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The Family Caregivers' Transitional Experience of Admitting a Family Member from Home to the Palliative Care Unit

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The Family Caregivers' Transitional Experience of Admitting a Family Member from Home to the Palliative Care Unit

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ABSTRACT

Canada's aging population and increasing incidence of cancer, in both older and younger adults (Canadian Cancer Society, 2007), has resulted in palliative care becoming a growing concern for Canadians. Family caregivers are expected to provide care to ill family members at home with limited training, support or community resources. While research has recognized numerous challenges of providing care at home along with the consequences on the caregiver, a thorough literature review showed little research has been published about the caregiver's transitional experience of admitting a family member from home to the palliative care unit (PCU). Thus, a Heideggerian phenomenology qualitative approach was used in this study to explore the question: What are the family caregivers' transitional experiences of admitting family members from home to the PCU? Ten participants completed in-depth interviews and Colaizzi's (1978) approach guided the study's analysis.

The findings produced a framework entitled: *Transitional Experiences of Family Caregivers: A Puzzle of Care Provision.* It contained eight themes of "*In the beginning - Searching for answers*", "*Managing at home - Juggling act*", "*Trying to get through it*", "*A shifting situation - Triggers leading to PCU admission*", "*The transition - Making the decision to go to PCU*", "*Getting near the end – PCU*", "*Looking back on care*", and "*Getting ready to move on*". Follow up interviews verified that the themes and framework accurately described participants' experiences. This study is the first to thoroughly illustrate the family caregiver's transitional experience of caring for a family member from home to the PCU. It is

hoped that this study raises greater awareness and understanding of the family caregivers' transitional experiences.

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This thesis is dedicated to all family caregivers who have cared and are caring for a loved one at home. May this study bring you acknowledgement of your daily challenges and hope that palliative caregiving will improve in the future as clearly expressed by the participants of this study.

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CHAPTER ONE: INTRODUCTION

1.0 Background

The Canadian Cancer Society (2007) has estimated that one in every four Canadians would die from cancer. Canada's aging population and increasing incidence of cancer in both older and younger adults (Canadian Cancer Society, 2007), has resulted in palliative care becoming a growing concern for Canadian health care providers, policy makers and researchers. In 2000, the Senate published a report called *Quality End-of-Life Care: The Right of Every Canadian.* This report acknowledged that each Canadian is entitled to "...skilled, compassionate, and respectful care at the end of life" (Carstairs & Beaudoin, 2000, p. 5). They also specified that quality of care is the right of every dying Canadian, thus they must have access to high quality end-of-life care. While cancer can happen to anyone, every death affects a minimum of five living Canadians (Canadian Cancer Society, 2007; Canadian Hospice Palliative Care Association [CHPCA], 2006; Carstairs & Beaudoin, 2000). Thus, Dame Cicely Saunders' statement still rings true today; she wrote "*how* people die remains in the memories of those who live on..." (Saunders, 1994, p. 861).

The Canadian health care system relies on family caregivers for ongoing palliative home care of the patient (CHPCA, 2006; Carstairs & Beaudoin, 2000; Decima Research Incorporate, 2002; Fast, Niehaus, Eales, & Keating, 2002; Stajduhar, 2003). Subsequently, how do family caregivers manage when their loved ones' pain becomes uncontrollable, even when they have given hourly pain medication and there are challenges of increased weakness, enhanced confusion and

sudden falls? As a case manager and home care nurse, there had been many times that the researcher witnessed family caregivers physically fatigued and emotionally tired from nights of no sleep as they tried to provide 'nurse like care' to their dying loved one. The researcher often wondered how family caregivers managed to deal with complex and physically demanding care essential to sustain the patient at home. This care involved (1) giving injectable medications, (2) repositioning the patient in bed, (3) changing disposable diapers, (4) bathing the patient, (5) monitoring the patient's condition, and (6) making care decisions. In the researcher's experience, these family caregivers frequently provided skilled care to the patients. Yet, they were not given any professional training beyond what the physician and home care nurse had advised.

But, there came a turning point when either the patients' symptoms became uncontrollable at home or the family caregiver had exhausted or injured themselves. As a result, the patient was moved into an institutional care setting, such as an acute care hospital or a palliative care unit (PCU). This pivotal change stimulated the researcher to ponder questions such as: How did the patient and the family caregiver reach this turning point? What was it like caring for a dying loved one? How did they manage giving injectable drugs while the patient was suffering? How did it feel when the home care nurse suggested admission to PCU? What was the transition from home to PCU setting like? How and when did the family caregiver fit into the PCU setting when a loved one was admitted there?

Research has documented the family caregiver's experience of caring for a dying loved one in the family home. However, the researcher wanted to gain a greater

understanding of the transition in care experience from home to the PCU, and, how this change affected the patients and their families' lives. A review of the literature revealed that much research has been published on family caregivers' experiences admitting a family member to a nursing home; however, there are no studies specifically investigating this transition of care from home to a PCU. The researcher was therefore interested in exploring the following question: What was it like for family caregivers' to admit a family member from home to a palliative care unit? This question formed the focus of this current study.

