to palliative care.

The second transition occurred when a loss of capacity (either physical or cognitive) was reached by the patient (this may or may not coincide with awareness that the patient had become palliative). At this point, the family caregiver needed to adapt to the ways in which the patient coped with his or her loss of capacity. If the patient denied the transition, by refusing to use adaptive devices or wear adult diapers for example, the caregiver was placed in the role of trying to determine the best way to manage this situation, and to manage the consequences of the decisions that were made. The word *go* at this stage is illustrated by the phrase "it was difficult to go on".

The process indicators that facilitated the second transition stage were the situation of the family dyad in time (i.e., living in the moment rather than with the uncertainty of the diagnosis), and in space (i.e., their home, and no longer attending hospital appointments), and the security of the patient-caregiver relationship. Hindering the transition was the "dropping away" of other relationships that had been important to the dyad. For example, when friends and family no longer visited, the dyad felt isolated in the home. In some cases, the family caregiver recognized this void and was able to reach out on the patient's behalf and encourage visitors to the home. If this did not occur, these individuals became particularly reliant on volunteers or health care personnel and wanted them to step up and support them. When they were able to do so, the transition proceeded. This feeling of connection was facilitative for both the patient and the family caregiver and ensured that the second transition occurred smoothly. It is unlikely, in my view, that an exhausted caregiver who was unable to reach out to friends and family and who was not supported by health care personnel could navigate this transition alone and maintain the patient in the home. Admission to a palliative care hospital unit or hospice would, therefore, be sought.

In this second transition stage, the dyad also engaged together in an anticipatory grieving process that mourned the loss of their future plans, such as the potential birth of a child or travel after retirement. The anticipatory grief experienced at this time seemed very different from the anticipatory grief that occurs closer to the end of a dying family member's life (Johnson, Cook, Giacomini, & Williams, 2000). In that latter situation, the patient may have already died a "social death", and, therefore, his or her physical death was merely a formality. In this study, even if the dying family member's cognition or physical status was severely compromised, he or she was very much "alive" to the family caregiver and remained so until death occurred. I surmise that this was so because the care occurred mainly in the home, and the caregiver actively managed the daily functions of the dyad.

Transition stages in this study were also recognized by health care personnel who often forewarned the family caregiver that a new phase in the cancer trajectory was about to occur and offered advice regarding coping techniques. Recognition of transition phases by others is congruent with the literature (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). In the cancer trajectory, the patient’s status may change relatively quickly and it may be difficult for a caregiver who is exhausted from lack of sleep to recognize that a new phase is approaching and that preparations need to be made. Also, the dying and death of a family member may be a new experience for the family caregiver, and without expert guidance and preparation, they may have difficulty recognizing when transitions occur.

The word *go* in the third transition was often illustrated by the phrases “he wanted to go” or “it was time for him to go”. This phraseology presaged movement from the second transition to the third transition stage for both the patient and the family caregiver. It was employed most commonly when the patient planned to move physically from home to hospital or at the end of life when death was imminent.

Another phrase, “letting go”, was utilized in a psychological sense and meant that the patient actively loosened his or her hold upon physical life. This stage was facilitated by the caregiver’s intimate connection to and knowledge of the patient. If the family caregiver was appropriately supported, then he or she was able to take the time to recognize that this final transition was imminent and to facilitate the patient’s “letting go”. This was a peaceful time for the family dyad and a culmination of all that they had worked toward.

Patients who were admitted to a palliative care hospital unit also found peace; they may have been holding on for the caregiver and were now able to turn inward and let go. At the time of hospital admission, both members of the dyad usually felt that the decision to leave the home was correct. It was only after the family member's death that the caregiver began to have regrets and wondered if they had "done all that they could".

The final (or fourth) transition was experienced alone by the caregiver. The word *go* at this stage could not be captured in one phrase that was applicable to all participants; instead differing phrases signified the stages of the bereavement process. Those who were still processing the experience would say, "it's a very hard thing for people to go through", those that felt adrift shortly after the death said, "it was three months before you could go to a group", others stated, "it is important to go through some grieving process", and a person who was about to embark upon a new way of life stated that she was "free to go".

The fourth transition was facilitated by support from family, friends, or counsellors. The caregiver needed to process the experience and come to terms with everything that had happened. Those who did not seek assistance were doubtful about the care that they had provided and wondered if they could have done more. Those who sought education and support were able to master this stage and were acutely aware that they had been changed by the experience.

As noted in the literature (Meleis & Trangenstein, 1994), the usual outcome of a transitional stage is confidence in one's abilities or mastery of the situation. Transitions do not necessarily change a person, although change can be a component of a transition. It is significant, therefore, in this study that some family caregivers did perceive that they had changed in some way. This change seemed to help these family caregivers "go on" in their lives. For those who had not yet perceived a change, the rawness of their loss seemed as palpable as the first moment that it had occurred.

