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Sandra Keet-Sai Young
AUTEUR DE LA THÈSE / AUTHOR OF THESIS

M.Sc. (Nursing)
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Decision Making Needs of Family Caregivers of Terminally Ill Patients Regarding Place of Care at the End of Life: A Pilot Study

TITRE DE LA THÈSE / TITLE OF THESIS

Annette O'Connor
DIRECTEUR (DIRECTRICE) DE LA THÈSE / THESIS SUPERVISOR

CO-DIRECTEUR (CO-DIRECTRICE) DE LA THÈSE / THESIS CO-SUPERVISOR

EXAMINATEURS (EXAMINATRICES) DE LA THÈSE / THESIS EXAMINERS

Jo Logan

Dawn Stacey

Gary W. Slater
Le Doyen de la Faculté des études supérieures et postdoctorales / Dean of the Faculty of Graduate and Postdoctoral Studies

DECISION MAKING NEEDS OF FAMILY CAREGIVERS OF TERMINALLY ILL PATIENTS REGARDING PLACE OF CARE AT THE END OF LIFE: A PILOT STUDY

Sandra K. Young, RN, CHPCN(C)

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ABSTRACT

Objective: To conduct a pilot study describing the decision making needs of family caregivers of terminally ill patients when making or supporting decisions regarding place of care at the end of life.

Design: A pilot needs assessment using a semi-structured interview questionnaire.

Setting: Palliative Care Unit (PCU), hospice, and a community served by a Palliative Care Consultant Team.

Participants: Convenience sample of 14 family caregivers of terminally ill patients.

Outcome measures: Standardized semi-structured interview guide and scales eliciting family caregivers': Perceptions of the decision (perceived options, stage and predisposition, decisional conflict, knowledge, expectations, values); perceptions of others (support, pressure, roles); personal and external resources; preferred resources; and participant and patient characteristics.

Results: Home, PCU, hospice, long term care facility, and hospital were identified as decision options, with home and PCU equally considered the best. Most participants were 'very sure' about their decision, considered it easy to make, perceived the patient to be 'very sure,' felt informed of the options and their pros and cons, had adequate support and advice, felt no pressure, preferred to share decision making, and had received information and emotional support. A minority of participants (3/14) expressed more decisional conflict as did those participants in earlier stages of decision making. The resource most needed was tangible support, and individual counseling and printed information were preferred over discussion groups and Internet information.

Conclusion: Family caregivers have important informational, emotional, financial, tangible, and decisional support needs. The results of this pilot study indicate that it is feasible to conduct this research with a larger, more diverse population with some revisions to the research methods. This study is a promising step in describing the decision making needs of family caregivers of terminally ill patients when making or supporting decisions regarding place of care at the end of life.

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CHAPTER ONE - INTRODUCTION

1.1 Research Problem

A shift in age demographics has increased the importance of end-of-life care (Austin & Fleisher, 2003). With an aging population and growing number of older people, demand for supportive care and palliative treatment will increase. This has important consequences for Canadian society, and attention is required to identify and address end-of-life needs, including place of care.

Decision making regarding place of care at the end of life is complex and multi-faceted (Murray, O'Connor, Fiset, & Viola, 2003). While many terminally ill patients would prefer to die at home, most die in hospital (Burge, Lawson, & Johnston, 2003; Davison, Johnston, Reilly, & Stevenson, 2001; Groth-Juncker & McCusker, 1983; Higginson, Astin, & Dolan, 1998; Karlsen & Addington-Hall, 1998; Lee & Pang, 1998; McWhinney, Bass, & Orr, 1995; Townsend, Frank, Fermont, Dyer, Karran, & Walgrave, 1990).

In Canada and in the United Kingdom, about 46-70% of cancer patients prefer home as the preferred place of death (Dunlop, Davies, & Hockley, 1989; Hinton, 1994; McWhinney, Bass, & Orr, 1995; Thomas, Morris, & Clark, 2004; Townsend, Frank, Fermont, Dyer, Karran, & Walgrave, 1990). In the United States, about 80-90% of terminally ill patients with cancer preferred to die at home (Pritchard et al., 1998; Tang, 2003a). Despite this preference, less than 30% of cancer patients in the United Kingdom and the United States achieved a home death (Addington-Hall & McCarthy, 1995a and b; Ellershaw & Ward, 2003; Gatrell, Harman, Francis, Thomas, Morris, & McIllmurray, 2003; Tang, 2003b). In Canada, over 230,000 deaths occur each year (Statistics Canada, 2005a), of which 52-87% take place in hospitals and long-term care facilities (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000; Standing Senate Committee on Social Affairs, Science and Technology, 2000). In a systematic literature review of patient preferences regarding place of care in advanced cancer (Higginson & Sen-Gupta, 2000), researchers found that in many countries, far fewer patients die at home than would prefer.

In order to remain at home, patients need adequate nursing care, good symptom control, committed family doctors, access to specialist palliative care when needed, effective coordination of care, financial support, and terminal care education (Brazil, Bedard, &

Willison, 2002; Cantwell, Turco, Brenneis, Hanson, Neumann, & Bruera, 2000; Stajduhar & Davies, 1998; Tang & McCorkle, 2001; Thorpe, 1993). Not only are these conditions necessary, but palliative patients also need a primary caregiver, usually a family member, living in the home. Terminally ill cancer patients without sufficient family resources but who require intensive nursing care are at a disadvantage to remain at home (Tang, 2003c). To enable family care-taking to take place and to minimize caregiver burden, adequate support is necessary, such as a personal support worker visiting the home to help with activities of daily living and/or to provide respite. Caregiver burden can be described as the emotional strain, distress, and physical exhaustion resulting from the demands of providing care to an ill, dependent, or confused person over time (Lantz, 2004). Reasons why dying people are admitted to hospital include poorly controlled symptoms, need for 24-hour nursing care, strain on the caregivers, and crisis situations, such as onset of severe pain or vomiting, or sudden illness of the caregiver (Thorpe, 1993). Elements of quality end-of-life care include: 1) receiving adequate pain and symptom management, 2) avoiding inappropriate prolongation of dying, 3) achieving a sense of control, 4) relieving burden, and 5) strengthening relationships with loved ones (Singer, Martin, & Kelner, 1999).

Considering that impaired decisional capacity is common in dying patients (Fainsinger, Moissac, Mancini, & Oneschuk, 2000), family caregivers often play a role in decision making regarding place of care at the end of life, particularly if a home death is preferred. The family caregiver may be responsible for making choices on behalf of the patient, or supporting decision making with the patient. The family caregiver's perspective is therefore important.

While the determinants of place of care at the end of life and reasons for hospital admission have been studied extensively, decision making regarding place of care has not been well researched. Moreover, little is known regarding the decision making needs of family caregivers considering options for place of care for their terminally ill loved ones at the end of life.

1.2 Objective of the Study

Therefore, the objective of the study is to conduct a pilot study describing the decision making needs of family caregivers of terminally ill patients when making or supporting decisions regarding place of care at the end of life.

There is a role for palliative care nurses and other health care professionals to assist and support patients and families in decision making in the clinical and community setting. Lack of a clear understanding of the decision making needs of family caregivers limits the ability of nurses and other health care professionals to advocate for the patient and family, encourage and facilitate the patient and family to participate in decision making in ways they prefer, and to provide decision support regarding place of care at the end of life. Research that addresses the current gap in knowledge regarding the decision making needs of family caregivers is necessary and important so that health care professionals may be better able to assist and support patients and families in decision making through the development of evidence-based interventions. The provision of decision support regarding place of care at the end of life may lead to a potential improvement in the quality of life at the end of life, and improving quality of life is a goal of palliative care.

CHAPTER TWO - LITERATURE REVIEW

2.1 Search Strategy

Papers cited in this literature review were identified by an English language search of the Cochrane Library, CINAHL - Cumulative Index to Nursing and Allied Health Literature (1982-2005), MEDLINE (1966-2005), Ovid Healthstar (1966-2005), and CANCERLIT (1975-2002) databases. Search terms used included “actual place of death”, “preferred place of death”, “place of care at the end of life”, “good death”, “place of death”, “family caregiver”, “caregiver burden”, “placement”, “decision making”, “palliative care”, and “home death”. The World Wide Web was searched using the keywords “good death,” “decision making,” “decide,” and “palliative care”. Hand searches of journal articles were also conducted.

2.2 Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems (World Health Organization, 2005). The goals of palliative care are to relieve suffering and improve the quality of living and dying (Canadian Hospice Palliative Care Association, 2002).

Palliative care programs allow patients to gain more control over their lives, manage pain and symptoms more effectively, and provide support to family members (Canadian Hospice Palliative Care Association, 2004). The process of providing palliative care is based on the development of a therapeutic relationship between those who provide care (health care providers) and those who receive it (the patient and family) (Canadian Hospice Palliative Care Association, 2002). One of the essential and basic steps during a therapeutic encounter is decision making, and the principles of decision making include the patient’s right to make informed decisions, determine goals for care, and establish priorities, and the involvement of family members whenever possible (Canadian Hospice Palliative Care Association, 2002).

Decision support can enhance patient participation and address values and preferences, so that the path that the patient takes is consistent with his or her values and preferences. Therefore, supporting decision making may improve the quality of life of terminally ill patients and their families, which is the goal of palliative care.

The need for palliative care in Canada is growing as the population is aging. A Canadian born in 1960, for example, can expect to live 20 years longer than a Canadian born in 1900 (About Canada, 2005). Meanwhile, birth rates have declined, so that a growing proportion of the population is aged 65 and over. Statistics Canada projects that by 2026, approximately 1 in 5 Canadians will be a senior (2001c), and the rate of deaths will increase from over 230,000 to 325,000 a year (2001a). Each death potentially affects the immediate well being of an average of five other people, or more than one million Canadians each year (Canadian Hospice Palliative Care Association, 2004).

2.3 Determinants of End of Life Place of Care

Multiple factors influence the place of death of terminally ill patients, including personal and cultural values and characteristics, physical and medical factors, and various healthcare systems' forces (Grande, Addington-Hall, & Todd, 1998; Grande, McKerral, Addington-Hall, & Todd, 2003; Tang, 2002). Factors determining the place of palliative care and death include physical symptoms, such as pain and decreased mobility; psychological issues, such as anxiety and denial; social concerns, such as housing and equipment; financial support; and the quality of the relationships between patient, family, and health care provider (Van den Eynden et al., 2000).

Regarding the influence of gender and age on place of death, some studies found men more likely than women to die at home (Carlsson & Rollison, 2003; De Conno et al., 1996), and that the probability of dying at home diminishes with age (Grande, Addington-Hall, & Todd, 1998; Grundy, Mayer, Young, & Sloggett, 2004; Higginson, Astin, & Dolan, 1998). However, other studies found no statistically significant differences regarding gender and age (De Conno, Panzeri, Brunelli, Saita, & Ripamonti, 2003; Fukui, Kawagoe, Masako, Noriko, Hiroko, & Toshie, 2003; Izquierdo-Porrera, Trelis-Navarro, & Gomez-Batiste, 2001).

Patients in socio-economically disadvantaged circumstances are more likely to die in hospital than those with a higher level of socioeconomic status (De Conno et al., 1996; Grundy, Mayer, Young, & Sloggett, 2004 ; Hunt, Fazekas, Luke, & Roder, 2001; Maida, 2002). In some studies, marital status is not significantly associated with place of death (Bass, Pestello, & Garland, 1984; Maida, 2002; Mann, Loesch, Shurpin, & Chalas, 1993); however, other studies found single, separated or widowed patients more likely to die in hospital than those married (Constantini, Camoirano, Madeddu, Bruzzi, Verganelli & Henriquet, 1993; De Conno et al., 1996). Patients with higher educational level are more likely to die at home than those less educated (Constantini et al., 1993; Jordhoy, Saltvedt, Fayers, Loge, Ahlner-Elmqvist, & Kaasa, 2003).

A diagnosis of a hematological malignancy tends to predict hospital death, as complications often develop that result in hospital admission (Bruera, Sweeney, Russell, Willey, & Palmer, 2003; Higginson, Astin, & Dolan, 1998; Tang & McCorkle, 2001). A longer prognosis is associated with a home death (Grande, McKerral, Addington-Hall, & Todd, 2003), perhaps because a longer prognosis may allow the patient's family to organize care at home (Constantini et al., 1993). Slow progression of disease may also allow the family time to adjust and develop skills to provide care at home; however, the family may lack the economic, psychosocial, and emotional resources to provide care for a prolonged period, resulting in terminal hospitalization (Tang & McCorkle, 2001).

Local system factors, such as the availability of specialist palliative care, hospital, or nursing home beds and staff (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000), and service infrastructure factors, such as program funding, national cancer and palliative care policies, and the existence of multi-disciplinary palliative care teams, are factors associated with location of death (Pritchard et al., 1998; Thomas, 2005). For example, a relatively small number of specialist palliative care beds in a region, a relatively high number of specialist palliative care professionals in community settings, and organizational and inter-professional agreement to invest in and support home deaths are predictors of death at home (Thomas, 2005). Proximity to a hospice increases the probability that a patient with cancer will die there, and likewise regarding hospitals (Gatrell, Harman, Francis, Thomas, Morris, & McIllmurray, 2003).

Factors associated with dying at home are the patient's and family's desire for a home death, a family member other than the spouse involved in the patient's care, and adequate community support, such as the use of shift care nursing (Fukui, Kawagoe, Masako, Noriko, Hiroko, & Toshie, 2003; Karlsen & Addington-Hall, 1998; McWhinney, Bass, & Orr, 1995). Other predictors of home death include support of the family physician, agreement between the patient desiring a home death and the caregiver supporting a home death (Cantwell, Turco, Brenneis, Hanson, Neumann, & Bruera, 2000), and a caregiver in good health living with the patient (Ahlner-Elmqvist, Jordhoy, Jannert, Fayers, & Kaasa, 2004; Brazil, Bedard, & Willison, 2002). The involvement of a hospice home care team also facilitates a significant increase in the proportion of patients dying at home (Tiernan, O'Connor, O'Siorain, & Kearney, 2002).

2.4 Policy Directions

In June 2000, the Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology issued its final report of *Quality End-of-Life Care: The Right of Every Canadian*, an update to *Of Life and Death*, tabled in June 1995 by the Special Senate Committee on Euthanasia and Assisted Suicide. In the 2000 report, the Subcommittee made 15 strong recommendations to the federal government of Canada, the first being to develop, in collaboration with the provinces, a national strategy for end-of-life care. Other recommendations included the incorporation of home care and pharmacare for the dying as essential medical services under the *Canada Health Act*, the commitment of the necessary funding to support these services, and the provision of income assistance and job security for family members who care for a dying relative (Standing Senate Committee on Social Affairs, Science and Technology, 2000). The Subcommittee also reported on the progress on the 1995 recommendations from *Of Life and Death*. The Subcommittee found insignificant or non-existent progress, and recommended that a 5-year plan be drawn to implement the 1995 unanimous recommendations. The recommendations were to make palliative care programs a top priority in the restructuring of the health care system, and that the delivery of care, whether in the home, in hospices, or in institutions, be coordinated to maximize effectiveness, with the provision of respite services as an essential component (Standing Senate Committee on Social Affairs, Science and Technology, 2000).

In September 2000, First Ministers of Canada agreed on a vision, principles, and action plan for health system renewal. In February 2003, Health Canada released the First Minister's Accord on Health Care Renewal, which sets out an action plan for reform that reflects a renewed commitment by governments to work in partnership with each other, with providers, and with Canadians in shaping the future of our public health care system (Health Canada, 2003). In the Accord, First Ministers agree to provide funding for home care, including end-of-life care, and that the Government of Canada would complement these efforts with a compassionate care benefit through the Employment Insurance Program and job protection through the Canada Labour Code.

In June 2003, the Employment Insurance Act and the Canada Labour Code were amended. Benefits are available to a maximum of 6 weeks to a person who has to be absent from work to provide care or support to a gravely ill family member at risk of dying (Government of Canada, 2005). "Family member" is defined as a spouse or common-law partner of the employee, a child of the employee or of the employee's spouse or common-law partner, a parent of the employee or a spouse or common-law partner of the parent, or any other person defined as a "family member" in subsequent regulations (Harnden, 2003). However, a parent of the employee's spouse or common-law partner is not included in the list.

In October 2005, the provincial government of Ontario, Canada announced its End-of-Life Strategy. Over three years, the Ontario Ministry of Health and Long-Term Care will invest $115 million to improve end-of-life care by providing home care funding, including residential hospice funding, support for volunteer home hospice visiting and other community support service agencies, and support to common practices and infrastructure (Government of Ontario, Canada, 2005). The funding will provide better access to care, including enhanced levels of nursing and personal support care services in home and in residential hospices.

2.5 Decision Making

Decision making is the process of choosing between alternative courses of action (including inaction) (O'Connor, Jacobsen, & Stacey, 2002). The term *decide* has multiple definitions: 1) to arrive at a solution that ends uncertainty or dispute, 2) to select as a course of action, 3) to bring to a definitive end, 4) to induce to come to a choice, and 5) to make a choice or judgment (Merriam-Webster's Dictionary, 2005). When examining different instances of the concept of decision making, defining attributes, or characteristics, appear repeatedly (Walker & Avant, 1995). They include: 1) a deliberate choice being made, 2) careful, thorough consideration, 3) the end of uncertainty or dispute, 4) the selection of a course of action, 5) having two or more options, and 6) the decision is based on values and utility (Matteson & Hawkins, 1990).