1.1 Purpose

The aim of this study was to explore the family caregivers' lived experience of transitioning a family member from home to PCU. This study examined three periods: Home, 'at the moment' perspectives of being a family caregiver; Transfer between settings, how the transition between care settings occurred; and Settling in a PCU, what it was like for family caregivers.

1.2 Objectives

There were four objectives to this study. They were: (1) to explore the caregiver's experience pre-PCU admission, (2) to explore the caregiver's experience post-PCU admission, (3) to explore the factors leading to the patient being admitted to the PCU, and (4) to explore the factors that helped or hindered the caregiving role.

1.3 Operational Definitions

To maintain precision for this study, the following terms have been defined:

Palliative care is considered for persons with a terminal illness, for whom further aggressive treatment does not extend life with quality, or when the patient requests an end to curative treatment (Ferris, Balfour, Bowen, Farley, Hardwick, Lamontagne et al, 2002). The goal of care is providing the best quality of life for a terminally ill patient and their family by ensuring comfort, care and dignity at the end of the person's life (Health Canada, 2003; Claxton-Oldfield, Claxton-Oxfield & Rishchynski, 2004). The World Health Organization's (2003) widely accepted definition of ***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 problems, physical, psychosocial and spiritual. (p. 1)

A ***Palliative Care Unit*** **(PCU)** is a designated hospital unit where specialized health care professionals (HCPs) provide comfort care to palliative patients. Canada's first palliative care program began over thirty years ago in Winnipeg (Claxton-Oldfield et al, 2004).

Terminally ill refers to the condition of a person who has an incurable, life threatening disease, such as cancer, multiple sclerosis or AIDS. While palliative care is deemed as the last six to nine months of a terminally ill persons' life, several terms are used to describe the care for the dying. These terms are terminally ill, palliative

care, and end-of-life care. For clarity, this study will use the term palliative care to encompass the period from when the patient is diagnosed with a life-threatening illness through to their death.

A ***Palliative patient*** is a person diagnosed with an incurable chronic illness. Many palliative patients live with multiple chronic illnesses combined with the incurable disease. They have one or more family caregivers assisting with their care at home.

A ***Family*** consists of "two or more individuals who depend on one another for emotional, physical, and economical support. The members of the family are self-defined" (Hanson, 2001, p. 6). This definition recognizes family members of common law and same-sex unions.

Family caregivers are "...unpaid individuals such as family members and friends who provide care" (Derby & O'Mahony, 2006, p. 638). The family caregiver is the primary care provider who has a strong commitment to meeting the patient's continuous comfort needs within the family home.

A ***Primary caregiver*** is the main person designated by the palliative patient as his or her advocate for physical, emotional and financial needs when the patient becomes incapable of independently meeting these needs.

Transition is a change in location of care where in the patient moves from home to institutional care or from one care provider (family physician) to different care provider (palliative care physician) (Burge, Lawson, Critchley, Maxwell, 2005). Meleis (2007) described an individual's move from one care setting to another as a situational transition. This move involves both patient and family caregiver's

physical transfer to the new setting and adaptation to altered settings, care methods and care providers. For the purpose of this study, the transition will refer to change from care provided in the home to PCU and its impact on the patient and the family caregiver.

Transitional experience is a person's experience and adaptation within altered settings, care methods and care providers.

1.4 Delivery of Palliative Care

Palliative care is provided within various environments such as palliative care units (PCU), hospices, acute care hospitals, nursing homes, and the family home. Nevertheless, palliative care treatment focuses upon the patient's goal of quality care at the end of life where promotion of comfort, patient's wishes and physical abilities are respected. Specialized interdisciplinary teams are commonly available in palliative care settings. They consist of family physician, palliative care physician, oncologists, nurses, physiotherapists, occupational therapists, social workers, chaplains, pharmacists, nutritionists, and volunteers. Such interdisciplinary teams support a holistic, patient care approach where physical, emotional, spiritual and relational aspects of each patient's life are nurtured (CHPCA, 2006). To holistically care for a palliative patient, the interdisciplinary team collaboratively works with the patient and their family, particularly the family caregiver. "Life and death happen in the context of family. In palliative and bereavement care, the patient and family are considered the unit of care" (Victoria Hospice Society, Cairns, Thompson, &

Wainwright, 2003, p. 125). Thus, family caregivers are considered part of the interdisciplinary palliative care team.

1.5 Admission to the Palliative Care Unit

Patients may be moved to a PCU for uncontrolled symptoms such as severe pain, non-stop vomiting, poor appetite, excessive weakness, sudden confusion and any safety risks, such as falls (Evans, Cutson, Steinhauser, & Tulsky, 2006). When a patient is admitted, a family member is often present. Once a thorough assessment is completed by a nurse and a physician on the PCU, strategies to improve symptom control and well being are initiated.