Various other authors have explored the concept of transition (Davies, 2005; Duggleby & Berry, 2005; Elmberger, Bolund, Magnusson, Lutzen, & Andershed, 2008; Forss, Tishelman, Widmark, & Sachs, 2004; Kralik, Koch, & Eastwood, 2003; Wennman-Larsen & Tishelman, 2002; Wilkins & Woodgate, 2006) and most were built on the work of Meleis et al. (2000). This transition literature focuses mainly upon the person experiencing the transition, with some authors also comparing how the transition differed for family members, such as siblings or children. Generally, the comparisons indicated that each family member experienced the transition differently. My study was the first to discuss transitions from the standpoint of the family dyad.

Wennman-Larsen and Tishelman (2002) focused on the role transition experienced by family caregivers of cancer patients in a home care setting and on the caregiver's concerns about transition to a life alone after the death of their family member. Their study differed from my study in that its primary focus was on the transitions experienced by the caregiver prior to the death of their family member, while my study included transitions of both the caregiver and the dying family member prior to death, and the caregiver following the death of their family member. The findings of Wennman-Larson and Tishelman's study were hypothetical (i.e., "What will my future be like?"), while my study examined the perspectives of the patient, the family caregiver, and the bereaved caregiver, and as a result, I was able to provide a rich description of the actual experience at the end of life; both before and after the death.

The process indicators that were outlined by Meleis et al. (2000) were mirrored in all four transitional stages that were experienced by the family dyad in my study. Interestingly, the degree to which the process indicators were present or absent, seemed to facilitate or hinder the transitions that were necessary for the caregiver to feel that a good, or at least a good enough, death had occurred at the end of the third transition, which took the patient out of life and the caregiver out of the dyad relationship. The caregiver, once separated from the dyad, experienced another transition that was related to beginning a new life, one that was now no longer a part of the family dyad.

As noted by Duggleby and Berry (2005), transitions take time, and may require the assistance of counselling services or the support of family and friends. This is consistent with my study, in which health care personnel were credited with the ability to guide the family dyad through transitions. The nature of the transitions I identified, however, were different from those that were identified by Duggleby and Berry. The transitions in my study had a temporal dimension, which is consistent with the conceptual definition of transitions developed by Meleis et al. (2000). The transitions of my study were also heavily influenced by the family dyad's decision-making, while those that were identified by Duggleby and Berry focused more on the shifting goals of care.

As study participants moved through the fourth transition, they all acknowledged change. Some were able to come to terms with the decisions that they had made and the loss of the deceased family member, but all had at least some regrets. The availability of support during this time helped caregivers move through the transition more smoothly. I noted, however, that the transition for those without help was prolonged, and was generally manifested to others as continuing grief or "not moving on". Moving on does not necessarily have positive or negative connotations, it may merely be different. It can, however, be peaceful, in the sense that one has "no regrets".

Family caregivers consistently requested that health care personnel be given additional education that would allow them to assist caregivers with these transitions. For most caregivers, it was a new experience, and there were no sign posts to guide them. Even if they had experienced the death of a person that was close to them before, they found that the swirl of emotions accompanying this current relationship was so overwhelming that they needed help to navigate through the situation.

Uncertainty

I have discussed the concept of uncertainty in this study in the context of transition, as the two are interconnected in this study. The two concepts were originally connected in the literature as well by Selder (1989). Prior to the first transition stage, there is an initial state of equilibrium in this study which was the time that preceded the first transition associated with "having cancer". Uncertainty in this study seemed to be most pronounced during periods of disequilibrium that preceded the transition stages. Each transitional stage in the study was precipitated by a period of disequilibrium. When a status quo was again reached, the transition occurred, and the dyad moved on to the new transitional stage. This is congruent with a concept analysis that redefined the concept of transition as "a process that involves movement from a state of equilibrium to a state of disequilibrium and to a new state of equilibrium" (Wilson & Woodgate, 2006, p. 263). A new period of disequilibrium for the dyad that has not previously been discussed in the literature is the patient's death, after which the caregiver continued on to another transitional stage until his or her own "personal" state of equilibrium was reached again.

Uncertainty for the participants in the current study was implied rather than stated directly. From their stories, one could ascertain that there had been a period of disruption prior to each transitional stage, but when asked directly participants did not articulate this as uncertainty. I think this was because the caregiver and the dying family member were experiencing a very advanced stage of cancer where death was imminent.

Uncertainty can be identified in the phases of the cancer trajectory as indicated in the literature: at the diagnostic stage (Liao, Chen, Chen, Chen, 2008), throughout the treatment phase (Shaha, Cox, Talman, Kelly, 2008), during discussions of prognosis (Hancock et al., 2007), and finally at the time of palliative surgery (Juarez, Ferrell, Uman, Podnos, Wagman, 2008). In my study, once the first two transitions had passed and participants were in the third transition, the patients entered into a period of "withdrawal" and the caregivers entered into a "numb", robot-like state. Both conditions were devoid of overt emotion, and thus, uncertainty, though present, was not expressed. As was noted previously, it was a peaceful time, and it could also be construed as a time of acceptance, but the family dyad was exhausted by all that had gone on before and hence seemed emotionless. This emotionless peaceful time seemed to be a new state of equilibrium that was reached before the patient's death.