Decisional conflict is the uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret, or challenge to personal life values (North American Nursing Diagnosis Association, 2005). Signs of decisional conflict include uncertainty about choices, concern about undesired outcomes, vacillation between choices, delayed decision making, questioning of personal values, and physical signs of distress (O'Connor, 1997). Factors that contribute to decisional conflict are lack of information, conflicting or unclear personal values, lack of knowledge or skills to implement decisions made, interference from others, an inadequate support system, and unrealistic alternatives or expectations (O'Connor, 1997). Unresolved decisional conflict may lead to delay in decision making, preference reversals, dissatisfaction, regret, and tendency to blame others for bad outcomes (Gattellari & Ward, 2005; Sun, 2005).

Individuals who are involved in the care of a person with a terminal illness will often classify the death as 'good' or 'bad' (Kristjanson, McPhee, Pickstock, Wilson, Oldham, & Martin, 2001). An identified component of a 'good death' is clear decision making, which entails patient participation in treatment decisions with the patient feeling empowered (Steinhauser, Clipp, McNeilly, Christakis, McIntyre, & Tulsky, 2000). Other components of a 'good death', as understood by patients, families, and providers involved in end of life care, are: pain and symptom management; preparation for death, completion (spending time with loved ones, and saying goodbye); contributing to others; and affirmation of the whole person (seeing the person in the context of their lives, values, and preferences, and not as diseases) (Steinhauser, Clipp, McNeilly, Christakis, McIntyre, & Tulsky, 2000).

A 'bad death' is described in terms of patients feeling disregarded, family members feeling concerned about the patient suffering, health care providers experiencing feelings of being out of control and not being able to provide good care and decisions not previously discussed being made during crisis, when emotional reserves are low (Steinhauser, Clipp, McNeilly, Christakis, McIntyre, & Tulsky, 2000). Nurses can help promote ‘good deaths’ for terminally ill patients by assisting with and actively supporting decision making (Winslow & Jacobson, 1998).

Previous studies have been conducted examining decision making, specifically among terminally ill populations, and regarding place of care. Murray, O’Connor, Fiset, and Viola (2003) examined the decision making needs of a sample of 20 terminally ill women regarding location of care in the last weeks of life. Home, hospital, and the palliative care unit were identified as possible options for end of life care. The most frequently mentioned consequences for each option concerned burden on family, strengthening relationships, pain and symptom control, and maintaining a sense of control over their environment. Thirteen study participants indicated that home was the preferred location of care under ideal conditions while 16 participants considered the regional palliative care unit as the best location of care under current circumstances. The researchers suggested that discrepancies about place of care might be related to conflicting subjective factors such as being a burden to family versus having the opportunity to strengthen relationships with family and friends. Participants who were actively engaged in decision making scored the highest levels of decisional conflict. The researchers acknowledge that the small sample size, relatively homogeneous group, and use of a single recruitment centre limit generalization of the results. While this study examined decision making needs regarding place of care at the end of life, the perspective was from that of patients, not of family caregivers.

Stajduhar and Davies (2005) explored the variations in and factors influencing family members’ decisions to provide home-based palliative care by interviewing 13 family members providing care to a palliative patient at home, 47 bereaved family members, and 25 health care providers. Although the decision making process was unique for each individual family member and family situation and was influenced by many factors, there was some commonality in how these caregivers constructed their decisions (Stajduhar & Davies, 2005). Some caregivers made uninformed decisions, giving little consideration to the implications of their decisions. Others made indifferent decisions, whereby they reluctantly agreed to provide care at home, and still others negotiated decisions for home care with the dying person. Regardless of the types of decisions made, three major factors influenced family members' decision for palliative home care: 1) a promise caregivers made to the dying person to care for them at home; 2) the caregiver's desire to have the dying person in an environment where a 'normal life' could be maintained; and 3) a desire to avoid institutional care (Stajduhar & Davies, 2005). The researchers suggested that interventions are needed to better prepare caregivers for their role, enhance caregivers' choice in the decision making process, improve care for the dying in hospital, and consider the development of alternate options for care.

In a qualitative study, McCall and Rice (2005) explored factors influencing decisions around the place of care for terminally ill cancer patients. Eight patients were interviewed, and determinants for the desired place of care were organized into three main themes: caregiver resource and support; past experiences with death; and communication of wishes. When making a decision regarding ongoing care in advanced disease, patients who perceived themselves as a burden took into consideration the overall care burden on others, whether family or friends. However, decisions reflected the patient's perceptions of resources rather than those of the caregiver, even when the caregiver was available and able. Five of the 8 participants spoke of previous experiences in dealing with the dying and/or death of a close relative at home, and none were reported as good experiences from a home nursing perspective. The researchers noted that participants rarely communicated their preference for place of care with any definite feeling, but always acknowledged that events might change and, therefore, influence the choice.

Lewis, Pearson, Corcoran-Perry, and Narayan (1997) explored the scope of decisions encountered by elderly cancer patients and/or their family caregivers, and the types of decision-making assistance requested and required within one practice setting, by interviewing five cancer centre nurse coordinators. The study uncovered 11 categories of decision making topics: symptom management, use of chemotherapy, ancillary choices, selection of a medical provider, alternative therapy, vacation planning, weekend-pass planning, discharge planning, family survivor issues, involvement of adult children in the elder's care, and planning for end of life care. The *planning for end of life* category included concerns about preparation for loss of independence and planning for death. Family caregivers raised these concerns more frequently than did elderly patients. Also, the nurse coordinators perceived that patients and/or their family caregivers needed information clarification, reassurance about their decisions, a listener, permission to change the treatment regimen, and help with communication among health professionals, the elderly patient, and the family. The researchers acknowledged the limitation that because data was collected in one health care setting, findings cannot be generalized to other populations. Also, the use of the nurse coordinators as the primary sources of information was a limitation, as it was not possible to ensure that participants validated their perceptions of decision making topics or the need for decision making assistance. Therefore, it is unknown whether the nurse coordinators' perceptions accurately reflect the issues raised by the elderly cancer patients and/or their family caregivers.

Previous studies have explored decision making from the perspective of the family caregiver. Sims, Boland, and O'Neill (1992) examined 17 families to describe the experiences of caring for an ill family member in the home, and to elicit descriptions of decision making and problem framing from the perspective of the family caregiver. Family caregivers were either caring for chronically ill children or parents, all previously hospitalized. The researchers found that during the course of providing care, family caregivers progressed from passive to active decision making as they became more familiar with their new lifestyle and the needs of the care recipients. For most caregivers, the decision to provide home care seemed simple, as they did not think they had any other options. Results also indicated that most caregivers considered home as the best place over a facility, and that the responsibility of taking on decision making was often forced, due to the patient's lack of energy or inability to participate because of illness.

Lundh, Sandberg, and Nolan (2000) examined the experiences of 14 spouses relating to the decision making process of placing a partner in a care home for elderly people. For a majority of participants (11/14), the placement decision was the result of a growing awareness of their inability to carry on in a caring role. Often, it was not the caregiver who raised the possibility of alternative caring arrangement, but broached by home help, nurses, or children. Despite this legitimation, spouses still often felt they had let their partner down, describing this as a form of treachery, or if the cognitive status of the partner had precluded their involvement in decision making, participants described feelings of guilt. Kellet (1999) also explored family caregivers' experience of nursing home placement and uncovered five shared meanings from 14 participants' responses: 1) feelings of guilt, sadness, and relief simultaneously, 2) experiencing a loss of control, 3) being disempowered, 4) possessing a sense of failure, and 5) and having to make a forced and negative choice.

Hagen (2001) explored the factors influencing caregivers' decision making process related to placing an elderly family member with dementia in a nursing home. All 5 participants reported that making such a decision was difficult and heart wrenching. Six factors influencing decision making emerged: 1) the degree of independence between caregiver and care recipient, 2) level of assistance and support available, 3) fear of loneliness, 4) negative attitudes of nursing homes, 5) sense of existential self (the extent to which caregivers saw themselves as having a distinct meaning and purpose in life apart from caregiving), and 6) guilt.

Other studies have examined the hospice decision, or the decision to enter hospice care (Greipp, 1996; Norton & Bowers, 2001; McNeilly & Hillary, 1997). The use of the term hospice decision in these studies does not refer to the admission of terminally ill patients into a hospice setting, but to the choice of no active treatment and palliative care versus continued curative, and perhaps aggressive, treatment of the disease.

In conclusion, further research exploring the decision making process from the family caregiver's perspective about the place of care during the last days or weeks of life is important and necessary, and clearly there is a gap in knowledge. While the studies by Murray, O'Connor, Fiset, and Viola (2003), Stajduhar and Davies (2005), McCall and Rice (2005), and Lewis, Pearson, Corcoran-Perry, and Narayan (1997) examined decision making and planning for care at the end of life, more research to further explore decision making from the caregiver's perspective is needed. The studies by Sims, Boland, and O'Neill (1992), Lundh, Sandberg, and Nolan (2000), Kellet (1999), and Hagen (2001) examined decision making from the family caregiver's perspective; however, the care recipients were not terminally ill considering place of care at the end of life. Supporting decision making about place of care at the end of life may improve the quality of life of terminally ill patients and their families. The aim of palliative care is to achieve quality of life and a dignified death, preferably in a place of the patient's choosing (Pemberton, Storey, & Howard, 2003).

2.6 Conceptual Framework

The conceptual framework used to guide this study is the Ottawa Decision Support Framework (ODSF) (O'Connor et al., 1998). The ODSF is based on concepts from cognitive psychology (Tversky & Kahneman, 1981), social psychology (Ajzen & Fishbein, 1980), decision analysis (Keeney & Raiffa, 1976), decisional conflict (Janis & Mann, 1977), social support (Norbeck, 1988; Orem, 1995), and expectancy-value decision theories (Feather, 1980). It is an evidence-based conceptual framework that is used to support patients in making difficult health or social decisions (O'Connor et al., 1998). The ODSF uses a three-step process to: 1) assess determinants of decisions to identify decision making needs, 2) intervene by providing decision support according to needs, and 3) evaluate support by examining the decision making process and outcomes. The assessment of decision determinants is most relevant to this study.

According to the ODSF, the determinants of decisions that may be sub-optimal include:

- Problems in perceptions of the decision such as inadequate knowledge of options, unrealistic expectations of benefits and harms, unclear values regarding the personal importance of benefits and harms, decisional conflict (uncertainty regarding the course of action), being in a stage of decision making which is not conducive to careful contemplation, and having a strong predisposition toward an option which closes ones mind toward alternatives prematurely;
- Problems with perceptions of others such as uninformed perceptions of others' opinions and practices, inadequate support for decision making, pressure from others to choose one option, or having a mismatch between preferred and actual roles in decision making;
- Inadequate personal and external resources for decision making;
- Personal characteristics that require special types of support based on age, sex, education etc.

Figure 1 illustrates the ODSF and Table 1 lists the definitions of the decision determinants identified in the ODSF.

Figure 1: Ottawa Decision Support Framework

Assess Needs (Determinants of Decisions)	**Provide Decision Support**	**Evaluate**
Perceptions of Decision Knowledge Expectations Values Decisional conflict Stage of decision making Predisposition **Perceptions of Others** Perceptions of others' opinions & practices Support Pressures Roles in decision making **Resources to Make Decision** Personal: Previous experience Self-confidence Motivation Skill in decision making External: Support (information, advice, emotional, instrumental, financial, professional help) from social networks and agencies **Characteristics** Client: age, sex, marital status, education, occupation, culture, locale, medical diagnosis & duration, health status Practitioner: age, sex, education, specialty, culture, practice locale, experience, counseling style	**Provide access to information regarding:** • Health situation • Options • Outcomes • Others' opinions and choices **Re-align expectations of outcomes** **Clarify personal values for outcomes** **Provide guidance/coaching in:** • Steps in decision making • Communicating with others • Handling pressure • Accessing support & resources	**Decision making** Reduced decisional conflict Improved knowledge Realistic expectations & norms Clear values Agreement between values &choice Implementation of chosen option Satisfaction with decision making **Outcomes of Decision** Persistence with choice Improved quality of life Reduced distress Reduced regret Informed use of resources

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Table 1: Definitions of Decision Determinants in the ODSF (O'Connor et al., 1998)

Participants' Perceptions of the Decision

Knowledge	cognizance of the health problem or situation, options, and outcomes
Expectations of outcomes	perceived likelihood or probability of outcomes of each option
Values for outcomes	desirability or personal importance of outcomes of options
Decisional conflict	uncertainty about course of action to take
Stage of decision making	phase of decision making in the context of stages of change: not thinking about the options (interested in considering further?); considering the options; close to selecting an option (interested in re-considering options?); taking steps towards implementing option (interested in re-considering options?); have already carried out choice (interested in re-considering options?)
Predisposition	degree to which a person is leaning strongly towards choosing an option or is uncertain

Participants' Perceptions of Others Involved in Decision Making

Perception of others' opinions and practices	perceptions of what others decide or what others think is the appropriate choice. For the client, important others may include their spouse, family, peers, and practitioner(s). For the practitioner, it may include the client, professional peers, and personal network
Support	informational, emotional, and tangible help from important others to bolster and sustain decision making
Pressure	perception of persuasion, influence, coercion from important others to select one alternative
Role in decision making	the way a participant is or wants to be involved in decision making with others; do they wish to make the choice themselves after considering other opinions, do they want to share decision making with someone else, do they want others to make the decision after considering their opinion

Participants' Resources for Decision Making

Personal	
Previous Experience	previous exposure to the situation, options, outcomes, decision making process
Self-confidence	belief in one's abilities in decision making, including shared decision making
Motivation	readiness and interest in decision making, including shared decision making
Skill	abilities in making and implementing a decision
External	assets from others that are required to make and implement the decision: type: -availability and access to information, advice, emotional support, instrumental help, financial assistance, and health & social services source: -social networks, professional networks, support groups, voluntary agencies, and the formal health care, education, and social sectors

Participants' Characteristics

Client	age, gender, marital status, ethnicity, education, occupation, locale, diagnosis and duration of condition, health status (physical, emotional, cognitive, social)
Practitioner	Age, gender, ethnicity, clinical education and specialty, practice locale, years of experience

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2.7 Rationale for Use of the Conceptual Framework

The Ottawa Decision Support Framework provides a practical and functional model to guide the assessment of the decision making needs of family caregivers of terminally ill patients regarding place of care at the end of life. The ODSF applies to all individuals that may be involved in making the decision, including the patient, family members, and health care professionals.

The framework was developed for health decisions in which patients are experiencing decisional conflict and particularly for decisions that: 1) are stimulated by a new circumstance, diagnosis, or developmental transition; 2) require careful deliberation because there is no clear choice due to the uncertain and/or value-sensitive nature of the benefits and risks; and 3) need relatively more effort during the deliberation phase than the implementation phase (O'Connor, Jacobsen, & Stacey, 2002). Given the complex and sensitive nature of decision making regarding place of care at the end of life, the ODSF is particularly suited to address the study topic.

The ODSF is less useful in situations: 1) with no immediate stimulus for deliberating about options (for example, the choice of a university for a child in kindergarten); 2) whose key challenge is implementing and maintaining actions rather than making a choice (such as in smoking cessation); or 3) in which decision making is rapid, repetitive, automatic, impulsive, or deferential to authority rather than deliberative in nature (e.g., addictions, behavior in emergency situations) (O'Connor, Jacobsen, & Stacey, 2002).

A specific limitation of the framework is its minimal validation for palliative care decision making, which tends to vary considerably relative to other clinical decisions studied. Moreover, the strong emotional and spiritual elements of palliative care are not prominent in the framework.

2.8 Previous Use of the Conceptual Framework in Populations with Life-Threatening Illness

The ODSF has been used in previous health studies regarding decision making in populations facing life-threatening illness. De Grasse (1995) examined women's decision making and breast cancer screening. Stacey, O'Connor, De Grasse, and Verma (2003) developed and evaluated a breast cancer prevention decision aid to address the needs of women at high risk for breast cancer. Fiset, O'Connor, Evans, Graham, De Grasse, and Logan (2000) developed and evaluated a decision aid for patients considering options for stage IV non-small cell lung cancer.

The ODSF has been validated in a previous study involving a patient population facing the decision regarding location of care in the last weeks of life (Murray, O'Connor, Fiset, & Viola, 2003). The ODSF has not been validated in a population of family caregivers considering place of care at the end of life. This study will contribute information regarding its validity in this specific population.

CHAPTER THREE - METHODS

3.1 Research Design

A pilot needs assessment was conducted using a cross-sectional survey of family caregivers who were in the process of making or supporting a decision regarding place of care at the end of life. A needs assessment is a systematic set of procedures undertaken for the purpose of setting priorities and making decisions about program or organizational improvement and allocation of resources (Witkin & Altschuld, 1995). The priorities are based on identified needs. Needs assessment research produces information about people's ideas, attitudes and preferences to help determine what people want, to help identify and define problems, and to help identify different solutions (Abbey-Livingston & Abbey, 1982).

A pilot study is a small-scale version, or trial run, of the major study, and its function is to obtain information for improving the major study or for assessing its feasibility (Polit & Hungler, 1999). The pilot study may reveal that revisions are needed in one or more aspects of the project (Polit & Hungler, 1999). For example, perhaps the target population may not have been appropriately defined, the cooperation of people was difficult to secure, the data collection plan was inadequate, the respondents found the questions objectionable, or perhaps the respondents were not able to understand and answer the questions (Polit & Hungler, 1999).