1.6 Summary

In summary, this study will focus on the lived experience of family caregivers transitioning a family member from home to the PCU. In depth understanding of the caregivers' experience while transitioning a family member to the PCU can facilitate increased awareness of issues for the palliative care interdisciplinary team during this pivotal period of time.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

A review of the literature concentrated on three areas of interest: (1) family caregiver, (2) transitions of care, and (3) transition from home to PCU. CINHAL, Ovid, Medline, and PsychInfo databases were searched for all relevant literature. Keyword search terms included *palliative care*, *terminally ill*, *family caregiver*, *home care*, *transition*, *transitional experience*, *care transition*, *transfer*, and *palliative care unit*. There has been a growth in palliative care research over the past decade, predominately in developed countries. Thus, the focus of this review was to examine the literature published over the past 10-15 years (1991 to 2007). The search was limited to English language articles only. In addition, an internet search using Google was conducted to obtain other general palliative care information, such as the Carstairs and Beaudoin (2000) Senate report of recommendations.

2.1 *Becoming a Family Caregiver*

Stoltz, Willman and Ulén (2006) observed that when a family member's health declined and active treatment was no longer feasible, "a shift in care" occurred where one or more family members became the family caregiver to the patient in the home. This "shift in care", from health care professionals, for example hospital nurses, to a family member, has been acknowledged by previous researchers (such as Aoun, Kristjanson, Currow, and Hudson, 2005; Given, Wyatt, Given, Sherwood, Gift, DeVoss et al, 2004; Sherwood, Given, Given, Schiffman, Murman, Lovely et al, 2006). Health Canada (2003) reported that family caregivers were typically a

spouse or an adult child of the patient. They identified three common reasons why family members accepted to become caregivers: (1) family responsibility, (2) personal choice to provide care, and (3) lack of home care services or no one else was available (Dunbrack, 2006; Hudson, 2003; Stajduhar, 2003). Several studies have shown that family caregivers might impulsively "promise" the patient that they will provide end-of-life care in the home, particularly after a displeasing hospital experience (Aranda & Peerson, 2001; Stajduhar, 2003; Syrén, Saveman, & Benzein, 2006). Yet, the literature suggested that caregivers have romantic idealizations of home caregiving rather than a true understanding of the complexities involved in providing palliative care in the family home (Dunbrack, 2006; Hudson, 2003; Stajduhar, 2003).

2.2 *Making the Decision to be a Caregiver*

In a Canadian study, Stajduhar and Davies (2005) conducted ethnographic research to explore factors that affected the decision to provide home care. They completed 13 participant observations and interviewed 12 patients and 13 caregivers in the family home followed by further interviews of a retrospective nature with 47 caregivers, as well as focus groups with 28 HCPs (home care nurses and home support workers), and 10 administrators. They identified three types of decisions made by family caregivers. The first decision type was "uninformed". Uninformed decisions were created early in the patient's diagnosis to please the patient's request to die at home; it was an impulsive agreement by the family caregivers. The second decision type was "indifferent". Indifferent decisions were made when family

caregivers had minimal decisionary power about the place of care. This commonly occurred when family caregivers were previously caring for the patient at home. These family caregivers often lacked pertinent information about the community resources to provide alternative caregiving options to them; therefore, their lack of knowledge contributed to their indifferent decisions. The third decision type was "negotiated". Negotiated decisions occurred when family caregivers and patients openly discussed dying and the preferred place of care. This discussion promoted mutual understanding so the decision accommodated both the caregivers' and patients' preferences and needs. The negotiated decisions allowed family caregivers greater preparation time and better coping abilities compared to the other two caregiver decision types. Regardless of the decision type, most family caregivers felt guilty when failing to sustain their promise and had to send the patient to the hospital or PCU for care. Since this study focused on caregiving at home and the decisions surrounding becoming a caregiver, it missed the patient's and caregiver's perspective during the transition period from home to a hospital or PCU.

Patients' preference to die at home has been recognized as a factor in the decision to become a caregiver. Place of care preferences have been studied by researchers over the past decade and their findings indicated that home was the preferred place of care at the patient's end of life (Brazil, Bedard, Krueger, Abernathy, Lohfeld, & Willison, 2005; Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005; Csikai, 2006; Higginson & Sen-Gupta, 2000; McCall & Rice, 2005; Pritchard, Fisher, Teno, Sharp, Reding, Knaus et al, 1998; Stajduhar & Davies, 2005; Tang, 2003). Indeed, there is a growing desire by Canadians to die at home (CHPCA, 2006). In a