If one subscribes to Selder's (1989) definition, which is that uncertainty is ubiquitous in lived experience and recedes from consciousness until a disruption occurs to force it to the forefront of awareness, one could apply another interpretation to the events in this study. The participants' reality was disrupted once they entered the stage of "having cancer" and remained disrupted such that even when a semblance of equilibrium was restored, they remained on guard for the next disruption and were, therefore, in a constant state of uncertainty. This state was so overwhelming, that by the time they reached the third transition stage, it was manifested as the withdrawal and numb-like condition of the members of the family dyad. Since they were unaware of the uncertainty, they were not able to articulate that they were uncertain at this stage.

Based on this study, it seems that the caregiver underwent another transition after the death of the patient, initially continuing on in a numb-like state that carried them through the events of the funeral. At this point, disequilibrium occurred again, and uncertainty was once again overtly recognized by the caregiver. It was manifested at this point as a feeling of "regret" that the caregiver needed to process. Were the decisions made during the dying process of his or her family member the correct ones? Support from family, friends, or professional counsellors seemed to help the caregiver make peace with these decisions and move on to a new state of equilibrium.

Decision-Making

As was stated in Chapter Two, my starting point in this thesis was that if both patients and family members are involved in key decisions, their decisions will be less likely to result in conflict within the family, and thus, are more likely to decrease uncertainty. Based on the results of this study, the decision-making process that I uncovered may have lessened conflict and uncertainty; however, despite the involvement of both patients and family members, I cannot state unequivocally that joint decision-making decreased either conflict or uncertainty. The discussion that follows will again be structured according to the transition stages that I found.

Initially, during the first transition stage, decisions were made with the patient and oncologist regarding a treatment regime of radiation, chemotherapy, or surgery. The family caregiver may have expressed an opinion but generally deferred to the patient, who tended to follow the recommendations of the physician. This is congruent with research that examined the initial stages of decision-making following a cancer diagnosis, which found that patients defer to the expertise of the physician (Gattellair, Voigt, Butow, Martin, & Tattersall, 2002). Also, in this transition stage, if the dyad perceived that the type of cancer had a good prognosis, the future seemed less uncertain, and there seemed to be less conflict and a greater sense of control around the decisions that needed to be made. This is congruent with a study that found that having a "good" cancer, increases one's sense of control (Maliski, Heilemann, & McCorkle, 2002).

In my study, I also found that the age of the patient was a bigger factor in the decision-making process than I expected it to be. Younger female patients wished to be very involved in decision-making, while older male patients were more accepting of their diagnosis and the physician's recommendations. This finding is consistent with the literature that indicates that younger female patients tend to participate more in decisions about cancer treatment than older male patients (Meyer & Talbot, 2007). Recent research also indicates, however, that regardless of age, patients' involvement in decision-making tends to center around quality-of-life issues (Andersen, Bowen, Morea, Stein, & Baker, 2009).

At the end of the first transition stage, the patient was often actively considering (not necessarily with physician input) the feasibility of continuing with the treatment regime. At this point, the family caregiver was a "sounding board", helping the patient to weigh the positive and negative aspects of the recommended treatment options. If the patient made an active decision, the caregiver most often supported it (even if he or she did not agree with it). If the patient asked for input, the caregiver often indicated that the decision was up to the patient. In some cases, there was subtle pressure from the caregiver and other family members to “not give up … to continue on … to remain positive”. One patient, whose family was urging her to be positive in spite of the overwhelming side effects of her treatment regime, was depressed in my view, because she was not allowed to grieve for her lost abilities, and had to remain hopeful. Her family members did not allow her to speak negatively about the future; her husband told me that it was his job to maintain this positive viewpoint. He stressed that the choice to continue treatment was hers alone and that he would support her decision, but he seemed unable to do this.

The tension regarding “giving up” was palpable between some patients and caregivers in this study. This is consistent with the work of Drought and Koenig (2002), who suggested that death in the context of advanced cancer is inevitable, and that patients, therefore, do not really have a choice between life and death. Interestingly, giving up is really a matter of time, with the perception being that those who give up die sooner rather than later. The caregiver in the paragraph above who pressed the patient not to give up seemed to be capitalizing on this perception in order to delay the patient’s death. This patient stated that her caregivers were relentless in their insistence that she not give up, and did not allow her the space to be sad, or to squarely face the reality of her impending death. Other patients in this study who mourned their lost abilities with their family caregivers seemed to move to the second transition more easily.