3.1.1 Data Collection

Data collection involved face-to-face interviews using semi-structured questions. The interviews were audio-taped using two separate recorders, in case one failed. As a back up, notes were also made throughout the interviews.

3.1.2 Rationale for the Interview Method

A survey is designed to obtain information from populations regarding the prevalence, distribution, and interrelations of variables within those populations (Polit & Hungler, 1999). Collecting survey information through personal interviews is a method in which interviewers meet with individuals face-to-face, and while personal interviews require considerable planning and are time-consuming, they are regarded as the most useful method of collecting survey data because of the quality of the information they yield (Polit & Hungler, 1999). This method also allows the interviewer to clarify questions if required and build rapport with the participant, which can enhance the information provided. Given the sensitive nature of the research study, conducting personal interviews is an appropriate method of obtaining survey data from the study population.

In a semi-structured interview, the interviewer uses a list of areas of questions to be covered with each study participant, and the interviewer's function is to encourage participants to talk freely about all topics on the list and to record the responses, usually by tape recorder (Polit & Hungler, 1999). Semi-structured interviews offer the researcher flexibility in gathering information from study participants, and the interviews tend to be conversational and interactive in nature (Polit & Hungler, 1999). Allowing flexibility is important because it does not restrict responses and may provide insight into the area that is not based on the researcher's own assumptions.

3.2 Sample

The target population consisted of a convenience sample of family caregivers of terminally ill patients residing in the city of Ottawa, Ontario. Fourteen family caregivers were recruited. Participants were recruited from the Pain and Symptom Management Team at Élisabeth Bruyère Health Centre (EBHC), Sisters of Charity of Ottawa (SCO) Health Service, the Palliative Care Unit at EBHC, and the Family Support Group Program offered by the Hospice at May Court. The plan was to recruit 20 participants for this pilot study. This number was sufficient in the study done by Murray, O'Connor, Fiset, and Viola (2003).

3.3 Eligibility Criteria

Persons eligible for recruitment to this study were:

1) Adults, 18 years or older,
2) Living in the City of Ottawa, which includes Cumberland, Gloucester, Goulbourn Township, Kanata, Nepean, Osgood Township, Ottawa, Rockcliffe Park, Rideau Township, Vanier, and West Carleton Township,
3) Able to participate in an English language interview,

4) Family caregivers of patients who were diagnosed with a terminal illness (life expectancy 9 months or less) as defined by the attending physician, and whose prognosis does not indicate imminent death,
5) Assessed by a palliative care clinician to be physically, emotionally, and cognitively able to participate, and
6) Had given voluntary, informed consent to participate.

3.4 Setting

The SCO Health Service has a 36-bed Palliative Care Unit (PCU) where patients are admitted for terminal care and for short-term pain and symptom management. The number of total admissions for fiscal year 2003-04 was 384 and total discharges was 380 (Sisters of Charity of Ottawa Health Service, 2004). The mean length of stay for patients in 2003-04 was 31.1 days (Sisters of Charity of Ottawa Health Service, 2004). Total admissions for fiscal year 2004-05 was 419 and total discharges was 426 (Sisters of Charity of Ottawa Health Service, 2005). The mean length of stay for patients in 2004-05 was 27.1 days (Sisters of Charity of Ottawa Health Service, 2005).

The SCO Health Service also houses the Pain and Symptom Management Team (PSMT), an interdisciplinary regional resource that provides palliative care consultation to assist and support primary care doctors and nurses in the community. The PSMT provides in-home palliative consultation to non-ambulatory palliative care patients in the Ottawa-Carleton region who live at home, in rest/retirement homes or in long term care facilities. In the fiscal year 2003-04, the PSMT visited 304 new patients and made 694 follow-up visits. In the year 2004-05, the PSMT saw 309 new patients, and made 663 follow-up visits (M. Bouvette, personal communication, June 7, 2005).

The Hospice at May Court (2005) is a community-based organization in Ottawa, Ontario committed to providing support and practical help for people and their families who are facing a life-threatening illness, regardless of age, religion or culture. The hospice offers a Family Support Program, through which family members caring for someone diagnosed with a life threatening illness may participate in a weekly evening support group, attend individual or family sessions with the program coordinator, and/or receive bereavement support. In 2004, 139 family caregivers were admitted to the Family Support Program, and

117 individuals were admitted for bereavement support (A. Bailliu, personal communication, June 9, 2005). In 2004, attendance for the weekly evening support group was 161 family caregivers and 192 individuals in bereavement (A. Bailliu, personal communication, June 9, 2005).

3.5 Measures and Procedures

A semi-structured questionnaire tool and a modified Decisional Conflict Scale (DCS) were used to yield interview data on participants' decision determinants. An expert panel validated development of the questionnaire and the modified DCS, and the tools were pre-tested. Following pre-testing, no changes were made to the questions; however, the order of the questions was revised.

The interview started with Questions 1, followed by Questions 5-7, then Questions, 2-4, and then 8-14. After Question 14, the participant was given the Decisional Conflict Scale to complete by him/herself. The remainder of the interview consisted of Questions 15-32. The rationale for changing the order of the questions after pre-testing is explained in Section 3.5.6: Revision of the Data Collection Process.

3.5.1 Questionnaire Development

Appendix A illustrates the semi-structured study questionnaire used to elicit participants' decisional needs. The questionnaire was adapted from Murray, O'Connor, Fiset, and Viola's (2003) participant interview questionnaire, which focused on female terminally ill patients and location of care in the last weeks of life, and from the Standard Needs Assessment Interview Tool (Jacobsen & O'Connor, 1998), which is based on the Ottawa Decision Support Framework (O'Connor et al., 1998). The study questionnaire, consisting of 32 questions regarding perceptions of the decision, perceptions of others, personal and external resources to make the decision, and characteristics of the participant and ill family member, was tailored specifically for the study.

Under 'perceptions of the decision', the family caregiver's knowledge, expectations, values, decisional conflict, stage of decision making, and predisposition were measured. Under 'perceptions of others', the opinions of others were measured, as well as the amount of the support available to the caregiver, the amount of pressure felt, and the preferred and actual roles in decision making. The 'resources' measured were previous experience and information and instrumental help needed to make and implement a decision. Previous experience was not formally defined in the questionnaire, but could include previous experience with caring for the terminally ill, and/or previous experience making a similar decision. 'Personal characteristics' included the family caregivers' age, gender, and education, and the patient's medical prognosis, current location of care, and living situation were also measured.

Potential responses for semi-structured study questions were used as probes during the interview. The potential responses were based on: the standardized needs assessment interview tool (Jacobsen & O'Connor, 1998); Singer, Martin, and Kelner's five domains of quality end-of-life care (1999); and probes previously used in Murray, O'Connor, Fiset, and Viola's study on decision making needs of terminally ill women regarding place of care at the end of life (2003). Potential probes were also based on personal clinical palliative care experience, and advice from a panel of palliative care and decision support experts.

3.5.2 Scales to Measure Patients' Physical Functioning

The Eastern Cooperative Cancer Chemotherapy Group (ECOG) Scale (Zubrod et al., 1960) measured the family caregiver's perception of the ill family member's physical performance capacity. The ECOG performance status scale is a 5 point Likert scale rated from 0 to 4: '0' for normal activity; '1' for almost fully ambulatory; '2' for needing to be in bed for less than half of the day; '3' for needing to be in bed for more than half of the day; and '4' for being unable to get out of bed. The ECOG scale is well recognized among clinicians and used extensively in health studies. For example, in a study examining the influencing factors of place of death among home care patients with cancer in Taiwan (Tang, 2002), the ECOG scale was used to measure patients' functional status. In a study examining the use of red blood cell transfusions in terminally ill cancer patients admitted to a palliative care unit (Monti, Castellani, Berlusconi, & Cunietti, 1996), the ECOG scale was used to measure participants' pre-transfusion performance status.

The family caregiver's perception of the ill family member's level of confusion was measured using the Confusion Rating Scale (CRS) (Gagnon, Allard, Masse, & DeSerres, 2000). The CRS comprises four items: 1) Disorientation, such as verbal or behavioural disorientation to person, place, or time, 2) Inappropriate behaviour, such as pulling at tubes or dressings, or attempting to get out of bed, 3) Inappropriate communication, such as incoherence or uncommunicative, nonsensical, or unintelligible speech, and 4) Illusions or hallucinations, such as seeing or hearing things that are not there or distortions of visual objects (Gagnon, Allard, Masse, & DeSerres, 2000). Each of the four behaviors was coded as 0 for "behavior not present," 1 for "behavior present, but mild," or 2 for "behaviour present, and pronounced".

In the clinical use of the CRS, the nurse assesses the duration and intensity of each symptom at the end of each work shift and codes each behavior from 0 to 2 to reach a final CRS score of 0 to 8. The patient is positive on CRS screening with a score of 2 or higher. The CRS has previously been used. In a study determining delirium frequency and outcome in cancer patients consecutively hospitalized for terminal care, screening for delirium symptoms was performed using the CRS (Gagnon, Allard, Masse, & DeSerres, 2000). In another study, researchers evaluated the incidence of delirium following cataract surgery in community-dwelling patients using the CRS (Milstein, Pollack, Kleinman, & Barak, 2002).

The sensitivity and specificity of the CRS are 0.762 and 0.816 respectively (Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005). Sensitivity, or the true positive rate, is defined as the likelihood that a patient with a given disease will have a positive test result (DeKeyser & Pugh, 1997). Specificity, or the true negative rate, is the probability that a patient without the disease will have a negative test result (DeKeyser & Pugh, 1997). No test has 100% sensitivity and specificity, and a test that has higher specificity usually has lower sensitivity (DeKeyser & Pugh, 1997).

3.5.3 Modified Decisional Conflict Scale (DCS)

A modified Decisional Conflict Scale (DCS) (O'Connor, 1995), illustrated in Appendix B, was used to measure participants' decisional conflict, defined as the uncertainty about choosing among alternatives (O'Connor et al., 1998). The DCS also elicits modifiable factors contributing to uncertainty, such as feeling: 1) uninformed about options, advantages, and disadvantages, 2) unclear about values concerning the advantages and disadvantages, and 3) unsupported in decision making (O'Connor et al., 1998). The DCS is a 12 item, 5 point Likert scale with responses ranging from "strongly agree" to "strongly disagree" with a midpoint of "neither agree nor disagree". Scores below 2.00 indicate lower decisional conflict. Scores that exceed 2.50 usually corresponds to uncertainty and delay in decision making.

The psychometric properties of the DCS have been evaluated with 909 individuals deciding about influenza immunization or breast cancer screening (O'Connor, 1995). A sub sample of respondents was retested two weeks later. The test-retest reliability coefficient was 0.81, and internal consistency coefficients ranged from 0.78 to 0.92. The psychometric properties of the scale were found to be acceptable, and the scale feasible and easy to administer (O'Connor, 1995). Subsequently, the scale has been used in a variety of clinical contexts including palliative care.

3.5.4 Validation of the Questionnaire by an Expert Panel

Decision support and palliative care professionals familiar with the Ottawa Decision Support Framework validated the questionnaire by reviewing and commenting on the interview questions. The expert panel consisted of Dr. Annette O'Connor (Canada Research Chair in Health Care Consumer Decision Support; Full Professor, University of Ottawa), Dr. Jo Logan (Associate Professor, University of Ottawa; Affiliate Member of the Ottawa Health Research Institute), and Ms. Mary Ann Murray (Advanced Practice Nurse in Palliative Care, Élisabeth Bruyère Health Centre, SCO Health Service). The expert panel provided feedback on content, face validity, and methodological weaknesses.

3.5.5 Pre-Testing of Data Collection Tool

The data collection process was pre-tested on a sample of 3 study participants. The purpose of the pre-test was to test interview questions for clarity and ease of understanding, determine the time required to complete the interview, test the sequence of questions in preparation for the main research study, and assess interview burden on the participants. There were no concerns raised about the clarity or ease of understanding the interview questions (Appendix A) or the Decisional Conflict Scale (Appendix B) during pre-testing.

3.5.6 Revision of the Data Collection Process

No editing changes were made to the study questionnaire (Appendix A) or the modified Decisional Conflict Scale (Appendix B) after the pre-test interviews; however, the sequence of questions asked in the study questionnaire was changed. When asked, "Have you thought about where your family member would like to receive care during the last days or weeks of life?" (Question #1), participants immediately engaged in conversation regarding possible options for place of care (Question #5: "What do you see as the main options for where your family member would like to receive care during the last days or weeks of life?"). The discussion was directed back to the original sequence of questions, but the flow of the conversation and the participants' train of thought were interrupted. Following the pre-test interviews, Question #1 was asked first, followed by Questions #5, #6, and #7, and then Question #2 and the remainder.

Three participants not part of the pre-testing experienced some confusion with the Decisional Conflict Scale (DCS) or had comments to share. One participant found part of the introductory statement "the choice regarding where your terminally ill family member would prefer to receive care" confusing because during previous study questions, the differentiation between the participant's preference and the participant's opinion of the patient's preference had been made. The statement was not clear in describing whose preference was to be considered when completing the DCS. The researcher notes that to minimize confusion, the introductory statement should have read, "the decision regarding place of care at the end of life" to indicate that the decision as a whole was to be considered. There were two comments about Statement #1. One comment was to add a new statement, "I am comfortable with this decision" following Statement #1, while another comment was to divide Statement #1 into two components, "1a: This decision is easy to make with respect to the last days of life," and "1b: This decision is easy to make with respect to the last weeks of life."

3.6 Ethics

Ethics approval was granted from both the University of Ottawa and the Sisters of Charity of Ottawa (SCO) Health Service Research Ethics Board to recruit study participants from the SCO Health Service. Following SCO Health Service guidelines, in order to protect patient privacy, only members of the health care team initiated contact with potential participants. As no treating clinician or clinical team member is allowed to actively recruit participants into a study, treating clinicians or team members approached a potential participant to ask permission for the researcher to make contact if interested to learn more about the study. The researcher made follow-up contact to share more information about the study and described informed consent. Appendix C illustrates the Participant Consent Form.

In February 2004, permission was granted from the Executive Director of the Hospice at May Court to recruit study participants from the Family Support Program. Copies of the Letter of Permission and a modified Participant Consent Form for the new setting were forwarded to the University of Ottawa Research Ethics Board. Appendix D illustrates the modified Participant Consent Form for the Hospice at May Court.

Participants were reminded at the interview that they were under no obligation to participate, their participation was voluntary, if they did take part, they could withdraw at any time, and that participation or lack of participation would have no effect on the quality of care their ill family member receives. Information they share would be kept confidential. However, the researcher could have breached confidentiality if information regarding potential or imminent harm or abuse to them or others is disclosed. For their safety and the safety of others, the researcher would share this information with the palliative care team caring for their ill family member.

Participants were made aware that code numbers would be assigned to all data, that data would be stored in a locked filing cabinet, and that on any publication or presentation, no personal identifying information would appear. Although quotations from interviews were used, no personal information appeared with these quotations. Study participants were informed that the time required to complete the interview would be approximately 45-60 minutes.

3.7 Data Preparation and Analysis

All the interviews were transcribed verbatim and analyzed using content analysis and descriptive statistics, such as frequencies. A data set was constructed using SPSS Version 11.0 software. Data was numerically coded and entered into the data file. Following data entry, data was cleaned and frequency distributions and descriptive analyses were performed for each variable.

Content analysis was chosen to explore study participants' responses to the semi-structured questions. Content analysis is a data reduction technique where large volumes of information are reduced into a smaller number of categories with similar meanings (Weber, 1985). Traditional content analysis is a quantitative approach, where the emphasis is on counts and frequencies, with greater frequency equated to greater significance. However, it can also be used in a more qualitative way where emergent codes and themes are identified (Patton, 1990). A quantitative approach was used in this study as an *a priori* coding scheme rather than an emergent or inductive approach.

Coding of participants' responses was deductive using the ODSF. For outcome expectations, (e.g. advantages and disadvantages of place of care options), the deductive codes were derived from five domains of quality end-of-life care identified in a previous health study: 1) receiving adequate pain and symptom management, 2) avoiding inappropriate prolongation of dying, 3) achieving a sense of control, 4) relieving burden, and 5) strengthening relationships with loved ones (Singer, Martin, & Kelner, 1999). To illustrate and provide further context to the pre-categorized responses, specific quotes were selected from the transcribed interviews. No single participant was quoted more than once per outcome measure.

Of the 14 participants, 99 responses for outcome expectations were provided. Multiple participants repeated some responses, and the 99 responses were reduced to 56 segments. Each segment represented a different advantage or disadvantage of an option considered, regardless of how frequently it was reported. In order to ensure the comprehensiveness and appropriateness of the content analysis, the researcher and a member of the thesis committee, Mary Ann Murray, independently coded the segments and then organized them into Singer, Martin, and Kelner's (1999) five domains of quality end-of-life care. These domains have been previously used in a health study as an *a priori* coding scheme. Murray, O'Connor, Fiset, and Viola (2003) used this coding scheme to examine the decision making needs of terminally ill women regarding place of care in the last days or weeks of life.