Canadian study, Brazil, Howell et al (2005) interviewed more than 200 bereaved family caregivers about preferences regarding the place of care and death of their loved one. They discovered that patients had a greater likelihood of dying at home when their caregivers (1) lived with the patient, (2) favoured the home setting, (3) had good health, as well as (4) received a regular visiting physician to the home. While caregivers favoured the home over the institutional setting, they were more agreeable to a hospital death compared to the dying patients. The study showed that caregivers' preferences changed as the patients' health declined. The home setting provided a familiar setting, supportive environment, dignity and comfort for family and friends when the patient was more physically active. However, the institution provided continuous nursing care and effective symptom management essential to the care for a dying patient. While only 30% of patients did die in an institutional setting, these family caregivers believed that the patient died in the most appropriate care setting (Brazil, Howell et al, 2005). Interestingly, Higginson and Sen-Gupta's (2000) systematic literature review commonly recognized the patient's preferred place of care at the end of life was their family home, yet the family caregiver's preferences were not addressed.

2.3 What Helps Caregiving

In the literature, only a few studies have identified factors that positively influenced palliative caregiving at home and the role of a caregiver. Quality time spent with the patient, deepened relationships with other family members, greater awareness of their own strengths, changed views of the meaning of life and death, and

support received from others have been highlighted (Aranda & Hayman-White, 2001; Brazil, Bedard et al, 2005; Hudson, Aranda & Kristjanson, 2004; Perreault, Fothergill-Bourbonnais, & Fiset, 2004; Strang, Koop, & Peden, 2002; Strang & Koop, 2003; Stajduhar, 2003; Stajduhar & Davies, 1998; Stoltz et al, 2006; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). Brazil, Bedard et al (2005) surmised that home caregiving offered the patient an improved quality of life while creating contentment and meaning to the caregiver. "Meaning making", as described by Waldrop et al (2005), referred to caregivers' reflections upon the patient's life, their caring experience, and the sense of loss and death.

2.3.1 Personal Support

Stoltz et al (2006) interviewed 20 caregivers of frail elders to gain an understanding of caregiver support. Caregiver support relied upon the person's assurance in oneself and others' resourcefulness. It had two central meanings: (1) a "sense of togetherness with oneself", and (2) "experiencing togetherness with others" (Stoltz et al, 2006). The first meaning referred to the family caregiver's inner strength of having self reliance to support oneself. The family caregivers' ability to access additional resourcefulness within themselves assisted their determination to continue providing hands-on physical care. Although family caregivers initially turned to their family and friends for support (Stewart, Barnfather, Neufeld, Warren, Letourneau & Liu, 2006; Perreault et al, 2004), both close companions and strangers facilitated the caregiver by providing a greater support network (Stewart, 1989). Strangers were considered to be other cancer patients and other family members, who

were not part of the family caregiver's social support network prior to the patient becoming ill.

2.3.2 Community Support (Professional and Other)

In a Canadian study by Brazil, Bedard et al (2005), the most valuable services for caregivers consisted of home care nurses, family physicians, medical specialists, housekeeping and religious support. In this study, 370 Canadian caregivers were interviewed by telephone at two time periods (palliative diagnosis and approximately five months later) over two years. While most respondents reported their care services as supportive, caregivers did wish for additional housekeeping, respite, home nursing care, personal support workers, and support groups. The desire for one to three additional services was perceived as enhancing their supportive needs. They also wanted greater communication between HCPs and family caregivers. There were two limitations in this study. First, the participant inclusion criteria narrowed the sample to patients 50 years or older. Second, the study only included family caregivers who lived in the same geographical area as the patient. As a result, the findings have limited generalizability.

Rabow, Hauser, and Adams (2004) stressed the importance of the physician and patient relationship, and, the physician and family caregiver relationship. The authors emphasized that family caregivers were the patient's health care representatives in the home as they provided medical care, assessments, and decisions about the patient's care. They specified that the physician's responsibility was to support both the patient and the patient's family; thus, the family caregivers' abilities and coping skills

should be assessed. The authors identified ways for physicians to enhance their support to family caregivers: (1) excellent communication with family, (2) advance care planning and clear decision making, (3) support for home care, (4) empathy for family emotions and relationships, and (5) attention to grief and bereavement. For instance, they recommended that physicians provide proactive information to family caregivers about medical treatments and palliative care options available to the patient.

Strang and Koop's (2003) exploratory qualitative study, of how 15 bereaved Canadian caregivers coped with home caregiving, found home care nurses were a helpful professional support, particularly in the final home care days. The nurses' key contributions were: (1) demonstrating respect to the patient, (2) being sensitive and accessible to the family, (3) providing caregiving tips, and (4) guiding the family through the daily changes. Although this study identified some positive points of the HCPs support, the participants were only interviewed after the patient had died. Thus, they may have lost their original, at the moment, thoughts and reactions of being a caregiver.