As stated previously, movement to the second transition stage required clarity regarding the cancer prognosis. During this stage, as the patient’s physical or mental status declined, the family caregiver took over decision-making. Sometimes this was ceded to the caregiver by the patient, as in “you take care of it” and became one of the managing or covering duties that the caregiver engaged in. This was not an active act of delegation and was not perceived as a relinquishment of control (Carter, MacLeod, Brander, & McPherson, 2004; Olson, Morse, Smith, Mayan, & Hammond, 2001). It occurred subtly and implicitly, was not questioned by either member of the dyad, and seemed to be almost intuitive. The family caregivers then acted for the patient in the way that the patient would have wanted things to be done. In a study that focused on caregivers living with family members with advanced dementia, this process was referred to as maintaining a “sense of self” (Jansson, Nordberg, & Grafstrom, 2001, p. 810).

In my study, this was manifested in the degree of determination that the caregiver had in doing what their dying family member would have wanted. Family caregivers told me that the patient had, therefore, remained in “total control” until the end. There was very little uncertainty in this process. The caregivers were convinced that what they were doing was right, and they did not waiver from their determination. I found, however, that in some cases, the patient-caregiver decision-making process seemed to increase conflict with extended family members who found it difficult to support the family caregiver’s decision to follow the lead of the patient. For the caregiver, decision-making in this study was geared toward maintaining the patient’s control. The “right” decision according to others may not have been the decision the patient would have made; therefore, the family caregivers in this study consistently stated that they did not choose any decision other than the one the patient would have “wanted” when they took over the decision-making process.

This manner of decision-making continued into the third transition stage. At no point did caregivers indicate that their dying family member was not an active participant in decision-making. Even when the family caregiver was making all of the decisions, the patient was an “active presence” in the household. All decisions were discussed, in spite of cognitive disturbances that made this a difficult process. The caregivers felt that the patient “understood” even though he or she may have been unresponsive at the end of life. For example, one patient had to be transferred to a palliative care hospital unit because her son could no longer care for her at home. At this point, she was incapable of speech, but her son said he “knew” that his mother understood the decision and would have agreed with it. It rings true in the third stage that this may be so, caregivers in this stage often stated that they gave their dying family member permission to “let go”, and in most cases the patient appeared to understand, as death occurred shortly after.

For the majority of the family dyads, their relationship was long-standing, a lengthy marriage or partnership, or a bond with siblings or parents. Conversations regarding various issues had, therefore, taken place over the years, and the family caregivers were certain that they knew what their dying family member would have wanted. The patients themselves simply “trusted” that their spouses and children would do what they thought was best. As one participant stated:

> I think he is confident that he’ll do what’s best for me, and if the roles were reversed I think that he would have confidence that I would do what’s best … and when I’m at a stage where I’m too addled to make a decision, what does it matter?

This process occurred without active deliberation and was spoken of in the same manner by both caregivers and patients. This trust in the family caregiver was, therefore, the most significant component of decision-making in my study.

Trust according to Austin (2005), is essential to the human experience. It is notable in all relationships either by its presence or absence. Austin also states that concepts such as trust can help us to understand "how to act and behave toward others" (Austin, 2005, p. 318). This study, therefore, gives us an indication that a patient dying of cancer requires a trusted advocate. In the absence of a family member, health care personnel might be able to fill this role, but they will have to be a consistent presence if trust is to be maintained.

The participants in this study did not have advance directives. Most had a will or had made provisions to designate the caregiver as power of attorney for their estate. However, in most cases there was a last minute scramble to make funeral arrangements. This is consistent with research indicating that the legalities of advance directives are burdensome for the lay public, and they do not necessarily cover all of the different circumstances that may need to be addressed (Lo & Steinbeck, 2004). In western society we also live in a death denying culture that seems to hamper our ability to adequately make decisions related to death (Northcott & Wilson, 2001). As one participant of the study said – "we have a birth plan, why don't we plan for death as well"? This, then, remains another area for future research.

It also appeared that the caregiver was more concerned with the patient's autonomy than were the patients themselves, which is congruent with literature indicating that client "autonomy and choice" (Lange, Edwards, & Fleiszer, 2007, p. 130) are predominant issues in home care. There was a universal desire among all caregivers to do what the patient wanted. Interviews with patients did not reveal such a high concern about this issue. Perhaps it was because they trusted that their caregivers would maintain their autonomy. Patients seemed surprised by questions about “control” or “being in charge”, but caregivers readily agreed that the patients had been “in charge” until the end.

I had not expected that trust would play such a strong role in the decision-making process. This trust was manifested in the caregiver’s determination to do the right thing, and in the sense that the patient was an active participant throughout the dying process. Thus, trust seemed to be an important part of the feeling of peace that caregivers described at the end of the patient’s life. Health care personnel, who stepped in to cover, fostered the decision-making process and protected the trust between the caregiver and the patient; they seemed to be buffers between the dyad and the health care system.