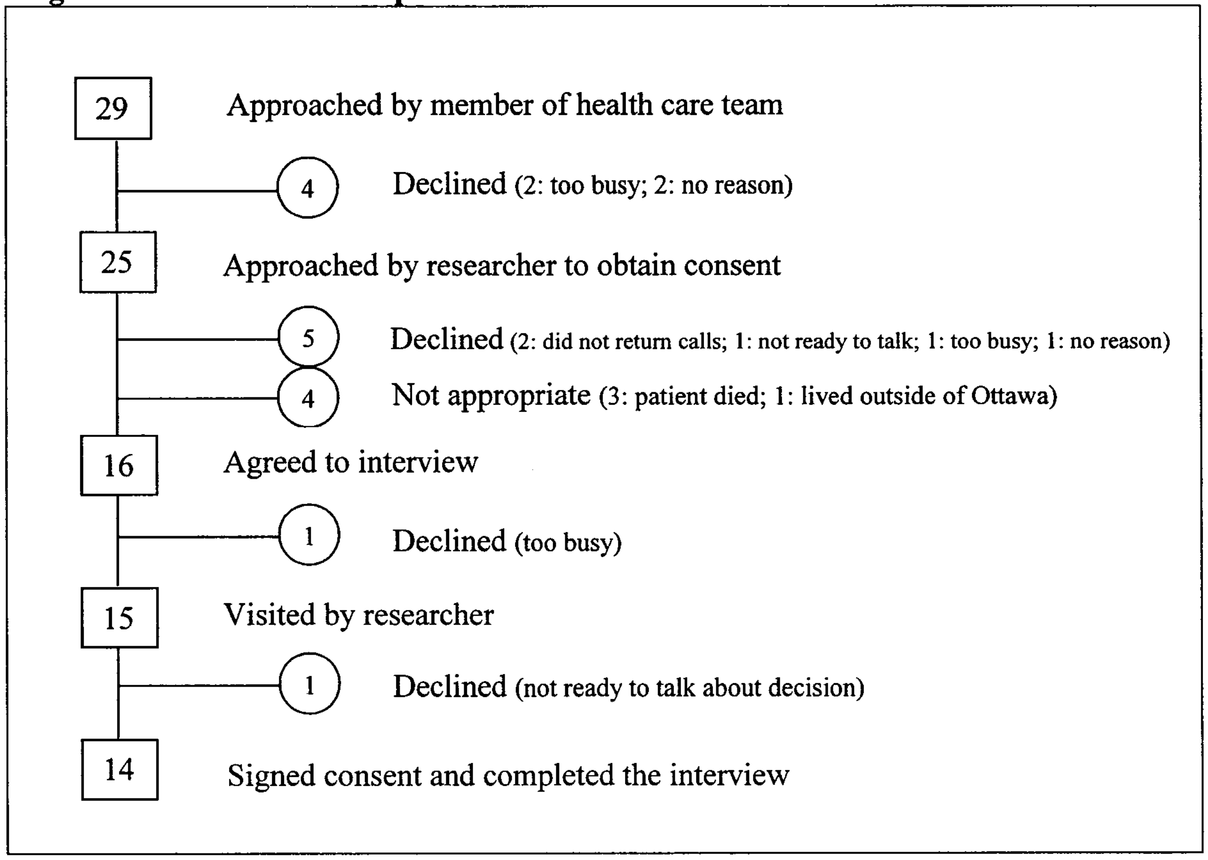
Cohen's (1960) kappa statistic was chosen as a reliability estimate because it accounts for chance agreement between coders. Kappa values range from 1, perfect agreement, to 0, no agreement other than what would be expected by chance. Of the 56 coded segments of information, the coders agreed on 52. The kappa value (k =0.86) indicated excellent agreement. Discrepancies were resolved through discussion and re-alignment of interpretive differences.

CHAPTER FOUR - RESULTS

4.1 Recruitment and Interview Completion

Participants were recruited from December 2, 2003 to March 22, 2004. Figure 2 illustrates the accrual and completion rates. Of 29 family caregivers approached by a member of the health care team, 25 agreed to be approached by the researcher, and 14 gave consent and were interviewed.

Figure 2: Accrual and Completion Rates



The interviews took 45 to 60 minutes to complete and were completed in one sitting. Three participants were tearful during the initial stages of the interview and the interview was stopped briefly. The 3 participants wished to continue with the interview, were able to do so, and at the end the interview, showed no signs of distress or discomfort. Participants were reminded that their copy of the consent form contained contact information in case they were in need of support after the interview, but the researcher did not receive any calls.

4.2 Characteristics of the Sample

Figure 3 illustrates the age range of the participants, and Table 2 illustrates their characteristics. The typical participant was recruited from the community, female, a high school graduate, married or living common-law, retired, and living at home with the terminally ill patient. The typical terminally ill patient had a prognosis of less than three months, had been diagnosed 1 to 2 years prior to the time of the interview, was unable to get out of bed, was being cared for at home (because home was preferred), and was in stable enough condition to remain at home.

Figure 3: Age of Participants

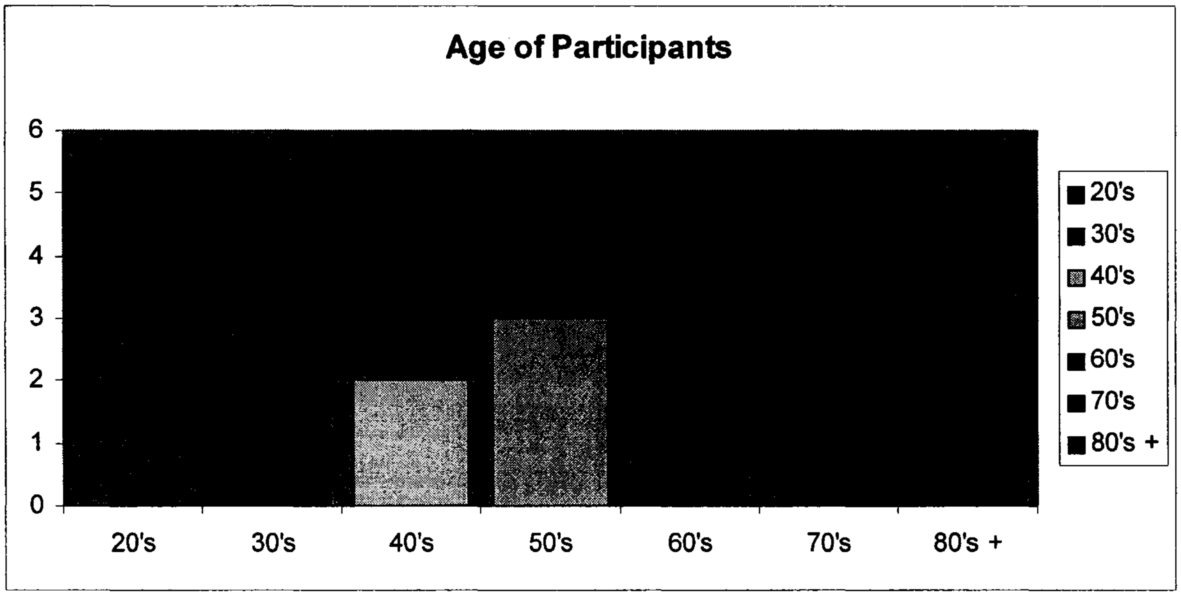


Table 2: Characteristics of the Sample (n=14)

Variable	Frequency	Variable	Frequency
Recruitment Location		**Lives Alone**	
Palliative Care Unit	4	Yes	0
Community	10	No	14
Age (in years)		**Lives With Terminally Ill Patient**	
30-39	2	Yes	13
40-49	2	No	1
50-59	3		
60-69	5	**Prognosis of Patient**	
70-79	0	<3 months	5
80+	2	3-5 months	2
		6+ months	3
Gender		Not Known	4
Male	4		
Female	10	**Time since Diagnosis**	
		>2 years	4
Highest Education Attained		1-2 years	5
Grade School	2	7-11 months	0
High School Diploma	6	4-6 months	1
College Diploma	1	<3 months	4
University Degree	5		
		Current Place of Care	
Marital Status		Palliative Care Unit	3
Single	3	Private Home	11
Married or Common-law	8		
Divorced or Separated	2	**Reason for Current Place of Care**	
Widowed	1	Preferred	8
		Condition stable enough for home	1
Employment Status		Preferred and stable condition	5
Full-time	4		
Part-time	1	**Power of Attorney (POA)**	
Unemployed	1	None, not discussed	0
Full-time Homemaker	2	Currently being discussed	3
Retired	6	Family caregiver has POA	9
		Family member not providing care has POA	2
Occupation			
Clergy	1	**Family Caregiver's Perception of Patient's Physical Ability**	
Clerk	1	Normal Activity	1
Heavy Equipment Operator	2	Symptoms, but nearly full ambulatory	3
Homemaker	2	Needs to be in bed <50% of usual day	3
Labour Relations Negotiator	1	Needs to be in bed >50% of usual day	2
Manager	1	Unable to get out of bed	5
Physiotherapist	1		
Public Servant	3		
Sales Representative	1		
Veterinary Technician	1		

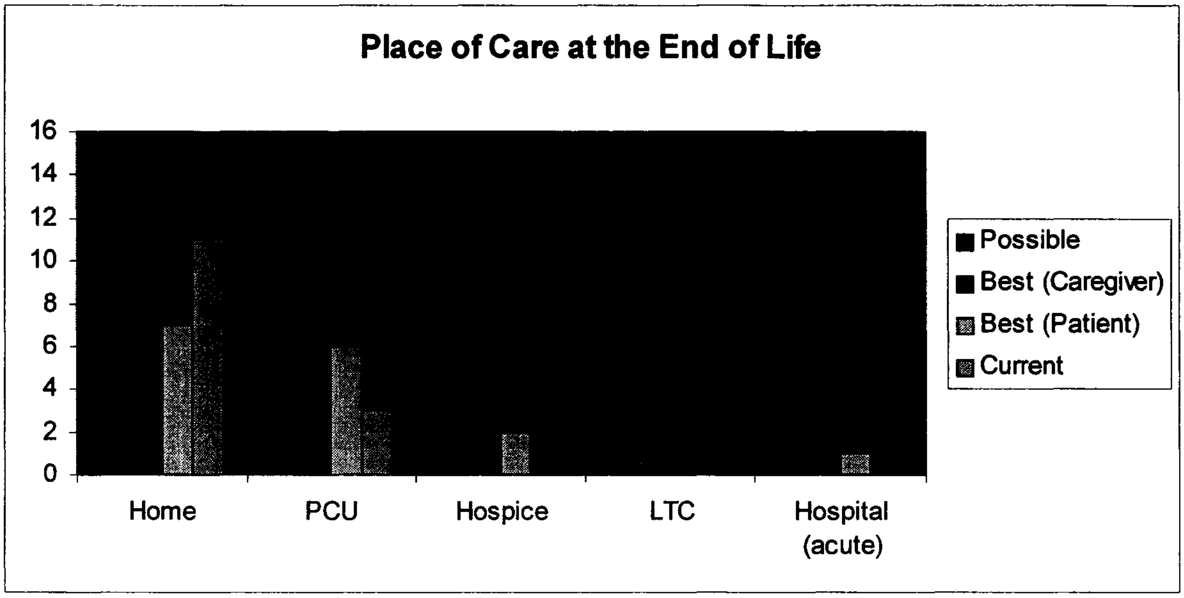
Table 2: Characteristics of the Sample (n=14) Continued

Variable	**Frequency**	**Variable**	**Frequency**
Family Caregiver's Perception of Patient's Level of Disorientation		**Family Caregiver's Perception of Patient's Level of Inappropriate Communication**	
Behavior not present	10	Behavior not present	10
Behavior present, but mild	2	Behavior present, but mild	2
Behavior present, and pronounced	2	Behavior present, and pronounced	2
Family Caregiver's Perception of Patient's Level of Inappropriate Behavior		**Family Caregiver's Perception of Patient's Level of Illusions/Hallucinations**	
Behavior not present	11	Behavior not present	12
Behavior present, but mild	2	Behavior present, but mild	2
Behavior present, and pronounced	1	Behavior present, and pronounced	0

4.3 Perception of the Decision

As Figure 4 illustrates, study participants' perception of possible options for place of care at the end of life include home, palliative care unit (PCU), a hospice, long term care facility, and hospital. All 14 participants identified PCU as a possible option for place of care, while 11 participants identified home, and 10 participants identified hospice. Home and PCU were equally perceived among participants as the best place of care with 7 participants choosing either. Regarding participants' perception of the patient's opinion on the preferred or best place of care, 7 participants selected home while 6 participants thought the patient would have considered PCU as the best place of care.

Figure 4: Place of Care at the End of Life

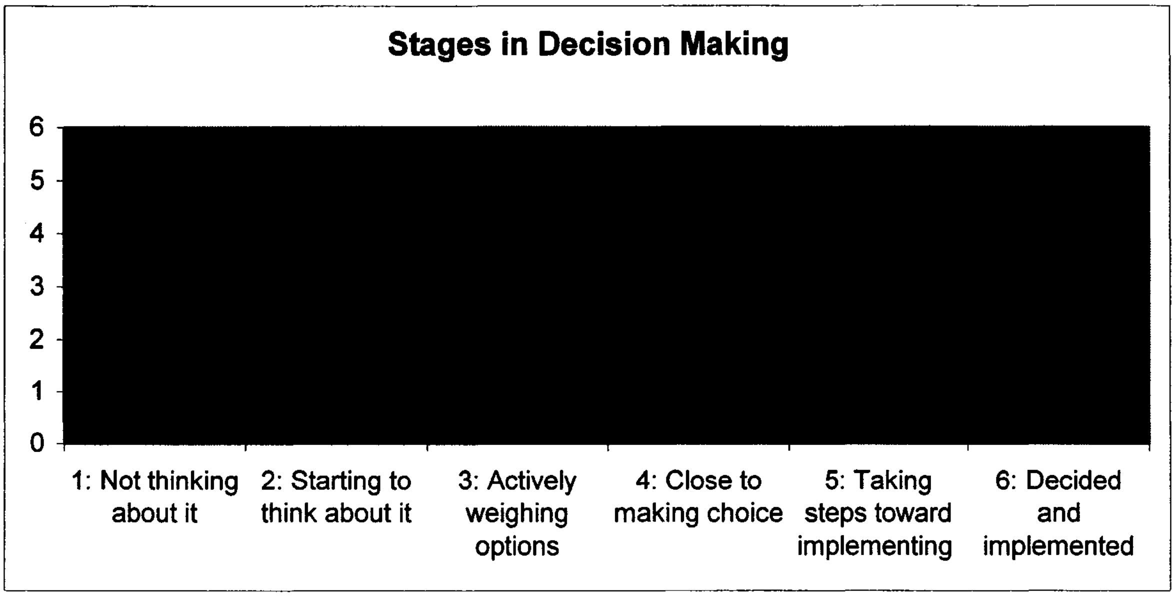


One participant stated, “I discussed it with my mother extensively over the course of her illness...and she said she wanted to die in the hospital because she felt that if she died at home...it would be too difficult for my family and for me to look after her in her bedroom.” Another participant stated, “She definitely wants to stay at home for as long as she is able to, if not for the whole duration. She is fairly adamant about that.”

4.3.1 Stage of Decision Making

There are six stages of decision making: 1) not thinking about it, 2) starting to think about it, 3) actively weighing the options, 4) close to making a choice, 5) taking steps toward implementing the decision, and 6) already decided and implemented. As illustrated in Figure 5, 4 participants were in Stage 3 and were actively weighing the options, such as discussing options regarding place of care with health care professionals. Five participants were in Stage 5 and were taking steps toward implementing the decision, such as completing application forms for admission to PCU or hospice. Five participants were in Stage 6 of decision making, had already decided on the place of care at the end of life, and had carried out the decision.

Figure 5: Stages in Decision Making



Some participants acknowledged that the decision still depended on the patient's condition. One participant, who was in Stage 5 of decision making, stated,

> *"It's one day at a time...right now, the decision is the palliative care unit. With brain mets, she could sleep and not wake up, and she would be gone [at home]. For me, the jury is still out, it depends on her medical condition."*

Participants also acknowledged that the decision may also depend on the availability of a bed in a facility. One participant, who was also in Stage 5 of decision making, stated, "*I think I would prefer hospice, but as long as she has somewhere to go, it will depend on availability and her needs. If one [facility] was available and the other [facility] wasn't, then I would rather her go wherever [a bed] was available.*"

4.3.2 Decisional Certainty

As illustrated in Figure 6, 11 study participants were 'very sure' about their decision while 3 were either 'somewhat sure' or 'unsure'. Nine participants perceived the terminally ill patient to be 'very sure' about the decision, while 5 participants perceived the patient to be either 'somewhat sure' or 'unsure'.