In another Canadian qualitative, interpretive study conducted with 15 bereaved family caregivers, Strang et al (2002) found that home respite provided by a HCP meant that the family caregiver could (1) actively live with the dying family member, (2) catch up on sleep, and (3) complete errands such as shopping and banking. Spending time with the patient, as the spouse or adult child, rather than being the caregiver, also provided meaningful respite opportunities. Caregivers identified respite as a "cognitive break" where they could give up responsibility and not worry

about caregiving while at home. Participants also valued quiet time alone when professional respite was not provided. They found that reading books, completing crossword puzzles, meditating, and knitting provided a "mental break" from being a caregiver. Mental breaks were valued more than physical breaks away from home caregiving according to Strang et al (2002). As Strang et al (2002) summarized "respite was not a complete break from caregiving, it was a tool caregivers used to sustain themselves in their intense and emotionally complex situations and it was valued only as a means of keeping themselves going" (p. 101).

Another qualitative study conducted in Canada by Stewart et al (2006) involved a weekly telephone support service to 66 caregivers. The caregivers were telephoned by 27 more experienced family caregivers over a six month period. The telephone support provided the new caregivers the following: (1) improved caregiver support, (2) enhanced coping skills, (3) greater competence and confidence, and (4) lessened caregiver burden and loneliness. They discovered that telephone support positively helped new caregivers in their role. The main study limitation was participants were caregivers of stroke and Alzheimer affected seniors. While this study has valuable information, there are issues regarding the transferability to the larger palliative cancer population.

2. 4 Caregiver Responsibilities

Common caregiver responsibilities have included completing personal hygiene, preparing meals, housekeeping, shopping, transporting, obtaining legal advice, managing treatments and symptoms, and making financial arrangements (Aranda &

Hayman-White, 2001; Cameron, Franche, Cheung, & Stewart, 2002; CHPCA, 2006; Dunbrack, 2006; Hauser, & Kramer, 2004; Hudson, 2003; Hudson, Aranda, & Kristjanson, 2004; Hughes, Ingleton, Noble, & Clark, 2004; Kristjanson & Aoun, 2004; Reese, 2000; Singer, Bachner, Shvartzman, & Carmel, 2005; Stadjuhar, 2003). As Hudson (2003) commented, "the focus of home-based palliative care by families has changed from a simple caring role to more complex care, often involving advanced skills such as opioid administration and symptom management" and "the level of responsibility of a family caregiver depended on the physical and psychosocial needs of the patient and the dynamics of the relationship between caregiver and patient" (p. 35).

Waldrop et al (2005) noted that family caregivers started their role through assisting the patients with minor care tasks, such as driving the patient to medical appointments, administering medications, and helping with their mobility. Caregiving progressed as the disease advanced. Aoun et al (2005) acknowledged that "families are increasingly replacing skilled health workers in the delivery of unfamiliar complex care" (p. 551). Both Aranda and Hayman-White (2001) and Hudson (2003) specified that caregivers provided basic as well as more advanced nursing skills at home. These skills were bathing, dressing, feeding, preparing meals, cleaning the home, shopping, paying bills, driving the patient, listening, providing emotional support, assisting with mobility and toileting, giving medications (such as opioid and injectable drugs), changing catheters and diapers, assessing symptom management, managing wound care, and coordinating patient's care (Aranda & Hayman-White, 2001; Decima Research Incorporate, 2002; Fast et al, 2002;

Hudson, 2003; Macmillan, Peden, Hopkinson, & Hycha, 2004). Over two survey periods with 42 caregivers, Aranda and Hayman-White (2001) identified that the common symptoms managed were pain, constipation, dry mouth, breathing difficulties, and dizziness. Thus, the patient's declining health and dependence led to greater physical assistance and complex care by the family caregiver (Given et al, 2004). Strang, Koop, Dupuis-Blanchard, Nordstrom, and Thompson (2006) emphasized that family caregiving was far more complex than providing physical care. Waldrop et al (2005) added that another advanced caregiver responsibility was functioning as an executor for the patient's end-of-life wishes. Duhamel and Dupuis (2003) also found more family caregivers were keen to assist with their ill family members' physical problems but they were reluctant to assist with emotional support. Additionally, Singer et al's (2005) study of 150 caregivers in Israel observed that caregivers had difficulty expressing their feelings related to providing care to a dying family member.

2.5 Impacts of Caregiving

2.5.1 *Physical*

Strang and Koop (2002) identified that caring for a patient with advanced cancer was an emotional, exhausting and intense experience. When challenges related to caregiving greatly exceeded the caregiver's ability, the consequences were physical, psychological, social, and financial in nature (Aoun et al, 2005; Aranda & Hayman-White, 2001; Ferrell, Grant, Borneman, Juarez, & ter Veer, 1999; Hauser & Kramer, 2004; Hudson, 2003; Kristjanson & Aoun, 2004; Stajduhar, 2003). Kristjanson and

Aoun (2004) termed family caregivers as "Hidden patients" because of their various physical impacts from caregiving. Short term physical impacts included sleepless nights, physical and mental exhaustion, greater infection exposure, and bodily injuries from unsafely moving the ill patient (Aoun et al, 2005; Dunbrack, 2006; Fast et al, 2002; Grbich, Parker, & Maddocks, 2001; Hudson, 2003; Kristjanson & Aoun, 2004; Macmillan et al, 2004; Stajduhar, 2003). There was also exacerbation of existing health problems. Long term physical impacts included increased chronic health issues such as weight loss, insomnia, fatigue, burnout, and depression (Hudson, 2003; Stajduhar & Davies, 1998).