Decision-making in the fourth transition stage occurred after the family member had died. Decisions regarding funeral arrangements were again made in the context of what the dying family member would have wanted. In some cases these decisions engendered conflict with other family or friends, who did not understand why they had been made. Decisions to seek support or counselling to process the events that had occurred during the family member’s dying process were made in the context of the dyad’s life stage. A dyad in an early life stage where plans had been curtailed, necessitated that the caregiver now had to fulfill these milestones alone and needed assistance to do so. On the other hand, if the dyad had been elderly, death was considered a normal part of life.

Bereaved caregivers made deliberate decisions to seek support and to move on, not necessarily because they wished to do so, but because of financial need or the urging of others. As was stated above, this was the stage in which uncertainty reoccurred, and regrets, and second guessing of decisions predominated. The length of time that was spent processing these issues indicated whether or not the caregiver was able to move out of the fourth transition stage.

Decision-making in this study was geared toward maintaining the autonomy and control of the patient, rather than reducing conflict or uncertainty. Indeed the decision-making process sometimes increased conflict and uncertainty for a period of time. Trust was a vital component of the decision-making process; when it existed the transitions were smoother, uncertainty was not overt, and a good death was possible. A good death in this study was not without problems. It meant that the basic social process *Dancing on the Stairs* occurred, and the final result was one that, in hindsight, could be considered good or good enough.

This discussion of the study indicates that further research, education, and policy changes could be implemented to advance the field of palliative care in a home care setting. These recommendations will be discussed in Chapter Six of this dissertation.

CHAPTER SIX

Study Implications

Since this study is the first exploration of decision-making by the family dyad at the end of life, the findings must be interpreted cautiously, and implications and recommendations that follow, are tentative, until further research is conducted. Nevertheless, this study provides a unique perspective about family caregivers, and patients who have chosen to die at home. As a grounded theory study, the results provide insight into the actual decision-making process that occurs within a family dyad. Previous studies regarding the necessity of support in the home, have informed us about the feelings or wishes of either the patient or caregiver regarding palliative care in the home. The current study, however, showed us what actually occurs between the patient and the caregiver as they struggle to cope with the palliative care process. The decision-making that occurs within the dyad is dependent on the degree of autonomy, trust, and good care that is present. Family dyad decision-making affects the good death outcome. The key components of such decision-making (i.e., autonomy, trust, and good care) can be enhanced or supported by health care providers who fully engage with the dyad.

Examination of the relationship between the transition stages and the *Dancing on the Stairs* family dyad decision-making process, suggests that they are integrally connected. Each facilitates the smooth progression of the other. Health care professionals may be able to utilize the transition stages and the stages and phases of the *Dancing on the Stairs* basic social process to guide family dyads by signaling upcoming challenges on the horizon during the palliative care journey. These challenges are often fraught with uncertainty, given the nature of the cancer trajectory. Health care providers can reassure dyads that this uncertainty is part of this phase of life. By providing such support, health care professionals may be able to help shape perceptions about the end of life experiences of the dyad, particularly, perceptions about the sense that the patient had a good, or a good enough, death.

Recommendations for Clinical Practice

Although this was the first study of decision-making of the family dyad at the end of life in individuals with advanced cancer, the findings suggest that nurses could use *Dancing on the Stairs* to target the three components - autonomy, trust, and good care - that are necessary to support family dyad decision-making. Nursing interventions that bolster autonomy, trust, and good care contribute to the empowerment of the family dyad. Thus, the dyad is able to make decisions that allow them to remain in the place of their choosing, and receive the necessary support to attain a good, or a good enough, death. These components are congruent with the basic tenets of palliative care and the WHO (2002) definition of palliative care.

As identified in Chapter Two, there is already a body of literature in existence that illuminates each component of the decision-making process. I propose that this literature be distilled into a format that can be utilized by nurses as background information for the components of *Dancing on the Stairs.* I will prepare an article to this effect for submission to a nursing journal, and recommend that it be used alongside the basic social process when used by nurses, and when taught in undergraduate nursing programs.

Recommendations for Nursing Education

The participants of this study stressed the importance of teaching nurses to be caring and compassionate, and to take the time to engage with the patient and the family caregiver, rather than remain aloof (“only doing your job”). Participants noted that this was a difficult time and that they required “care”. Second, participants asked that education regarding care and compassion be provided to all nurses, not just those working in palliative care. Health care personnel who have received palliative care training or who have entered this field of specialty were “heroes” to these participants. They “understood” and were “helpful”. All participants noted that those who gave care when the patient was hospitalized for a short time in a medical or surgical hospital unit were not compassionate and often made life more difficult for the family dyad. They did not involve the family caregiver in the care of the patient and treated the patient “harshly” (i.e., causing pain by moving the patient too quickly or not believing that the pain medication was not adequate for the palliative patient’s needs).