Figure 6: Certainty Regarding Decision Making

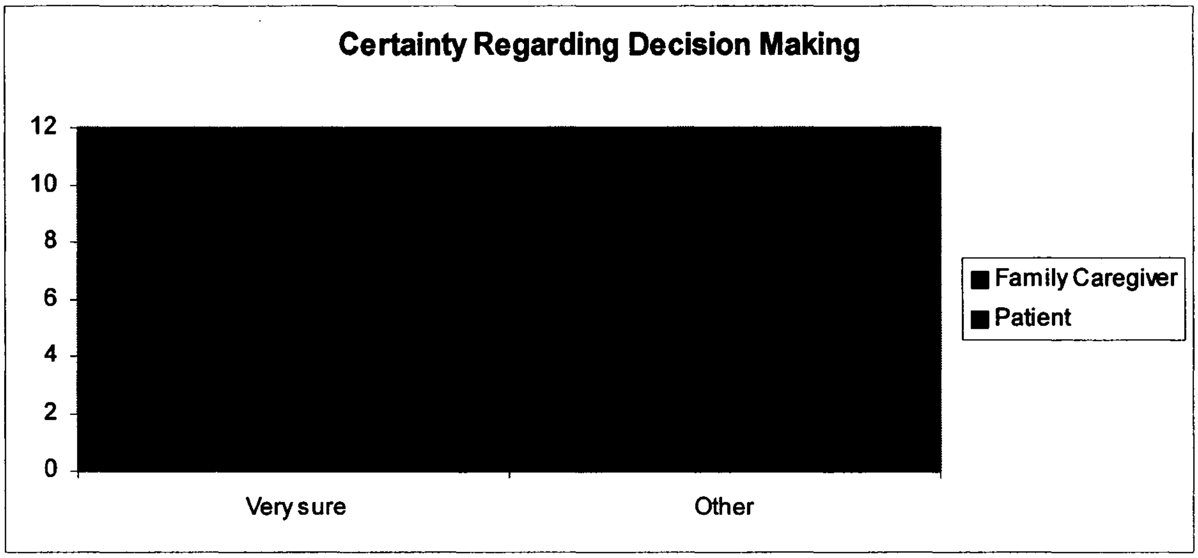


Table 3 illustrates participants' feelings regarding their certainty about the decision regarding place of care. A majority of participants were sure about what decision to make, and again, a majority reported that the decision was easy to make. One participant said, "*It certainly wasn't [difficult] for me... [or] for my wife.*" Another participant said, "*It wasn't very difficult to make...because that was what my mother wanted...I talked about it in length with my mother long ago when she was still feeling optimistic.*" Other participants' comments were, "*It wasn't a hard decision to make at all*" and "*Actually, there were no if's or but's about making the decision, it was an easy decision to make.*"

Table 3: Decisional Certainty regarding Choice for Place of Care at the End of Life

Decisional Conflict Scale	**VARIABLE**	**FREQUENCY**
• **Certainty Subscale Items**	**Easy Choice**	
	Strongly agree/agree	10
	Neither agree nor disagree	3
	Disagree/Strongly disagree	1
	Sure About What to Do	
	Strongly agree/agree	13
	Neither agree nor disagree	1
	Disagree/Strongly disagree	0
	Clear about Best Choice	
	Strongly agree/agree	11
	Neither agree nor disagree	2
	Disagree/Strongly disagree	1

A minority of participants found the decision difficult to make, and cited some reasons as a lack of information regarding the options as to place of care, the advantages and disadvantages of the options, and the patient's prognosis. Other reasons included feeling pressure and lacking support from others. One participant said, *"I think what makes this decision difficult is that making the decision enforces the reality. That's what makes it difficult."* Another participant said, *"What makes it difficult is that you know she is going to die...that's the most difficult thing. That's the hard part. You are helpless."*

Table 4 illustrates a comparison of the decisional conflict scores for the certainty subscale with decisional certainty and stage of decision making. Scores below 2.00 indicate lower decisional conflict. Scores that exceed 2.50 usually corresponds to uncertainty and delay in decision making.

Table 4: Decisional Certainty, Stage of Decision-Making, and Decisional Conflict Scores (Certainty Subscale)

		Decisional Conflict Rating	
Caregiver's Certainty about Decision	**Frequency**	**Certainty Subscale (Median)**	**Total Decisional Conflict (Median)**
Very sure	11	1.00	1.25
Other ('somewhat sure' and 'unsure' combined)	3	2.33	2.08
Stage of Decision Making			
Early (Stages 1, 2, and 3)	4	2.50	1.96
Later (Stages, 4, 5, and 6)	10	1.00	1.25

For the purpose of analysis, the six stages of decision making (as illustrated in Figure 5) were collapsed into two categories:

1. Early Stages (Stage 1 - not thinking about the decision; Stage 2 - starting to think about decision; and Stage 3 - actively weighing the options), and
2. Later Stages (Stage 4 - close to making a decision; Stage 5 - taking steps toward implementing the decision; and Stage 6 - decided and carried out the decision).

The median score for the certainty subscale for decisional conflict among participants who were 'very sure' about their decision was 1.00, which is lower than the score for participants who were not 'very sure' at 2.33. The median score for total decisional conflict among participants who were 'very sure' about their decision was 1.25, which is lower than the score for participants who were not 'very sure' at 2.08. The median score for the certainty subscale score for decisional conflict among participants in later stages of decision making was 1.00, which is lower than the score for participants still in early stages at 2.50. The median score for total decisional conflict among participants in later stages of decision making was 1.25, which is lower than the score for participants still in early stages at 1.96.

4.3.3 Knowledge and Expectations

Table 5 illustrates participants' feelings regarding their knowledge about the possible options for place of care. As illustrated earlier in Figure 4, the most commonly identified options as to place of care at the end of life were home, PCU, and hospice. All 14 participants felt informed and aware of the options available. All but 1 participant felt informed about the advantages of each option. Twelve participants felt informed about the disadvantages of each option.

Table 5: Knowledge and Expectations regarding Choice for Place of Care

Decisional Conflict Scale	**VARIABLE**	**FREQUENCY**
• **Feeling Informed Subscale Items**	**Aware of the Options**	
	Strongly agree/agree	14
	Neither agree nor disagree	0
	Disagree/Strongly disagree	0
	Know the Pros of Options	
	Strongly agree/agree	13
	Neither agree nor disagree	1
	Disagree/Strongly disagree	0
	Know the Cons of Options	
	Strongly agree/agree	12
	Neither agree nor disagree	2
	Disagree/Strongly disagree	0

Table 6 illustrates a comparison of the decisional conflict scores for the information subscale with decisional certainty and stage of decision making. The median score for the information subscale for decisional conflict among participants who were 'very sure' about their decision was 1.67, which is lower than the score for participants who were not 'very sure' at 2.00. The median score for the certainty subscale score for decisional conflict among participants in later stages of decision making was 1.67, which is higher than the score for participants still in early stages at 1.50.

Table 6: Decisional Certainty, Stage of Decision-Making, and Decisional Conflict Scores (Information Subscale)

		Decisional Conflict Rating	
Caregiver's Certainty about Decision	**Frequency**	**Information Subscale (Median)**	**Total Decisional Conflict (Median)**
Very sure	11	1.67	1.25
Other ('somewhat sure' and 'unsure' combined)	3	2.00	2.08
Stage of Decision-Making			
Early (Stages 1, 2, and 3)	4	1.50	1.96
Later (Stages, 4, 5, and 6)	10	1.67	1.25

Table 7 illustrates the frequencies of participants' responses regarding expected outcomes for the possible places of care. Among the 14 participants, 99 responses for advantages and disadvantages of the options considered were identified and organized into five domains of quality end-of-life care: 1) receiving adequate pain and symptom management, 2) avoiding inappropriate prolongation of dying, 3) achieving a sense of control, 4) relieving burden, and 5) strengthening relationships with loved ones (Singer, Martin, & Kelner, 1999).

Table 7: Frequencies of Responses for Expectations of Advantages and Disadvantages of Options Considered

Variable	**Home**		**Palliative Care Unit**		**Hospice**		**Long Term Care Facility**		**Hospital**	
Total Response Frequency n=99	Pro n=18	Con n=15	Pro n=20	Con n=15	Pro n=10	Con n=8	Pro n=4	Con n=4	Pro n=2	Con n=3
Sense of Control n=38	14	1		9	6	5	1			2
Pain and Symptom Management n=30		4	16	1	2		1	4	2	
Relieving Burden n=24	3	10	3	3	2	2	1			
Strengthening Relationships n=7	1		1	2		1	1			1
Prolonging Death n=0										

The most frequently reported advantages involved 'receiving adequate pain and symptom management' with respect to the palliative care unit, followed by 'achieving a sense of control' with respect to home as the place of care. Participants cited 24-hour care, specialized palliative care, and caring staff as some of the advantages of the palliative care unit. One participant stated, "*They have it all there [the PCU]...support for yourself, the family, not just for the patient. It's all-inclusive.*" Advantages of home included being in comfortable, familiar surroundings, being cared for by family members who are familiar with the care required, and the satisfaction of fulfilling the patient's wish. A comment about home was, "*That's her request, and that's also my desire too. Because at home she is familiar with the surroundings...she's familiar with the noise...the sounds around her...I think she would be happier, much happier at home.*"

The most frequently reported disadvantages were concerns of 'relieving burden' with respect to home, followed by 'achieving a sense of control' with respect to the palliative care unit. Disadvantages of home as a place of care included physical and emotional stress on the caregiver, no immediate access to health care professionals, the patient considering him/herself as a burden, the constant reminders in the home if a home death does occur, and the concern for the emotional impact on young children. One participant commented, "*If I had other members of the family that would be here...it would be great. But I'm alone with him. If I go to the grocery store, I'm rushing, and rushing back. I think for one person, it is very difficult. I am so tired...I'm 85...the years are there.*" Disadvantages of the palliative care unit included lack of privacy, noise, an unfamiliar environment, parking costs, distance to travel, and that the palliative care unit was not the patient's wish. One participant stated, "*She had two roommates [at the PCU], and they both passed on right in the room. That depressed her. People were dying right beside her...in the next bed.*"

4.3.4 Values

Table 8 illustrates participants' feelings regarding their values about the possible options for place of care. All 14 participants were clear about how important the advantages were to them. Twelve participants were clear about how important the disadvantages were to them. Thirteen participants felt clear about which of the advantages or the disadvantages was most important to them.

Table 8: Values regarding Choice for Place of Care

Decisional Conflict Scale	**VARIABLE**	**FREQUENCY**
Values Subscale Items	**Clear about Importance of Pros**	
	Strongly agree/agree	14
	Neither agree nor disagree	0
	Disagree/Strongly disagree	0
	Clear about Importance of Cons	
	Strongly agree/agree	12
	Neither agree nor disagree	2
	Disagree/Strongly disagree	0
	Clear about What is Most Important	
	Strongly agree/agree	13
	Neither agree nor disagree	1
	Disagree/Strongly disagree	0

Table 9 illustrates a comparison of the decisional conflict scores for the values subscale with decisional certainty and stage of decision making. The median score for the values subscale for decisional conflict among participants who were 'very sure' about their decision was 1.67, which is lower than the score for participants who were not 'very sure' at 2.00. The median score for the certainty subscale score for decisional conflict among participants in later stages of decision making was 1.50, which is lower than the score for participants still in early stages at 1.84.

Table 9: Decisional Certainty, Stage of Decision-Making, and Decisional Conflict Scores (Values Subscale)

		Decisional Conflict Rating	
Caregiver's Certainty about Decision	**Frequency**	**Values Subscale (Median)**	**Total Decisional Conflict (Median)**
Very sure	11	1.67	1.25
Other ('somewhat sure' and 'unsure' combined)	3	2.00	2.08
Stage of Decision-Making			
Early (Stages 1, 2, and 3)	4	1.84	1.96
Later (Stages, 4, 5, and 6)	10	1.50	1.25

Table 10 illustrates the frequencies of responses among participants regarding what they considered as the most important advantages and disadvantages of the options being considered for place of care. The advantages most valued involved 'achieving a sense of control' with respect to home as the place of care, and 'receiving adequate pain and symptom management' with respect to the palliative care unit. One participant's comments about home were, "*She is getting the best care...she is getting looked after by me.*" Another participant's comments about home were,

> "*I can check on him every hour on the hour and I don't need to ask the nurse to look in on him. I know he's comfortable because I know him, and if there's anything that needs to be done, I know I can take care of it right away, unless it's an emergency.*"

Comments about the palliative care unit from 2 different participants were, "*The staff are very special people. They are very comforting and passionate and caring for their patients...making sure they get everything they want,*" and "*If urgent and immediate care were necessary, then she would be in the right place for that.*" The most important disadvantages were concerns of 'receiving adequate pain and symptom management' and 'relieving burden', both with respect to home as the place of care.

Table 10: Frequencies of Responses for the Participant's Most Valued Advantages and Disadvantages of Options Considered

Variable	**Home**		**Palliative Care Unit**		**Hospice**		**Long Term Care Facility**		**Hospital**	
Total Response Frequency n=29	Pro n=7	Con n=7	Pro n=5	Con n=3	Pro n=0	Con n=3	Pro n=1	Con n=1	Pro n=1	Con n=1
Pain and Symptom Management n=12		4	5				1	1	1	
Sense of Control n=9	7					1				1
Relieving Burden n=5		3		1		1				
Strengthening Relationships n=3				2		1				
Prolonging Death n=0										

Table 11 illustrates the frequencies of responses among participants regarding their opinion of what their terminally ill family members would consider as the most important advantages and disadvantages of the options for place of care. Similar to Table 10, the advantages most valued involved 'achieving a sense of control' with respect to home, and 'receiving adequate pain and symptom management' with respect to the palliative care unit.

The most important disadvantages were concerns of 'relieving burden' with respect to home, and 'achieving a sense of control' with respect to the palliative care unit.

Table 11: Frequencies of Responses for the Patient's Most Valued Advantages and Disadvantages of Options Considered from the Participant's Opinion

Variable	**Home**		**Palliative Care Unit**		**Hospice**		**Long Term Care Facility**		**Hospital**	
Total Response Frequency n=30	Pro n=8	Con n=4	Pro n=5	Con n=4	Pro n=2	Con n=3	Pro n=1	Con n=1	Pro n=1	Con n=1
Sense of Control n=16	8	1		3	1	2				1
Pain and Symptom Management n=8			4		1		1	1	1	
Relieving Burden n=4		3	1							
Strengthening Relationships n=2				1		1				
Prolonging Death n=0										

4.4 Perception of Others

4.4.1 Support

Table 12 illustrates participants' feelings regarding the support they received regarding decision making about the possible options for place of care. Thirteen participants felt that the decision was being made without any pressure from others. Twelve participants felt that they had the right amount of support for their roles in decision making. Twelve participants felt that they had enough advice about the options.

Table 12: Support regarding Choice for Place of Care

Decisional Conflict Scale	**VARIABLE**	**FREQUENCY**
Support Subscale Items	**Making Choice without Pressure**	
	Strongly agree/agree	13
	Neither agree nor disagree	0
	Disagree/Strongly disagree	1
	Making Choice with Support of Others	
	Strongly agree/agree	12
	Neither agree nor disagree	2
	Disagree/Strongly disagree	0
	Have enough Advice to make Choice	
	Strongly agree/agree	12
	Neither agree nor disagree	1
	Disagree/Strongly disagree	1

Table 13 illustrates a comparison of the decisional conflict scores for the support subscale with decisional certainty and stage of decision making. The median score for the support subscale for decisional conflict among participants who were ‘very sure’ about their decision was 1.00, which is lower than those who were not ‘very sure’ at 2.00. The median score for the certainty subscale score for decisional conflict among participants in later stages of decision making was 1.00, which is lower than the score for participants still in early stages at 2.00.

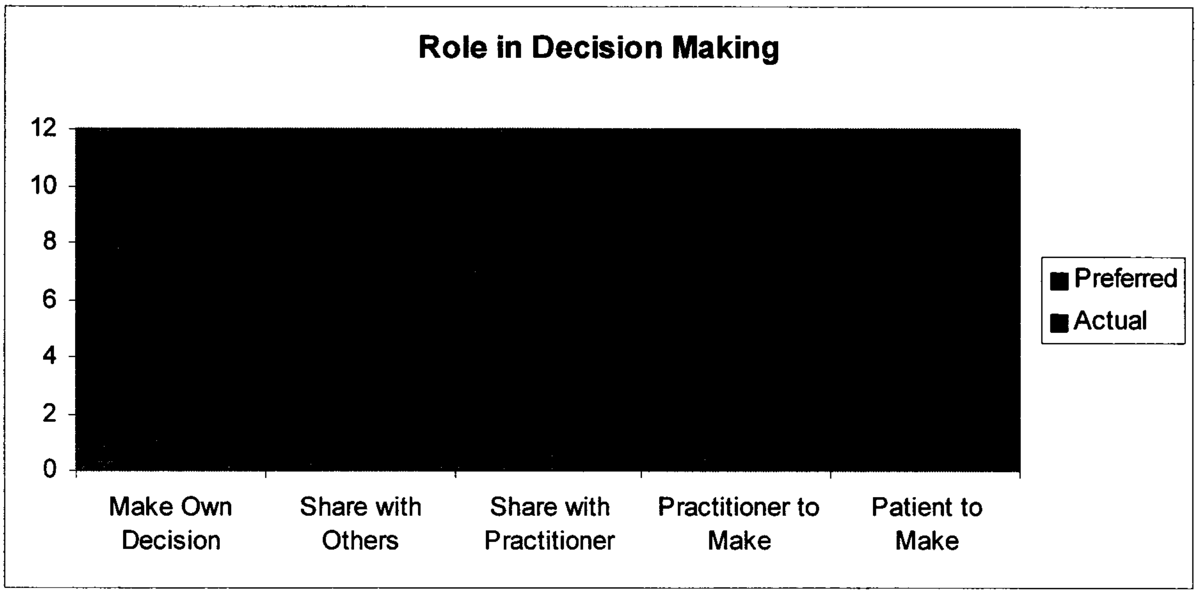
Table 13: Decisional Certainty, Stage of Decision-Making, and Decisional Conflict Scores (Support Subscale)

		Decisional Conflict Rating	
Caregiver’s Certainty about Decision	**Frequency**	**Support Subscale (Median)**	**Total Decisional Conflict (Median)**
Very sure	11	1.00	1.25
Other (‘somewhat sure’ and ‘unsure’ combined)	3	2.00	2.08
Stage of Decision-Making			
Early (Stages 1, 2, and 3)	4	2.00	1.96
Later (Stages, 4, 5, and 6)	10	1.00	1.25