2.5.2 *Psychological/ Emotional*

Aranda and Hayman-White (2001), Dunbrack (2006), and Perreault et al (2004) reported that family caregivers exhibited mental fatigue, or poor concentration, anxiety, and depression as psychological responses to watching the patient suffer. Dunbrack's (2006) report added headaches and muscle cramps occurred when the caregiver's emotional needs were ignored. Guilt, grief and reduced self-esteem have also been documented by Hudson (2003) while helplessness and worry were found in Perreault et al's (2004) phenomenological qualitative study of six caregivers and four persons identified as support persons to these caregivers. Cameron et al (2002) specified that caregivers' emotional distress influenced their ability to participate in their own daily activities such as employment and social functions.

Ferrell et al (1999) surveyed more than 200 patients with cancer about their experience of pain management, and their family caregivers about caregiving. They

discovered caregiving impacted both the patients' and family caregivers' wellbeing, and thus, their overall quality of life. Family caregivers were found to have a worse quality of life than the patients had. They rated higher impacts in the following areas: physical (sleep disturbances, fatigue, appetite problems, and pain), psychological (coping difficulties, anxiety, depression), social (distress from observing illness, isolation, disrupted home activities and employment, financial burden, and limited support), and spiritual (uncertainty of death and afterlife, and praying). These caregivers provided care over twelve hours a day, with more than three hours daily devoted just to pain management. All participants had at least a few hours of home care nursing support; therefore, Ferrell et al's (1999) findings cannot be generalized to caregivers without any home services as to the impact on quality of life.

Another study compared 400 family caregivers' quality of life in caring for patients with cancer undergoing active treatment versus palliative care in the United States (Weitzner, McMillan, & Jacobsen, 1999). Self-reported quality of life questionnaires were completed by both patients and their caregivers. Researchers documented the patient's performance status and disease site. They found that caregivers caring for palliative patients had lower quality of life than those caring for patients undergoing active cancer treatment. Weitzner et al (1999) related the lower quality of life scores to the patients' declining functional abilities and caregivers increased care responsibilities at home. Increased responsibilities involved greater physical care, more emotional support, greater role changes in the family, and increased financial concerns. The authors concluded that when patients were physically declining from incurable diseases, family caregivers' faced greater

demands, and greater psychological and physical impacts to their well being; these impacts on their health were less when additional resources were utilized to care for the patient.

2.5.3 *Social*

Social impact refers to the influence of caregiving on a person's lifestyle. As home caregiving continued and the patient's symptoms became more complex, family caregivers became increasingly helpless and isolated within their "shrinking" world while they also feared the uncertainty regarding the death of their loved one (Dawson & Kristjanson, 2003; Perreault et al, 2004; Stajduhar, 2003; Strang & Koop, 2003; Syrén, Saveman & Benzein, 2006). Isolation was found to be a significant concern in relation to emotional and social risks to the caregiver (Given et al, 2004; Hudson, 2003; Strang & Koop, 2003; Stajduhar, 2003). Stajduhar's (2003) ethnographic study identified that caregivers described feeling "…'tied down' and 'stuck' (at home), and began to see their role as a 'job'" (p. 30). Strang and Koop (2003), in a study of 15 caregivers, similarly found that 11 out of 15 felt "suspended" in a "cocoon-like world" of being isolated at home (p. 109). Similarly, Perreault et al (2004) found that caregivers tended to limit friends and family social visits as the patient's illness progressed because these social visits became burdensome. According to Stewart et al (2006), family caregivers initially turned towards their family and friends for support. However, family support often declined and became insufficient according to Stewart et al (2006) and became a disappointment for caregivers (Perreault et al, 2004). Hudson et al (2004) discovered two further

challenges regarding to family as support: (1) dysfunctional and unhappy family relationships and (2) patient and family caregivers' opposing needs.

Feeling isolated in one's own home raised caregivers' need for greater personal and professional support along with home care respite. Strang et al's (2002) study examined home care respite by interviewing caregivers at two intervals. They expected that home care respite would permit family caregivers to leave the home to take some time for themselves. Instead, this physical break was considered wasteful as family caregivers did not desire time for themselves but enhanced non-caregiving time with the ill patient. Indeed, physical separation caused greater stress for family caregivers. Family caregivers' trust in the replacement caregivers impacted their ability to take a break, and increased their concern while away from the home. Furthermore, family caregivers recalled being worried about what they would have to face when they returned home. A limitation of this study was the large variation in the time frame when subjects were interviewed (one month to one year) which could impact their recall of events.