Based on the findings in my study, I recommend that content regarding care for the family dyad at the end of life, including content on facilitation of family dyad decision-making, and content on the advocacy responsibilities of the nurse be added to undergraduate nursing educational programs.

Undergraduate Nursing Curricula

As noted earlier in the dissertation, continuing education for practitioners of palliative care is available, and as the participants of this study have indicated, it is effective; as none had complaints about their palliative care practitioners. Nurses from other nursing settings seemed to lack the necessary skills to address the concerns of palliative patients. This is understandable given the results of recent reviews which suggest that undergraduate nursing programs may not offer palliative care education courses (CASN, March 31, 2008). Courses that do exist may only be offered on an elective basis or as an option during students' final clinical practicum. Graduates of undergraduate programs who have not taken advantage of these elective opportunities may provide less than optimal care to palliative clients who are admitted to hospital units other than palliative care for symptom management. Participants in the study did indeed find that this was the case, and they were adamant that improvement was necessary. Incorporating palliative care education into undergraduate curricula would address this issue, particularly since Canada's burgeoning elderly population will soon require such care. Accordingly, I plan to submit an abstract about this study to an upcoming Canadian Association of Schools of Nursing (CASN) conference and will follow-up with a proposal to the CASN executive that lends my support to the integration of palliative care competencies into undergraduate nursing school education as outlined in their report submitted to Health Canada March 31, 2008.

Nursing Advocacy

As indicated earlier in this study, nurses themselves must be empowered, autonomous professionals if they are to advocate appropriately for their clients. The issues that arose in my study regarding nursing autonomy, while distressing, can certainly be modified. To address this, I recommend that undergraduate nursing programs start at a very basic level by incorporating active, rather than passive, educational methods into their curricula (Dyson, 2008). Team projects often take students out of their comfort zones and push them to engage with others in formats that will serve them well when they graduate (O'Connor & Yballe, 2007). Learning to engage with a variety of professionals in an empowered fashion is a rudimentary skill that all nursing programs need to address. While physicians may write orders, nurses' knowledge and skill enacts them. Thus, client advocacy skills ensure that the appropriate treatment is provided. Client advocacy is a basic nursing competency and a client right, as noted in community nursing and hospice-palliative care nursing standards of practice (CHPCA, 2006; Stamler & Yui, 2005).

Recommendations for Research

The current study provided a rich perspective on the experience of palliative care from the viewpoints of those dying of cancer in the home, their current family caregivers, and their bereaved caregivers. Additional study is necessary, however, to further explore these issues in other palliative populations (both cancer and noncancer), in order to understand the ongoing issues that occur in palliative care in the home care setting. I plan to do this by developing a partnership with community health workers in a large urban city in Ontario in the hopes that this approach will lead to a program of research in this area.

In April 2009, I attended a Research Day held by a Community Care Access Centre (CCAC) and listened to their plans for future research and strategic directions. I hope to capitalize on this day by proposing an ongoing research partnership with this CCAC. It was interesting to hear about the organization's strategic plans that included a move to a "population specific" approach to care, in which client self-managed care may be emphasized (CCAC, April 16, 2009). This move seemed to be motivated by the need to cope with the burgeoning elderly population requiring care in the future and fiscal constraints. The implication of this move is that family caregivers in the home will be called upon to provide more care than they have in the past, indicating that further study of the *Dancing on the Stairs* basic social process, particularly its relationship to caregiver burden, is a necessity.

I, therefore, propose to begin my program of research with a study that aims to understand the utility of the *Dancing on the Stairs* decision-making process for nurses who are helping family dyads manage care requirements in the home. I plan to begin with a focused ethnography to identify the beliefs and values of palliative care home care nurses about the essential elements of autonomy, trust, and good care in relation to their clients and the *Dancing on the Stairs* decision-making process. I will repeat this with bereaved caregiver participants and then compare the responses of the two groups.

A guide could be constructed from this information, which can then be evaluated by home care nurses. Based on the evaluation, future research could focus on the testing of nursing interventions that facilitated satisfaction with family dyad decision-making and its impact on the achievement of a good, or a good enough, death. These interventions may then be used with family dyads coping with cancer and with other terminal illnesses, such as Alzheimer's disease. Ultimately, I plan to engage in ongoing interprofessional research that contributes to effective palliative care in the home care setting.

Recommendations for Policy

I have made four recommendations for policy change; change that I think will positively impact palliative patients in the home care setting. The first recommendation involves the home care situation in Ontario, the province where this study took place. Ontario is the only province in Canada that requires home care agencies to "bid" for contracts to provide care. This may result in awarding the cheaper bids and may contribute to the situation detailed in Chapter Five, in which the health care workers claimed to have provided care but in fact had not visited the home. To what extent has the "contracts to provide care" approach lead to variation in home care services available across Ontario? There is some question about this already, as the policy was recently reversed by the Health Ministry of Ontario, and then reinstated (Community Action, Feb.20, 2008). It is, therefore, an area that requires ongoing monitoring, with the assistance of community nurses and, perhaps, eventual policy change, as the current approach may be detrimental to palliative patients and their families.