4.4.2 Role in Decision Making

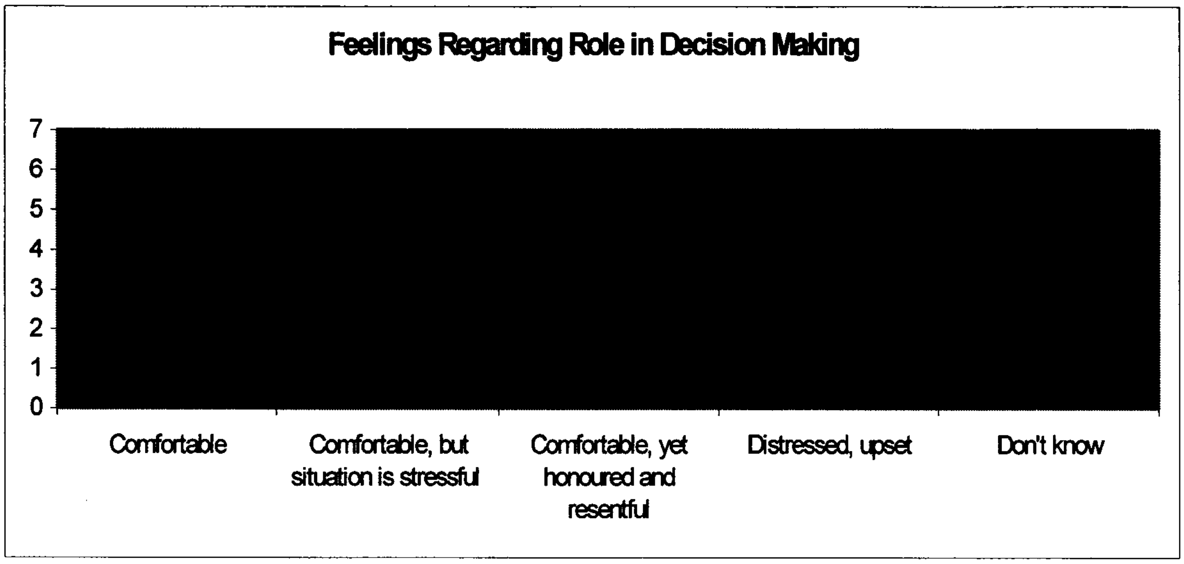
When asked about their preferred role in decision making, most participants responded that they prefer to share decision making with the patient after considering the opinion and advice of others, such as health care professionals and other family members. In reality, however, most were able to share the decision with their ill family member, but some had to make the decision on their own because the patient was too ill to be involved. Figure 7 illustrates participants' preferred and actual roles in decision making.

Figure 7: Role in Decision Making



Participants were asked how they felt about their role in decision making, as illustrated in Figure 8. The typical participant was comfortable with his or her role in decision making. One participant commented, *"I'm comfortable with it...there's no big concern...I have a fairly good understanding of what my father wishes and dislikes,"* while another participant stated, *"I feel comfortable with the role...I feel stressed with the nature of the decision."*

Figure 8: Feelings Regarding Role in Decision Making



One participant stated,

> *"I resent [my role in decision making], yet I am honoured. It's an imposition...why is [Dad] bailing and dumping this on me. But Mom relies on me, so I am honoured to fulfill this role. I don't feel quite appreciated...but I do feel comfortable with this responsibility."*

Another participant stated, *"I hate it...and every time I think about it, it just makes it difficult... I hate this...nothing is easy."*

4.5 Resources to Make the Decision

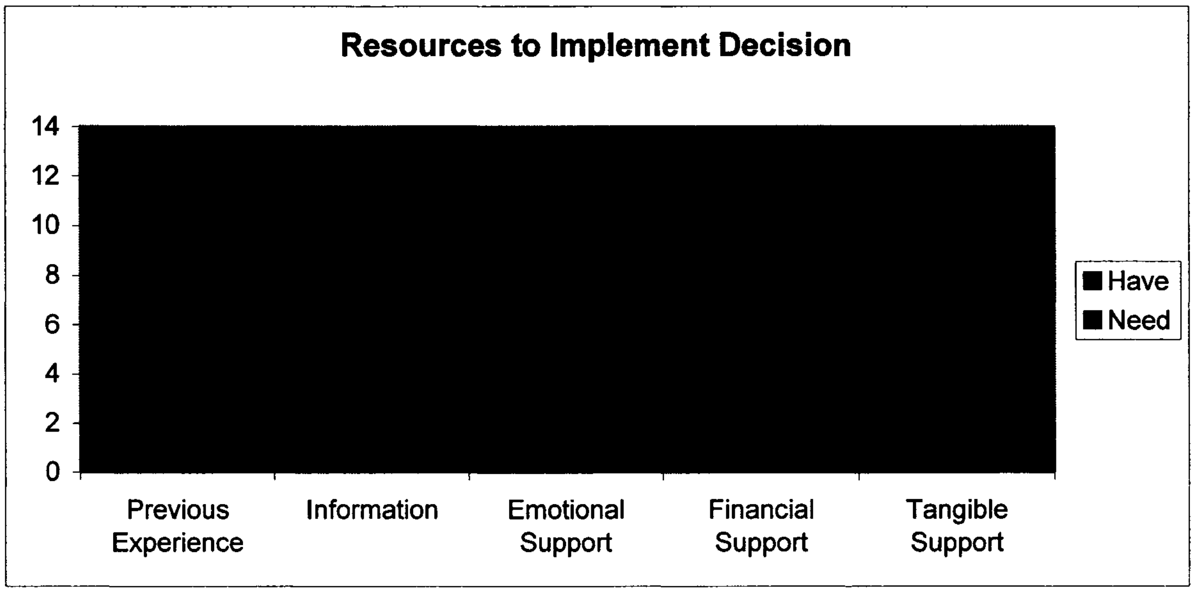
4.5.1 Resources on Hand

When asked about what resources they had to implement the decision, most participants responded that they had received information and emotional support, as illustrated in Figure 9. Some participants had financial support, tangible support, and personal experience to draw from. Tangible support refers to physical help such as a personal support worker visiting to help with meal preparation, bathing, and housework. Sources of support included health care professionals, friends, and family. One participant stated,

> *"I hope I don't leave anybody out. We have homecare...morning and evening homecare...a physiotherapist, an occupational therapist...we have the VON*

> *palliative care, we have our physician, we have the palliative care doctor, we have our church, and the people that come…we have a friend cleaning my house…we have a hospice volunteer…"*

Figure 9: Resources Available and Needed to Implement Decision



4.5.2 Resources Needed

When asked about what resources would be needed to carry out their choice, participants mentioned information, emotional support, financial support, and tangible support, as previously illustrated in Figure 9. The most frequently identified resource required was tangible support, mentioned by 7 participants. If tangible support were already in place, then more was needed. One participant commented, "*I think we need 2-3 hours of help everyday to take care of her. Right now, it's 1-2 hours a week. The compassionate care from the government care would not cover my mortgage.*" Another participant stated, "*We can't be taking more time off from work…we'd need a nurse to stay for longer.*"

While tangible support was identified most often, information, emotional support, and financial support were also identified as needed resources. One participant commented that "*the supportive encouragement to face reality…whether that's from medical people or from friends*" was needed.

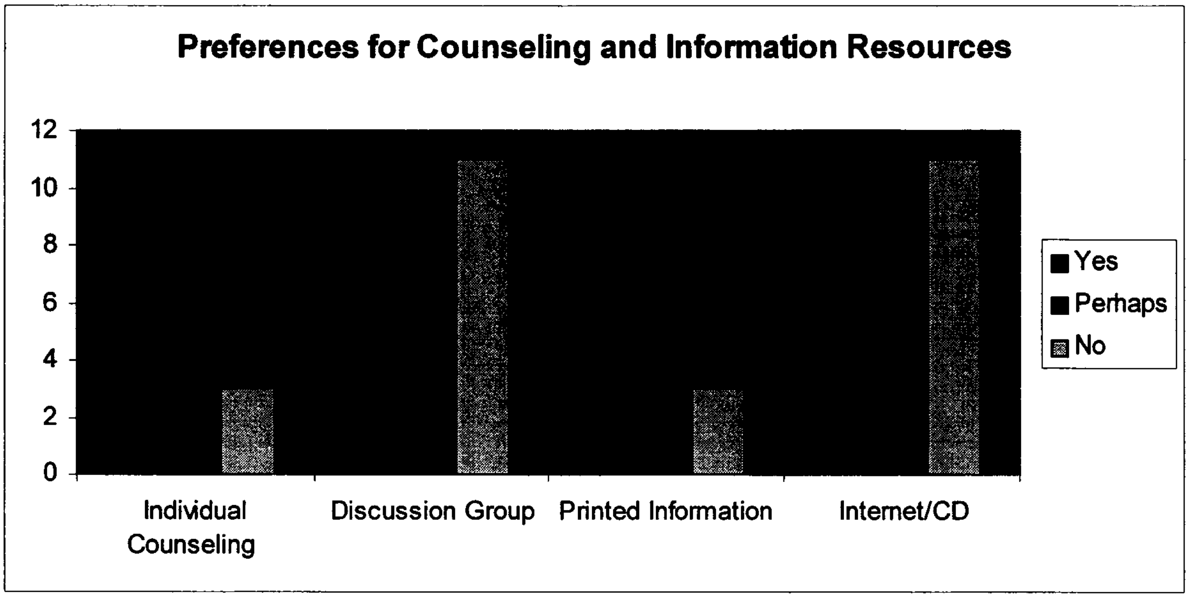
4.5.3 Preferences for Counseling and Information Resources

Figure 10 illustrates participants' preferences for sources of support and information considered helpful in decision making. When asked about what resources would be of use to them, a majority of participants indicated that one-to-one counseling with a health care professional knowledgeable and experienced in palliative care would be helpful. One participant commented,

> "*One of the biggest things that put pressure on me was being made to express my point in front of my father and brother. One thing [health care professionals] can do is let everyone to have their time in private…encourage people to speak what's truly on their minds…and then have a family meeting to work together.*"

Some participants stated that knowing what to expect would be appreciated, as well as a tour of the facilities considered for end-of-life care. Written information in booklet or pamphlet form would also be helpful. Most participants did not consider a discussion group beneficial given that each family situation is different. Information from the Internet or a CD program was not considered helpful either. When asked where printed information should be made available, participants suggested the cancer clinic, hospitals, physicians' offices, and/or the home care nurse. One participant stated that information should come from "*whichever health care professional makes first contact with the family when the patient is deemed terminal to discuss the options.*"

Figure 10: Preferences for Resources



4.6 Summary of Results

Fourteen of the 29 potential participants gave consent and were interviewed. Participants identified home, palliative care unit (PCU), hospice, long term care facility, and hospital as possible options for place of care at the end of life. Participants were equally divided between home and the PCU when identifying the best place of care. Regarding participants' perception of the patient's opinion on the best place of care, a slight majority selected home.

Participants fell almost equally into three of the six stages of decision making: Stage 3, actively weighing options; Stage 5, taking steps toward implementing the decision; and Stage 6, decided and carried out the decision. However, for the purpose of analysis, the six stages of decision making (as illustrated in Figure 5) were collapsed into two categories: Early Stages (stages 1, 2, and 3), and Later Stages (stages 4, 5, and 6). A majority of participants were 'very sure' about their decision, reported that the decision was easy to make, and perceived the patient to be also 'very sure' about the decision. Generally, participants who were 'very sure' of the best option for place of care reported less decisional conflict than those who were 'somewhat sure' or 'unsure'.

All participants felt informed of the options available, and a majority felt informed of the advantages and disadvantages of each option. Five domains of quality end-of-life care

(Singer, Martin, & Kelner, 1999) were used to categorize the advantages and disadvantages identified by the participants. Participants' most frequently reported advantages involved 'receiving adequate pain and symptom management' and 'achieving a sense of control'. The most frequently reported disadvantages were concerns of 'relieving burden' and 'achieving a sense of control'. Most to all of the participants felt clear about how important the advantages and disadvantages were to them, and which were most important.

A majority of participants felt that in making the decision, there was adequate support, sufficient advice, and no pressure from others. Most participants preferred to share decision making with the patient after considering the advice of others. However, in reality, some participants had to make the decision on their own because the patient's condition had deteriorated. Most participants had received information and emotional support to implement the decision, and the resource most needed to carry out the decision was tangible support. Some participants commented that a tour of the facility being considered for end of life care would have been helpful. Most participants indicated a preference for individual counseling and printed information, perhaps when the patient is first considered palliative, over discussion groups and information available from the Internet or computer program. Some participants commented that although resources were in place and a decision had been made, the decision might not be implemented if, for example, a hospital bed or tangible support were not available.

CHAPTER FIVE - DISCUSSION

5.1 Characteristics of the Sample

Six of the 14 participants, or 43%, had earned a college diploma or university degree, which is higher than the national average of 34% (Statistics Canada, 2001b). The participants' level of education may have had an effect on their perception of the decision, of others, and of resources to enact the decision. Level of education may influence employment opportunities and therefore earning potential, which may have an effect on the perception of available options. The impact of education, employment, and income on decisional determinants is an area for further study.

Though cultural background was not formally addressed in Section D of the questionnaire, 'Participant and perceived family characteristics', the researcher did observe that all of the study participants were Caucasian. The national average of Caucasian people is 87%, as 13% of the Canadian population in 2001 identified themselves as belonging to a visible minority group (Statistics Canada, 2005b). Visible minorities are defined by the Employment Equity Act as "persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour" (Statistics, Canada, 2003). Ethnic background may influence decisional determinants, such as expectations and values, and the impact is another area for further study.

5.2 Perception of the Decision

The number of participants who considered the PCU as the best place of care was slightly greater than the number of participants who believed that the PCU would have been chosen by patients as the best place of care. This may suggest that family caregivers and terminally ill patients may not necessarily share the same preference for place of care. A possible explanation for this finding is that the experience and burden of providing care may have influenced participants' preferences, given that a majority of the study participants were actively providing care to terminally ill family members at home during the time of the interview. Burdens of family caregiving include time and logistics, physical tasks, financial costs, emotional burdens and mental health risks, and physical health risks (Rabow, Hauser, & Adams, 2004). The personal characteristics and emotional strain of family caregivers may create barriers to placement of patients in appropriate care settings, leading family to inappropriately insist on or reject care in the hospital, long term care setting, home, or institutional hospice (Rabow, Hauser, & Adams, 2004).

5.2.1 Stage of Decision Making

A majority of participants were in later stages of decision making. A possible explanation is that because a majority of the patients had been diagnosed with a terminal illness for at least one year, the decision had already been considered. Perhaps if time since diagnosis had been shorter, more participants would have been in earlier stages of decision making.

5.2.2 Decisional Certainty

Generally, participants who were 'very sure' about the decision had lower decisional conflict scores for the certainty subscale than those who felt 'somewhat sure' or 'unsure'. This finding is consistent with results from other health decision making studies using the ODSF (Fiset, O'Connor, Evans, Graham, De Grasse, & Logan, 2000; Murray, O'Connor, Fiset, & Viola, 2003; Stacey, O'Connor, De Grasse, & Verma, 2003). As well, participants in later stages of decision making had lower decisional conflict scores than those in earlier stages. In this study, 'early' stages of decision making refers to: Stage 1, not thinking about the decision; Stage 2, starting to think about decision; and Stage 3, actively weighing the options. 'Later' stages refer to: Stage 4, close to making a decision; Stage 5, taking steps toward implementing the decision; and Stage 6, decided and carried out the decision. The finding of lower decisional conflict scores among participants in later stages of decision making than those in earlier stages might have occurred because individuals would perhaps experience less uncertainty after having already weighed the options, and therefore be in a position to make a decision, take steps towards implementation, and/or carry out the decision.

In a previous study using the ODSF, Murray, O'Connor, Fiset, and Viola (2003) found that participants in active stages of decision making had higher decisional conflict scores than those in earlier stages. Comparing the findings of this study and the present study may be difficult because the six stages of decision making are organized differently. The 2003 study divided the stages into 'preliminary' (Stages 1 and 2), 'active' (Stages 3, 4, and

5), and 'completed' (Stage 6). In this study, there were no participants in Stage 1 or 2 of decision making, therefore the stages of decision making were not organized as they were in Murray et al's study.

A majority of participants reported that the decision was easy to make. However, this finding was inconsistent with results from a previous health study conducted by Murray, O'Connor, Fiset, and Viola (2003), who found that most participants, who were terminally ill women, found the decision regarding place of care at the end of life difficult to make. A possible explanation for the inconsistency is that this study examined family caregivers of terminally ill patients, not the patients themselves. Murray, O'Connor, Fiset, and Viola reported that their terminally ill participants found the decision difficult to make because of concerns related to what could go wrong, independence, and impact on family members (2003). Perhaps the decision was easy for the participants in this study to make because as family caregivers, they did what was needed to meet their family members' needs. A strategy often seen in family caregivers' efforts to support their family members is to prioritize both the physical and emotional needs of the ill family member over their own needs (Meeker, 2004).