Family caregivers have also been shown to neglect their own needs in order to manage the patient's home care (Given et al, 2004). In Given et al's (2004) study, caregivers were torn between their work, family, and caregiving roles where they experienced "reprioritization or relinquishment of responsibilities" (p. 1106). Thus, the caregivers had restricted time or even abandoned their personal leisure activities, altered their routines to accommodate unexpected interferences, and overlooked their own health needs (Aoun et al, 2005; Aranda & Hayman-White, 2001; Given et al, 2004; Hudson, 2003).

Studies have revealed higher caregiver stress in younger (adult children) than older (spousal) caregivers (Given et al, 2004; Shyu, 2000; Vachon, 1998). Health Canada (2003) further specified that caregivers less than forty-five years of age voiced greater stress. Younger caregivers described competing responsibilities with employment and family obligations (caring for their children), whereas older caregivers were usually retired and felt a marital duty to provide home caregiving, although they often had limited financial income. Younger caregivers had to spread their time between their employment, home, children, spouse, and patient responsibilities (Andreassen, 2005; Dunbrack, 2006; Health Canada, 2003). The consequences, as Perreault et al (2004) revealed, were young children suffered when they managed without their mother while she provided home caregiving.

Surprisingly, Strang and Koop (2003) discovered that professional caregivers (HCPs) often caused additional stress to caregivers. In Perreault et al (2004) phenomological qualitative study, five out of ten participants received inadequate and sporadic HCP support along with longer wait times for nurses during the night and in rural areas. Pain management and community follow up after emergency department visits was insufficient; moreover, participants found that they received better pain management and palliative care support through the emergency department rather than the community services. Although participants were content with the family physician, physician specialists were difficult to contact once the patient was diagnosed as palliative. Home care support was only given when the patient's prognosis became poor. As Perreault et al (2004) discovered, when both professional

and family support was lacking, "it accelerated the decision to admit" the patient to PCU (p. 142).

2.5.4 *Financial*

In a study of 74 American caregivers, Waldrop et al (2005) found that family caregivers had several financial and employment concerns. Amongst these were inflexible work schedules, worry about job loss, unsympathetic work colleagues, and the need to make multiple requests for leave or be excused from business travel. In a study by Perreault et al (2004), caregivers had to modify their scheduled vacations or alter their employment status so they were more accessible to the patient at home. As a result, financial concerns increased with the cost of medical expenses, such as prescription drugs, or decreased income from being unable to work full time as palliative care responsibilities grew in the home. Further financial strains developed when family caregivers gave up their job all together to care for the patient at home full time.

Dunbrack's (2006) document added that significant financial risks occurred when caregivers were required to pay for expensive drugs, medical supplies, and additional nursing care for the home patient while having to take time off work or resign their employment. According to Decima Research Incorporate (2002) report on Canadian family caregivers' profiles, 23% of caregivers spent $100-200 "out-of-pocket" expenses per month while 17% spent up to $300 per month. Furthermore, 33% of Canadian caregivers experienced some interference with their work while 19% of caregivers reported significant job disruptions (Decima Research Incorporate, 2002).

Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle et al's (2004) three year longitudinal Canadian study measured occupational and financial impacts compared to the psychological impact on 89 pairs of caregivers and patients with breast cancer. The authors reported that caregivers were unable to work regular hours at their employment and lost hours of work because of caregiving. Those without extended health insurance incurred greater financial burdens due to the expense of prescription drugs. This study's focus on patients' with breast cancer limited its generalizability to other populations with a terminal illness.

2.6 *Factors Which Contributed to the Impact of Caregiving*

2.6.1 *Lack of Information*

Both Andreassen et al (2005) and Syrén et al (2006) acknowledged that family caregivers had difficulty providing care at home when they lacked knowledge of the patient's disease or community resources available to them. For instance, Andreassen et al's (2005) study looked at family caregivers of patients with oesophageal cancer where uncertainty was found regarding information on: (1) care for the patient, (2) understanding the patient's deterioration, and (3) contemplation of their own future. In recognizing uncertainty and lack of informational support, Aoun et al (2005) recommended that family caregivers be provided with information on the patient's diagnosis, prognosis, and treatment options.

Dunbrack's (2006) report surmised that family caregivers did not know what services were available to them; therefore, they could not ask for specific services. In addition, this report acknowledged a lack of 24 hour HCP informational services for

family caregivers who were expected to provide home care to the patient during the day, evening, night, weekends and holidays. When HCP coordination and communication were limited, it lessened the interdisciplinary team's comprehension of the patient's care requirements.