My second recommendation involves instances of mistaken or delayed diagnosis that were reported by participants in my study. Bereaved caregivers felt that they may have had more time with their dying family members if these issues had been resolved in a more timely fashion. I was, therefore, particularly attuned to news events that related to cancer care in Canada during the data collection phase of the study. I found many reports that substantiated the claims made by the participants. For example, the Dean of Medicine at the University of Calgary noted, "there's tremendous inconsistency across the country" (Montgomery, March 6, 2009, p. 12), in the time it takes for patients to receive MRI results regarding their tumours. There are "no federal guidelines for MRI waiting times" (p. 12), and no consistent rules that ensure that "urgent cases are handled quickly" (p. 12). Similarly, authors of a report from an inquiry into Newfoundland and Labrador's breast cancer testing program found that patients were "failed by the health system at every level" (Moore, March 4, 2009, p. 1), with "nearly 400 patients receiving incorrect test results" (p. 1). This is another area that requires further monitoring and policy change in the context of our collective responsibility to provide equitable services across our nation as outlined in the Canadian Health Care Act (Stamler & Yiu, 2005).

My third recommendation involves the discrepancy in health care funding between the hospital and home care sectors in Canada that was illuminated by the "Senate Report on End-of-Life Care" (CHPCA, 2002). With a more equitable distribution of funding across the sectors those who wish to do so will be able to exercise their right to die in the place of their choosing, which, in most cases, is at home (Wilson et al., 2009). However, with support lacking in the home, their family caregivers cannot maintain them there, and an admission to a hospice or palliative care hospital unit is the more likely scenario.

Nurses and allied health care workers (i.e., personal support workers) are the employees who predominately receive remuneration from the community health sector. And, in this era of nursing shortages, the better paid hospital sector (Wilson et al., 2002) is attracting our new nursing graduates. I am, therefore, concerned about the future quality of home care nursing, not only that of palliative care, but the quality of home care as a whole. If we are not attracting the "best and brightest" to community nursing, we will not be able to provide quality health care for our vulnerable populations.

The foregoing are issues in Canadian health care that are systemic and subject to the political processes of our country. They are currently publicized in the Canadian media, and I can only add to the urgency of the need for a resolution to these matters by reporting on the effects they have had on Canada's palliative population.

Lastly, my fourth recommendation concerns the perception by patients that "home" is the only acceptable place to die. This study has indicated that, although one may wish to die at home, it is not always possible. Sometimes, even with support in the home, the family caregiver cannot necessarily maintain the patient there until he or she has died. We must, therefore, educate the health care consumer about alternative care options. Family caregivers in this study who availed themselves of such an option (i.e., a palliative care hospital unit or a hospice) consistently reported that the care was "exemplary".

In this study, participants considered it a failure if the patient could not be maintained at home until death. Family caregivers indicated that they had become fearful of hospital admission based on their experiences with the health care system and their dying family member. They, in turn, do not wish to die in a hospital setting and will place added pressure on their own caregivers to maintain them at home until death. Such sentiments may be detrimental to their care and place additional strain upon their caregivers.

A study conducted in Britain concludes that all options should be available to those at the end of life, stating, "Good 'home care' characterized by attention to patient-centered needs and flexible in design and scope, does not have to be located within the private sphere" (Exley & Allen, 2007, p. 2317); it can and should, therefore, be extended to hospice or hospital palliative care. It behooves us, then, to establish policy that would support education of the health care consumer about the availability of differing palliative care venues, and the suitability of these venues for various stages of palliative care.

Conclusion

It is apparent that palliative care is a hidden mystery to the Canadian public. We only think about it when it is thrust upon us. One participant in my study stated that her husband was an educated man, but he had “never heard of the term palliative care, and did not know what it meant”. Unfortunately, since it is also not at the forefront of our health care sector, it will remain hidden, until political will, health care provider advocacy, and consumer demand force it into prominence. Speculation that our aging baby boomer population will assist with these forces has not yet come to fruition. In my view, it is difficult to be an advocate when you are in the midst of a crisis; I, therefore, do not believe that we should wait until consumer demand forces change in the Canadian health care system. We, as health care professionals, who have insight into the system, must continue to advocate, monitor, and study the issue, because, as Bergum (2004) has emphasized, “we are the health care system” (p. 489).