5.2.3 Knowledge and Expectations

Singer, Martin, and Kelner's (1999) five domains of quality end-of-life care guided the analysis of the study participants' expectant outcomes for the various options for place of care. The rank priority found in this study was inconsistent with results from the 1999 study, and also inconsistent with results from another study examining decision making needs of a terminally ill population (Murray, O'Connor, Fiset, & Viola, 2003). 'Relieving burden' was most frequently identified in Murray, O'Connor, Fiset, and Viola's study (2003), and 'avoiding inappropriate prolongation of dying' in Singer, Martin, and Kelner's study (1999). There are several possible explanations. This study described the perspective from the family caregiver, whose perception of burden is that of providing care, whereas the other studies described the patient's perspective, the perception of being a burden to others.

Another possible explanation is that the relatively small sample of this study limits the confidence of the rank priority, as the sample may not be representative of the population of family caregivers of terminally ill patients. Also, the level of the family caregivers' understanding of technological interventions is not known. Perhaps the study participants did not understand the scope of possible interventions, such as artificial nutrition and hydration, chemotherapy, radiation therapy, surgery, and intravenous medication, or perhaps advance directives (cardiopulmonary resuscitation orders) had already been established, and the concern for inappropriate prolongation of death was diminished. Further investigation is needed to determine if this finding is truly reflective of family caregivers' ranking of expectations.

5.2.4 Values

The domain of quality end-of-life care most valued by participants in this study was found to be 'adequate pain and symptom management' whereas 'achieving a sense of control' was most valued by their terminally ill family members, according to the participants' opinion. These findings are consistent with results from a previous study (Libbus & Russell, 1995), which found that patients considered the ability to care for themselves to be most important, whereas potential surrogate decision makers, such as family members, rated amount of pain as their first criterion in decision making when presented with hypothetical scenarios. Libbus and Russell (1995) also found that patients ranked burden on family as third most important, but surrogates did not choose this criterion at all. Other researchers also noted discrepancies in priority ranking. Hare, Pratt, and Nelson (1992) reported that patients considered "burden on family" and "time left to live" as the most important factors in choosing among difficult decision options, while surrogates identified the patients' pain as the most important factor. This suggests that patients and their family members have differing values, and use different criteria when making decisions.

Despite the imperfect ability of family caregivers to match patient preferences, at least in hypothetical vignettes, family surrogates are usually the best available spokespersons, and their participation in decision making has become widely accepted over the past 10 years (Meeker, 2004). According to Miles, Koepp, and Weber (1996), the validity of family surrogacy is not dependent on predictive accuracy; the trust that lies behind their selection may justify their authority.

5.3 Perception of Others

5.3.1 Support

Most participants felt that the decision was being made without pressure, and that they had adequate support and advice to make the decision. A possible explanation is that because all of the study participants were recruited from palliative care programs from which they or their terminally ill family members were receiving care, participants were already connected to supportive networks. Participants were already known to health care professionals available to provide support and advice.

5.3.2 Role in Decision Making

A majority of participants indicated a preference to share decision making with others. This may be due to the fact that family caregivers likely to consent to participate in this study have a greater desire for information and participation in decision making. A majority of these participants were able to achieve their preferred role. This finding is consistent with a previous study that examined preferred and actual decision making roles among patients with cancer (Gattellari, Butow, & Tattersall, 2001). However, this study focused on treatment rather than place of care, and participants were patients, not family caregivers.

5.4 Resources to Make the Decision

A majority of participants had information and emotional support resources in place to support decision making. This finding is consistent with a previous health study examining decision making regarding place of care (Murray, O'Connor, Fiset, & Viola, 2003). Only some participants in this study had previous experience in making similar decisions previously, whereas a majority of participants in the 2003 study did have prior personal experience. A possible explanation is the difference in the study population. This study examined male and female family caregivers, and the latter study examined terminally ill female patients.

As noted earlier in Section 5.2.2 Decisional Certainty, a majority of participants in this study, who did not have previous personal experience with a similar decision scenario, reported that the decision was easy to make, while the participants examined by Murray, O'Connor, Fiset, and Viola (2003) who were terminally ill patients with previous experience, found the decision difficult to make. This may suggest that having had previous experience with decision making regarding place of care at the end of life would not make future decision making easier, but more difficult. In a previous health study exploring factors influencing decisions around the place of care for terminally ill cancer patients (McCall and Rice, 2005), participants with previous experiences in dealing with the dying and/or death of a close relative at home did not report good experiences from a home nursing perspective. Most of the participants discussed the burden of care and the difficulty in providing care over a long period (McCall and Rice, 2005). Perhaps the knowledge and experience gained from caring for a terminally ill person causes one to consider more carefully future decisions regarding place of care at the end of life. Further research is needed to examine previous experience and how it affects prospective decision making.

Tangible support was most frequently identified as a resource needed to implement the decision. When access to home-based services is limited, or when the services provided are unsuited to the individual needs of patients and families, caring for a terminally ill family member at home is demanding for families (Stajduhar & Davies, 1998). For example, in the home support sector where workers are often not assigned to care for the same patients and families on a continuing basis, the need and want of families to develop trusting relationships with health care providers become a challenge (Stajduhar & Davies, 1998). Further research is needed to explore what kinds of tangible support are needed, reasons why they are not more readily available, and how access can be improved.

Participants had a strong preference for one-to-one counseling from a health care professional experienced and knowledgeable in palliative care to provide decision support, and to also prepare participants of what to expect at the end of life. This finding is supported by previous health studies. Norton and Talerico (2000), who examined health care provider behaviors that facilitated the process of decision making near the end of patients' lives, found that providers who are more experienced and comfortable are more likely to engage in communication and assessment strategies. Communication strategies include being clear, avoiding euphemisms, outlining goals and expectations, and using words such as death and dying (Norton & Talerico, 2000). Assessment strategies include assessing patients' physical conditions and end-of-life wishes, patients' and family members' understandings of the disease and prognosis, and their expectations and goals (Norton & Talerico, 2000). McCall and Rice (2005), who explored factors influencing decisions around the place of care for terminally ill cancer patients, strongly recommend that health care professionals initiate discussions around end of life care options to ensure that patients and their caregivers knows that there are choices, and these choices can be explored in a sensitive manner.

5.5 Feasibility of the Pilot Study

The results of this pilot study indicate that it is feasible to conduct this research with a larger, more diverse population. For example, the target population was appropriately defined, cooperation of people was possible to secure, respondents found the questions acceptable, and respondents were able to understand and answer the questions.

However, the pilot study did reveal that revisions to the research methods are needed. For example, the pilot study identified the need to revise the order of the questions asked, to include a question addressing participants' ethnic background, and to modify the recruitment setting. A majority of participants in this study were in later stages of decision making with low decisional conflict. If the sample represented more participants in earlier stages of decision making, results may indicate higher decisional conflict and provide insight into the resources needed and preferred by participants for decision making. Broadening the recruitment setting to include acute care hospitals and home care may increase access to family caregivers whose terminally ill loved ones are in earlier stages of the disease process and perhaps in earlier stages of decision making. As well, broadening the recruitment setting may facilitate recruitment of a larger sample size.

5.6 Implications for Research

The questionnaire tool requires further investigation with a larger sample size to strengthen the internal and external validity of the results. The sample size needs to be extended to a culturally diverse population, representing multiple health care sectors and providers.

Other important research to be done in this population is to explore resource allocation. In this study, a majority of participants reported that they had resources such as information and emotional support in place to support decision making. However, only some participants reported having financial and tangible support. Further investigation is needed to examine how resources such as financial and tangible support are accessed and allocated, and to explain how and why patients and families receive varying degrees of support.

One-to-one counseling from an experienced palliative care clinician and information available in printed format were most frequently identified as preferred resources to help in decision making. Further research is needed to examine existing methods and media for decision support delivered by health care practitioners in end of life decision making, to determine the practitioners' needs in delivering decision support, and to determine how to address their needs. As well, further research is needed to examine what information family caregivers need, and how to disseminate the printed information.

Some participants could not share decision making with their terminally ill family members as they would have preferred because the patient's condition had deteriorated. Whether these participants' made a decision that would have matched what their ill family members would have chosen is unknown. In a study examining agreement between patients and their self-selected surrogates on difficult decision making (Hare, Pratt, & Nelson, 1992), researchers found a low rate of agreement. Exploring interventions in which clinicians, patients, and family caregivers discuss and plan for end-of-life scenarios before the onset of crises (Volicer et al., 2002) is another area for future study.

5.7 Implications for Practice

If the results of this study are replicated, there are implications for practice if identified needs are to be addressed. For example, care facilities considered as options for end of life care would need to consider supplementing or redirecting human resources to offer tours for patients and family members to visit the premises, address questions or concerns, and therefore help provide decision support. For terminally ill patients and families to receive counseling from an experienced and knowledgeable palliative health care professional for decision support regarding end of life care options, particularly at initial diagnosis of a terminal illness, links and continuity between health care professionals and programs would need to be established and organized. Providing or increasing financial and tangible support has implications for nursing and government organizations and resources.

The College of Nurses of Ontario Professional Standards Nurses, which describe the professional expectations for all nurses in every area of practice in Ontario, state that patients and their families are the central focus of the professional service provided by nurses, and as partners in the decision making process, patients and families ultimately make their own decisions (College of Nurses of Ontario, 2002). Nurses can facilitate the provision of decision support by advocating for the patient and family, providing needed support, and encouraging and promoting shared decision making between the patient and family.

Sainio, Eriksson, and Lauri (2001) explored factors that facilitate and restrict cancer patient participation in decision making, and results indicate that patients, nurses, and physicians all play a role in how patients participate in decision making. Patient participation involves asking questions, receiving information, being presented with and choosing from different alternatives, and offering opinions. The most important facilitator of patient participation in decision making was found to be the presence of a primary nurse who was responsible for their care. The patients felt a stronger sense of trust for the primary nurse, which made confiding easier. Other important factors of patient participation include encouragement from nurses and doctors, the treatment of patients as equals, and nurses and doctors having enough time.

Barriers to patient participation include patients' lack of knowledge regarding illness and treatment, lack of initiative or courage to ask questions, impaired physical and cognitive condition, shyness, and lack of courage to ask questions (Sainio, Eriksson, & Lauri, 2001). Other barriers include a tendency for health care professionals to treat patients like objects, rigidity of hospital routine, and problems with information dissemination such as misunderstandings or miscommunication. The results of the study conclude that while nurses and physicians play a crucial role in promoting patient participation in decision making, patients also need to take responsibility by showing interest and asking questions (Sainio, Eriksson, & Lauri, 2001).Nurses in advanced practice roles can facilitate the provision of decision support. Advanced Nursing Practice (ANP) is an umbrella term that describes an advanced level of nursing practice that maximizes the use of in-depth nursing knowledge and skill in meeting the health needs of patients (Registered Nurses Association of British Columbia, 1999). The Advanced Practice Nurse promotes excellence in nursing practice and serves as a role model and advocate for other nurses through the five sub-roles of clinician, researcher, consultant, educator, and leader (Hamric, Spross, & Hanson, 2000As educator and consultant, the advanced practice nurse can facilitate decision support for patients and family members through other health care providers. As a leader and researcher, the advanced practice nurse can work with other members of the health care team to develop and evaluate decision support interventions that can be used in the clinical setting.

5.8 Implications for Theory

The ODSF was relevant in studying the decision making needs of family caregivers regarding place of care at the end of life as it has been in examining the decision making needs of patients (Murray, O'Connor, Fiset, & Viola, 2003). However, there were variables in the framework that need further explanation or enhancement in this decision making context. For example, further exploration of the concept of burden in relation to decision support may provide new understandings of the experience of terminal illness. Further examination of resource allocation and the phenomena of making a decision among options for place of care that may no longer be available when needed may provide insight into the experience of caring for the terminally ill and the complexity of end of life decision making. Many of the participants' comments about decision making had a strong emotional tone. While emotional functioning is a participant characteristic in the ODSF, it fails to capture the emotional context in which family caregivers find themselves as they make decisions. Perhaps the original contruct by Janis and Mann (1977), which emphasizes the emotional effects of decision making should be made more prominent than the rather cognitive orientation of the ODSF.

The patient's condition, considered as part of patient's characteristics in the ODSF, requires further elaboration. For example, one study participant shared the circumstances regarding her decision scenario. The decision regarding place of care for her terminally ill family member depended on the patient's condition. If the patient were in stable condition, then home was the best choice. While supports and resources for a home death could be put in place, the patient could deteriorate at any time, and if so, admission to a facility would be the best choice. Though making this decision might have been easy, it may not be as easily implemented. If an admission to a facility were required, there is a possibility that a bed in the facility of choice may not be available, or worse, a bed in any facility may not be available.

Singer, Martin, and Kelner's (1999) categories of quality end-of-life care may need further explanation or enhancement. For example, one study participant had a perception that the local hospice was affiliated with the Anglican Church, and therefore described this affiliation as an advantage as an option for place of care since the patient and family were Anglican. Because 'loved ones' in the domain of 'strengthening relationships with loved ones' are described as family members (Singer, Martin, & Kelner, 1999), both the researcher and independent reviewer coded this advantage as 'achieving a sense of control' instead. Similarly, another participant, whose ill family member was a war veteran, considered a local long term care facility to have an advantage as an option for place of care because it had a nursing unit specifically for veterans. The definition of 'loved ones' as being family members as defined by the researchers does not necessarily extend to fellow Anglicans or war veterans, nor is it known if Anglicans consider members of their own faith as family, or if veterans consider other veterans as family. Perhaps the definition and interpretation of 'loved ones' need to be further examined, and the inclusion of 'communities of importance' in the definition could be considered.

5.9 Limitations

The limitations of this study are mainly related to problems with its internal validity and poor generalizability. For example, the small sample size may not be representative of the population of family caregivers of terminally ill patients. A sample representing diversity in cultural backgrounds may have revealed a different perspective on decision making. The interviews were conducted by one researcher, which may have introduced bias due to the one viewpoint. Also, potential bias may have been introduced as the sample represents only those family caregivers who are willing and able to participate. As clinicians made initial contact with potential participants and therefore made the final decision if contact was to be made, there may have been selection bias.

For example, regarding two potential participants, clinicians did not consider the individuals appropriate for the study because they were actively considering decision options and tension existed among family members, including the patient. Though the clinicians were informed that participants in active stages of decision making were appropriate, and perhaps their participation in the study may be helpful, the clinicians would not agree to approaching the family members to determine if they were interested in learning more about the study. This selection bias may have had an effect on the sample size, resulting in a possible over-representation of participants in later stages of decision making, and an under-representation of participants in the early stages of decision making. A sample representing participants more evenly in the stages of decision making may have introduced a different view on decision making.

The recruitment setting may also have introduced bias, perhaps leading to possible over-representation of participants in later stages of decision making. As participants were recruited from palliative care programs, as opposed to being recruited closer to initial diagnosis of their family members, participants may have had more time to consider the decision regarding place of care at the end of life, and therefore be in later stage of decision making. Expanding the setting to multiple sites representing different levels and acuity of care may offer different perspectives to the study.

There are limitations to using a deductive approach in data analysis. Deductive reasoning, the process of developing specific prediction from general principles, is not itself a source of new information, but an approach to illuminating relationships as one proceeds from the general (an assumed truth) to the specific (Polit & Hungler, 1999). Deductive logic therefore depends on the truth of the generalization to arrive at valid conclusions (Polit & Hungler, 1999). Restricting the analysis to fixed categories might exclude information that may be particularly relevant to the area of research. There is also disregard for context given that transcripts are simplified to frequencies, which equate to significance. Selecting quotes from participants' interviews were used to illustrate and provide further context to the pre-categorized responses.

5.10 Conclusions

To summarize the results, home, palliative care unit (PCU), hospice, long term care facility, and hospital were identified as decision options, with home and PCU equally considered the best. A majority participants did not experience decisional conflict, felt informed of the options and the associated advantages and disadvantages, had adequate support and advice, preferred to share decision making with the terminally ill patient, and had received information and emotional support. A minority of participants (3/14) expressed more decisional conflict as did those participants in earlier stages of decision making. The resource most needed was tangible support, and individual counseling and printed information were preferred resources over discussion groups and Internet information.

Family caregivers have important informational, emotional, financial, tangible, and decisional support needs. The use of the Ottawa Decision Support Framework was useful in directing the inquiry of family caregivers' needs. The results of this pilot study indicate that it is feasible to conduct this research with a larger, more diverse population with some revisions to the research methods. Despite its limitations, this study is a promising step in describing the decision making needs of family caregivers of terminally ill patients when making or supporting decisions regarding place of care at the end of life. These results also contribute to the growing body of knowledge examining how to best support patients and family members in making health care decisions and achieving their preference for place of care at the end of life.

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APPENDICES

Appendix A: Adapted Populations Needs Assessment Questionnaire.

Adapted Populations Needs Assessment Questionnaire

Participant Code #__________________
Date: __________________
Location: __________________

My name is Sandra Young. I am a student in the Masters of Science in Nursing program at the University of Ottawa. Thank you very much for taking part in this study.

I would like to talk to you about one of the decisions you may be facing as your family member's illness progresses. I want to learn more about your role in decision making regarding where your family member would prefer to receive care in the last days or weeks of life. Some patients may prefer to be at home, while others may prefer to be in a facility with 24-hour nursing care. I would like to talk to you about your preferences, your involvement in this decision, and what resources you might find helpful in making or supporting this decision.

All of the information I collect will be kept confidential. The interview will take approximately 45-60 minutes. Please let me know if you need to take a break, if you would like to skip some questions, or if you would like to stop the interview. Do you have questions before we start?