As an instructor in community health nursing, I can do my part by advocating for a community health awareness campaign that utilizes social marketing principles to educate the health care consumer about these issues. Awareness campaigns have contributed to the reduction of stigma for HIV/AIDS issues, smoking cessation, and, currently, are attempting to prevent the transmission of the H1N1 virus. Our death denying culture may be taken aback by such a campaign, but it will be a step to changing our cultural norms. Perhaps, in the future, “Have you had the conversation?” may not only refer to discussions about smoking and alcohol consumption for our adolescent populations, but may also refer to discussions with family members about one’s plans for a “good death”.

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APPENDIX: A

Information Letter and Consent

Information Letter

Project Title: Decision-Making in a Family Dyad in the Context of Advanced Cancer

Investigator: Susanna Edwards, RN, MSc., Ryerson University,
Toronto, Ontario, 416-979-5000 ext. 6311

Thesis Supervisor: Dr. Karin Olson, Faculty of Nursing
University of Alberta, 780-492-6403

Purpose:
The purpose of this study is to learn more about how day-to-day choices are made when a family member is very ill, and unable to make decisions in his or her usual way.

Procedure:
If you choose to take part, the researcher will interview you (1-2 hours) in your home. Ill family members and family caregivers will be interviewed separately. One or two follow-up interviews may be requested. You do not have to take part in the extra interviews unless you wish to do so. All interviews will be tape recorded and typed up. The researcher may also write notes about her meeting with you.

Possible Risks:
There are no known risks to taking part in this study. You may, however, feel some distress. If so, the researcher will end the interview if you wish. Follow-up counselling is available upon request.
Participants are free to withdraw from the study at any time, with no questions asked.

Benefits:
No direct benefit is expected, however, you may find that describing your experiences is helpful.

Confidentiality:
The researcher will remove your name and other identifying information when typing up your interview(s). The tapes and the typed copies will be kept in a locked filing cabinet in the researcher's office for 7 years.

Additional Contact:
If you have any concern about this study, please contact Dr. Christine Newburn-Cook, Faculty of Nursing, University of Alberta: 780-436-148.

Project Title: Decision-Making in a Family Dyad in the Context of Advanced Cancer

If you are interested in having the researcher contact you to learn more about this study please complete this form and leave it with the home care nurse.

Thank-you!

Name: ____

Home Telephone: ________________________ Cell Phone: ______________________

The best times to phone me are: ____

Participant Consent Form

Project Title: Decision-Making in a Family Dyad in the Context of Advanced Cancer
Investigator: Susanna Edwards, RN, MSc., Ryerson University,
Toronto, Ontario, 416-979-5000 ext. 6311
Thesis Supervisor: Dr. Karin Olson, Faculty of Nursing,
University of Alberta, 780-492-6403

Do you understand that you have been asked to be in a research study? Yes No

Have you read the information letter? Yes No

Do you understand the risks and benefits involved in this study? Yes No

Have you been able to ask questions and discuss this study? Yes No

Do you understand that you can refuse to participate in or withdraw from the study at anytime? Yes No

Has the issue of confidentiality been explained to you? Yes No

Do you understand who will have access to your records? Yes No

This study has been explained to me by: _______________________________________

I agree to take part in this study.

____________________________ ____________ ________________________
Signature Date Printed Name

I believe that the person signing this form understands what is involved in the study "Decision-Making in a Family Dyad in the Context of Advanced Cancer" and voluntarily agrees to participate.

__________________________ ____________ ___________________________
Signature of Investigator Date Printed Name

I also give permission for the researcher to use my information in other studies following ethics approval.
Signature: ______________________________________ Date: ___________________

I also give permission for the researcher to use my information for educational purposes.
Signature: ______________________________________ Date: ___________________

APPENDIX: B

Interview Approach

Interview Approach

Initial Interview Approach for Ill Family Members

I am interested in hearing about experiences that would help me understand what it is like to have advanced cancer. Please think of yourself as the teacher and me as your student. You are welcome to tell me as little or as much about the experiences as you like.

Initial Interview Approach for Family Caregivers

I am interested in hearing about experiences that would help me understand what it is like to provide care for a family member who has advanced cancer. Please think of yourself as the teacher and me as your student. You are welcome to tell me as little or as much about the experiences as you like.

Further Questions for Ill Family Members

Tell me about a decision about your care that you and _______had to make recently?

Probes:

- What was the experience like for you?
- How was it the same or different from the way you usually went about making decisions together?

Further Questions for Family Caregivers

Please tell me about a decision you and _______ had to make that was related to ____'s loss of his or her mental or physical capabilities

Probes:

- What was the experience like for you?
- How was it the same or different from the way you usually went about making decisions together?

APPENDIX: C

Recruitment Advertisement

Recruitment Advertisement

Research Study

If you are an English speaking adult age 18yrs + and have been a caregiver for an adult who died of cancer at least 3 months ago, I would like to hear your story. Please contact me at:

Prof. Sue Edwards, RN, PhD (cand.)
School of Nursing, Ryerson University
Phone: 416-979-5000 ext. 6311

Thank you.