1. Have you thought about where your family member would like to receive care during the last days or weeks of life?

____

____

____

Section A: PERCEPTION OF OTHERS

2a. What role do/did you prefer in this decision?

____

____

____

Probe: Do/did you:
☐ Prefer to make own decision, after considering the opinions of others
☐ Prefer to share decision making with other(s), (specify)______________
☐ Prefer to share decision with health care professional
☐ Prefer health care professional to make decision
☐ Prefer terminally ill family member to make decision

2b. What is/was your actual role in this decision?

____

____

____

Probe: Do/did you:
☐ Make own decision, after considering the opinions of others
☐ Share decision making with other(s), (specify)______________
☐ Share decision with health care professional
☐ Have the health care professional make decision

3. How do you feel about your role in this decision?

____

____

____

Probe: Are you:
☐ Unsure about what to do
☐ Distressed or upset
☐ Delaying the decision
☐ Questioning what is important to you
☐ Worried what could go wrong
☐ Constantly thinking about the decision
☐ Wavering between choices or changing your mind
☐ Feeling physically stressed, tense muscles, racing heartbeat, difficulty sleeping

4. Who else is/was involved in making this decision?

Relationship	Role this person plays in this decision	His/her opinion of what the best option is, neutral, unknown	Comments

Probe: How is this person involved in making this choice…is he or she:
☐ Making the decision
☐ Sharing the decision making with you
☐ Providing support or advice for you to make the decision on your own

Section B: PERCEPTION OF AN IMPORTANT DECISION

5. What do you see as the main options for where your family member would like to receive care during the last days or weeks of life?

Use table below to record answers ______________________________________

Probe:
- ☐ Private home
- ☐ Hospital
- ☐ Long Term Care Facility
- ☐ Other (specify) ________________
- ☐ Palliative Care Unit at Élisabeth Bruyère
- ☐ Hospice
- ☐ Retirement Home

6. What do you see as the most likely advantages (pros) and disadvantages (cons) of the options being considered? (expectations)

Options	Pros	Cons

Probe:
- ☐ Good control of pain and symptoms
- ☐ Not being a burden to family and friends
- ☐ Time spent with family and friends
- ☐ Other (specify) __________________
- ☐ Maintaining sense of control
- ☐ Access to health care professionals
- ☐ How comfortable the environment is

7a. Which of the advantages and disadvantages are most important to you? (values)

(Rank in order of importance)

Options	Pros	Cons

7b. Which of the advantages and disadvantages are most important to your terminally ill family member? (values)

(Rank in order of importance)

Options	Pros	Cons

8. How far along are you with this decision?

Probe: Are you:
- ☐ Not thinking about it
- ☐ Actively weighing the options
- ☐ Taking steps toward implementing the decision
- ☐ Starting to think about it
- ☐ Close to making a choice
- ☐ Decided and have carried out choice

9. When does this decision have to be made?

10a. What things make this decision difficult for you?

Probe: Are you:
- ☐ Lacking information about options, pros, and cons
- ☐ Lacking information on the chances of benefits and harms
- ☐ Unclear about what is important to you
- ☐ Lacking motivation or not feeling ready to make a decision
- ☐ Feeling pressure from others
- ☐ Lacking support from others
- ☐ Lacking information on what others decide
- ☐ Lacking skill/ability to make this type of decision
- ☐ Other (specify) ______________________

10b. What things make this decision difficult for your family member?

Probe: Are you:
- ☐ Lacking information about options, pros, and cons
- ☐ Lacking information on the chances of benefits and harms
- ☐ Unclear about what is important to you
- ☐ Lacking motivation or not feeling ready to make a decision
- ☐ Feeling pressure from others
- ☐ Lacking support from others
- ☐ Lacking information on what others decide
- ☐ Lacking skill/ability to make this type of decision
- ☐ Other (specify) ______________________

Section C: RESOURCES

11. At this time, what resources do you have to carry out the choice?

Probe: **Personal Resources**: ☐ Previous experience ☐ Tangible help
☐ Financial support ☐ Information or knowledge
External Resources: ☐ Information ☐ Emotional support
☐ Financial support ☐ Tangible support
Source: ☐ Family ☐ Friends
☐ Agencies ☐ Volunteers
☐ Other (specify) ________________

12. What resources are needed to carry out the choice?

Probe:
Resources: ☐ Tangible support ☐ Financial support
☐ Understanding of how others made this decision
☐ More information ☐ Emotional support ☐ Clearer idea of others' opinions and choices
Source: ☐ Family ☐ Friends ☐ Agencies
☐ Volunteers ☐ Other (specify) ________________

13a. At this time, what do you see as the best choice?

Probe: ☐ Private home ☐ Palliative Care Unit at Élisabeth Bruyère
☐ Hospital ☐ Hospice
☐ Long Term Care Facility ☐ Retirement Home
☐ Other (specify) ________________

13b. What does your family member see as the best choice?

Probe: ☐ Private home ☐ Palliative Care Unit at Élisabeth Bruyère
☐ Hospital ☐ Hospice
☐ Long Term Care Facility ☐ Retirement Home
☐ Other (specify) ________________

14a. At this time, how sure are you about the decision?

Probe: ☐ Very sure ☐ Somewhat sure ☐ Unsure

14b. At this time, how sure is your family member about the decision?

Probe: ☐ Very sure ☐ Somewhat sure ☐ Unsure

**Ask participant to complete self-administered Decisional Conflict Scale

15. Let's discuss possible ways to help people with this type of decision. What would you find helpful?

16. I will list possible ways to help some people with a decision. Which ones do you think may be useful to you?

☐ Counseling from health practitioner, IF YES, what type of practitioner ____________

☐ Discussion groups of people facing the same decisions, IF YES, what type of organization or group

☐ Information materials
If yes, type of medium----> ☐ Booklets, pamphlets ☐ Videos ☐ CD ROMS
☐ Internet ☐ Other (specify) ____________

17. Where do you think information and support should be available?

Probe: ☐ Physician's office ☐ Hospital
☐ Home Care ☐ Other (specify) ____________

Section D: PARTICIPANT and PERCEIVED FAMILY MEMBER CHARACTERISTICS

18. Age Category: ☐ Teens ☐ Twenties ☐ Thirties ☐ Forties
☐ Fifties ☐ Sixties ☐ Seventies ☐ Eighties +

19. Gender: ☐ Male ☐ Female

20. Education (Highest level attained):
☐ Grade School
☐ Grade 9
☐ Grade 10
☐ Grade 11
☐ High School Diploma
☐ Post-Secondary College Diploma
☐ Post-Secondary University Degree

21. Marital Status:
☐ Single
☐ Married or common-law partner
☐ Divorced or Separated
☐ Widowed

22. Occupation: ____

23. Employment Status:
☐ Full time ☐ Part time ☐ Casual ☐ Unemployed
☐ Short term Sick Leave ☐ Maternity Leave ☐ Disability Pension
☐ Full time homemaker ☐ Retired

24. Living alone: ☐ No
☐ Yes → With terminally ill family member ☐ No
☐ Yes

25. Household members:

Relationship	Age

26. Prognosis of family member:

____

____

Probe: ☐ Days ☐ Weeks ☐ Months ☐ Not known

27. When diagnosis of family member was made:

____

____

Probe length of time since diagnosis made:
☐ < 1 month
☐ Months (specify how many)______________
☐ Years (specify how many)______________

28. Current place of care of family member:

Probe:
☐ Private home
☐ Hospital
☐ Long Term Care Facility
☐ Other (specify) ______________
☐ Palliative Care Unit at Élisabeth Bruyère
☐ Hospice
☐ Retirement Home

29. Reason for current place of care:

Probe:
☐ Preferred place of care at end of life
☐ Short-term pain and symptom management
☐ Respite
☐ Convenience
☐ Lack of bed
☐ Other (specify) ___________

30. Power of Attorney (POA) for family member:

Probe:
☐ None, not discussed
☐ Other family member who is not providing care has POA
☐ Currently being discussed
☐ Family caregiver has POA
☐ Other (specify) ______________

31. Family caregiver's perception of family member's physical ability:

Probe using ECOG scale:
☐ Normal activity = 0
☐ Symptoms, but nearly full ambulatory = 1
☐ Needs to be in bed <50% of usual day = 2
☐ Needs to be in bed >50% of usual day = 3
☐ Unable to get out of bed = 4

32. Family caregiver's perception of family member's level of confusion, if any:

Probe using CRS scale:
☐ Disorientation (verbal or behavioural disorientation to person, place, time)
☐ Inappropriate behaviour (pulling at tubes or dressings, attempting to get out of bed)
☐ Inappropriate communication (incoherence; uncommunicative, nonsensical, or unintelligible speech)
☐ Illusions/hallucinations (seeing or hearing things that are not there; distortions of visual objects)

Code each of the four behaviours as follows:
0 = Behaviour not present
1 = Behaviour present, but mild
2 = Behaviour present, and pronounced

Appendix B: Modified Decisional Conflict Scale

Adapted Decisional Conflict Scale

At this time, thinking about the choice regarding where your terminally ill family member would prefer to receive care during the last days or weeks of life, please look at the following comments made by some family members when making decisions.

Please show how strongly you agree or disagree with these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree) that best shows how you feel about the choice [you just made, you made, you are about to make].

1. This decision is easy to make	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
2. I'm sure what should be done in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
3. It's clear which choice is best	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
4. I'm aware of the options in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
5. I feel I know the advantages of each option	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
6. I feel I know the disadvantages of each option	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
7. I am clear about how important the advantages are to me in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
8. I am clear about how important the disadvantages are to me in this decision	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

9. For the main options being considered, I am clear about which is more important to me (the advantages or disadvantages)	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
10.This decision is being being made without any pressure from others	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
11.I have the right amount of support for my role in decision making	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
12.I have enough advice about the options	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

Changes to title, instruction paragraph, and body of tool made by Annette O'Connor and Sandra Young, August 2003.

Participant Code # ____________________
Date: ____________________
Location: ____________________

Appendix C: Participant Consent Form

Information and Consent Form for Study Participant

Study: *The decision making needs of family caregivers of terminally ill patients regarding place of care at the end of life.*

Purpose: The purpose of this study is to describe the decision making needs of family caregivers of terminally ill patients who are considering options as to where to receive care in the last days or weeks of life. The study will explore how family caregivers make or support this decision. I hope that by doing this study, nurses and other health care professionals may achieve a greater understanding of the decision making process and be more able to support family caregivers who are making or supporting this decision in the future.

Procedure: Your participation will involve taking part in an interview. I will ask you questions regarding decision making about where your ill family member would like to receive care during the last days or weeks of life. With your permission, I will record the interview on tape. I will use two (2) tape recorders, in case one fails to operate. I may also take notes. The length of the interview will be approximately 45-60 minutes, and will take place in your home or in a quiet office. You may take a break at any time during the interview, or choose not to answer particular questions. The tape recording will later be transcribed in order to review your responses more carefully.

Possible Benefits: The potential benefits for you for participating in the research study would be the opportunity and experience in taking part and being involved in research, and the satisfaction that the information you share may help other family caregivers and improve care for the terminally ill. Other benefits may include the opportunity to share your experiences with someone who is neutral and nonjudgmental, and the possibility of increasing knowledge about yourself.

Potential Risks: The potential costs for you for participating in the research study may include emotional upset. During the interview, I will be sensitive to any signs that you may be uncomfortable, and I will give you opportunities throughout the interview to take a break, to stop, or to not answer certain questions and skip to others. To provide a source of support to you, I will notify the palliative care team at the Élisabeth Bruyère Health Centre if you experience emotional upset while participating in the study. Other potential costs include loss of time. I will coordinate with you a mutually agreeable time to hold the interview.

Rights of Participants: **You are under no obligation to participate in this study. Your participation is voluntary**. If you do take part, you may withdraw at any time. You do not have to answer any questions you do not wish to. Your participation has no effect on the quality of care your ill family member receives. Information you share will be kept confidential. However, there are limitations of confidentiality, and I will break confidentiality if information regarding potential or imminent harm or abuse to you or others is disclosed. For your safety and the safety of others, I will share this information with the palliative care team caring for your ill family member.

To protect your anonymity, a code number will be assigned to identify your personal information. Your name will not appear on any documents. Only people working on this research project will see this information and it will be kept in a locked filing cabinet. At the end of the study, tape recordings, computer discs, and paper files will be stored in a locked filing cabinet for 5 years, after which they will be destroyed. When the results of this study are presented or published, no personal identifying information will appear. Although quotations from interviews may be used in future presentations or articles from this study, no personal information will appear with these quotations.

__________________________________ Date ____________________
Sandra Young, RN, MSN student

<u>Consent</u>: I have read and understand the information in this form. I have had the opportunity to ask questions and have had them answered to my satisfaction. I agree to participate in this study.

Signature____________________________ Date ____________________

Name (please print) ____________________

You will receive a copy of this consent form. The original will be kept with the investigator. If you have any additional questions about this study, you may telephone the investigator, the thesis supervisor (named below) or either Research Ethics Board (named below).

Investigator: Sandra Young, RN, MSN student, University of Ottawa, Faculty of Nursing.
Telephone: (613) 842-5188

Thesis Supervisor: Annette O'Connor, RN, PhD. Canada Research Chair in Health Care Consumer Decision Support; Professor, University of Ottawa; Senior Scientist, Ottawa Health Research Institute. Telephone: (613) 798-5555 ext. 17582

University of Ottawa Research Ethics Board Contact Person: Protocol Officer
Telephone: (613) 562-5387

SCO Health Service Research Ethics Board Contact Person: Dr. Jean-Francois Kozak, Chair.
Telephone: (613) 562-6365

This study has been approved by the Research Ethics Boards of the SCO Health Service and the University of Ottawa.

(Valid until August 2004)

Appendix D: Modified Consent Form for Additional Setting

Information and Consent Form for Study Participant

Study: *The decision making needs of family caregivers of terminally ill patients regarding place of care at the end of life.*

Purpose: The purpose of this study is to describe the decision making needs of family caregivers of terminally ill patients who are considering options as to where to receive care in the last days or weeks of life. The study will explore how family caregivers make or support this decision. I hope that by doing this study, nurses and other health care professionals may achieve a greater understanding of the decision making process and be more able to support family caregivers who are making or supporting this decision in the future.

Procedure: Your participation will involve taking part in an interview. I will ask you questions regarding decision making about where your ill family member would like to receive care during the last days or weeks of life. With your permission, I will record the interview on tape. I will use two (2) tape recorders, in case one fails to operate. I may also take notes. The length of the interview will be approximately 45-60 minutes, and will take place in your home or in a quiet office. You may take a break at any time during the interview, or choose not to answer particular questions. The tape recording will later be transcribed in order to review your responses more carefully.

Possible Benefits: The potential benefits for you for participating in the research study would be the opportunity and experience in taking part and being involved in research, and the satisfaction that the information you share may help other family caregivers and improve care for the terminally ill. Other benefits may include the opportunity to share your experiences with someone who is neutral and nonjudgmental, and the possibility of increasing knowledge about yourself.

Potential Risks: The potential costs for you for participating in the research study may include emotional upset. During the interview, I will be sensitive to any signs that you may be uncomfortable, and I will give you opportunities throughout the interview to take a break, to stop, or to not answer certain questions and skip to others. To provide a source of support to you, I will notify the palliative care team at the Élisabeth Bruyère Health Centre or at the Hospice at May Court if you experience emotional upset while participating in the study. Other potential costs include loss of time. I will coordinate with you a mutually agreeable time to hold the interview.

Rights of Participants: **You are under no obligation to participate in this study. Your participation is voluntary**. If you do take part, you may withdraw at any time. You do not have to answer any questions you do not wish to. Your participation has no effect on the quality of care your ill family member receives. Information you share will be kept confidential. However, there are limitations of confidentiality, and I will break confidentiality if information regarding potential or imminent harm or abuse to you or others is disclosed. For your safety and the safety of others, I will share this information with the palliative care team caring for your ill family member.

To protect your anonymity, a code number will be assigned to identify your personal information. Your name will not appear on any documents. Only people working on this research project will see this information and it will be kept in a locked filing cabinet. At the end of the study, tape recordings, computer discs, and paper files will be stored in a locked filing cabinet for 5 years, after which they will be destroyed. When the results of this study are presented or published, no personal identifying information will appear. Although quotations from interviews may be used in future presentations or articles from this study, no personal information will appear with these quotations.

_______________________________ Date ____________________
Sandra Young, RN, MSN student

Consent: I have read and understand the information in this form. I have had the opportunity to ask questions and have had them answered to my satisfaction. I agree to participate in this study.

Signature_______________________________ Date ____________________

Name (please print) ____________________

You will receive a copy of this consent form. The original will be kept with the investigator. If you have any additional questions about this study, you may telephone the investigator, the thesis supervisor (named below) or either Research Ethics Board (named below).

Investigator: Sandra Young, RN, MSN student, University of Ottawa, Faculty of Nursing. Telephone: (613) 842-5188

Thesis Supervisor: Annette O'Connor, RN, PhD. Canada Research Chair in Health Care Consumer Decision Support; Professor, University of Ottawa; Senior Scientist, Ottawa Health Research Institute. Telephone: (613) 798-5555 ext. 17582

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This study has been approved by the Research Ethics Boards of the SCO Health Service and the University of Ottawa. (Valid until August 2004)

[Consent Form amended February 27, 2004 to include research study participants recruited from the Hospice at May Court, with the permission of Barbara O'Connor, Executive Director of the Hospice at May Court (613-260-2906)]