Informational needs, in terms of the type and amount of information, have been shown to change as the patient's condition declined (Dunbrack, 2006). Hudson et al (2004) emphasized that family caregivers may hold back their questions or concerns from the HCP due to perceived HCPs' time constraints and staffing shortages. Both Aoun et al (2005) and Dunbrack (2006) identified that family caregivers were reluctant to disclose their informational needs as they did not want to interrupt busy HCPs. Aoun et al (2005) suggested another explanation that caregivers feared that HCPs would perceive them as inadequate to provide home care to the patient. These reasons hindered the caregivers' access to valuable home care information and services.

2.6.2 *Poor Communication Between HCPs and Patients*

Communication challenges also existed between HCP and the patient. Hudson et al (2004) pointed out that poor communication impacted on the provision of care in the home. They suggested that HCPs might feel uncomfortable discussing death and dying with the patient or family caregiver. Furthermore, "health professionals may not want to give too much information too soon, fearful that they may cause more harm than good" (Hudson et al, 2004, p. 21). These responses could lead to the avoidance of pertinent care discussions with the patient and family caregiver

regarding goals of care and quality of life. A further difficulty HCPs faced in communicating with family caregivers and patients was the request to restrict information to others (Hudson et al, 2004). Such requests placed HCPs in an ethical dilemma when they attempted to provide supportive strategies to the patient and family unit of care.

In addition, medical jargon can be a barrier to communication (Dunbrack, 2006). Strang and Koop (2003) found that poor communication occurred between the physician and the home care nurses along with inaccurate coordination and scheduling of home care services. A further communication barrier identified in the literature was the family caregiver's coping mechanisms and inability to concentrate on the information given to them by HCP according to Hudson et al (2004). Caregiver's concentration, anxiety and information retention became impaired from sleep disturbances and disruptive environments (Hudson et al, 2004). The authors recommended that HCPs promote private, calm environments, and time for information to be understood and questions answered during meeting with family caregivers.

2.7 *Transitions of Care*

Meleis (2007) describes three types of transitions experienced by people: Health-illness, developmental, and situational. "Health-illness transitions" focus on specific medical changes that a person experiences. A cancer diagnosis would be considered a "health-illness transition" for both the person being diagnosed and their immediate family member. "Developmental transition" concerns a person's ability to change

into a new role, such as a person becoming a patient with cancer and attending chemotherapy appointments. "Situational transition" involves a person required to move or change their environment. Burge et al (2005) described one situational transition as a "transition in care". The patient moving from home to PCU is a good example of a situational transition.

2.7.1 *Developmental Transition*

The caregiver's developmental transition involves relinquishing aspects of their own life and that of the patient's life from pre-illness to palliative diagnosis (Strang et al, 2006). The developmental transition occurs when a spouse or daughter provides more hands on care, such as giving pills to the patient. Their caring actions modify their role to that of a caregiver; therefore, a role acquisition has occurred because of how the family member redefines lifestyle and responsibilities to accommodate the patient's care requirements (Kramer & Lambert, 1999; Waldrop et al, 2005). Waldrop et al (2005) conducted qualitative interviews with 74 American family caregivers to understand how caregivers transitioned into "end-stage caregiving". Caregivers became aware that the patient was dying when they: (1) received information of patient's disease progression, (2) observed patient's physical decline, and (3) witnessed a change in the patient's role and personality (Waldrop et al, 2005). Several limitations were found in this study. First, the caregivers were chosen based on the palliative patient's age (greater than 50 years) and Palliative Performance Scale of 40-50 (requiring greater physical care needs). Secondly, the recruitment

criterion was a minimum of two weeks caregiving experience; home caregiving for two weeks is a short time frame in the caregiver role.

2.7.2 *Situational Transition: The Transition to Palliative Care*

When patients are no longer receiving curative treatment, they transition from curative to comfort (palliative) care. Their diagnosis and treatment focus shifts; they often experience a change to being cared for by a new health care team and services (Dunbrack, 2006). A Canadian study explored how nurses helped families make the transition to being caregiver of a loved one who is dying (Reimer, Davies, and Martens, 1991). The researchers interviewed 24 family caregivers, either the spouse or adult child of the patient, in the home or the hospital environment. A transition process began with signifying the end of the patients' wellbeing (Reimer et al, 1991). Families noted four prominent, yet sudden, physical changes to the patient's health: (1) decreased mobility, (2) personal care dependence, (3) continuous weakness, and (4) reduced clarity of mind. These symptoms signified that the patient was "fading away" (Reimer et al, 1991). This realization caused distress and confusion because the person's death could no longer be denied. Changes occurred in relation to their family roles, relationships with other family members, own health, and their daily interactions. Shock, dismay, and resistance were common reactions to the change. This was particularly true when the realization of death was forced on caregivers.

Although caregivers recalled the patient's suffering, those, who managed a healthy transition, adapted or accepted the fact of their loved one's death. This was considered a new beginning in the transition process as the patient and family began

discussing death and initiating funeral arrangements. The authors suggested that nurses can help to normalize the families' transition by providing information, permitting "meaning making", and offering reassurance (Reimer et al, 1991). While this article provided valuable information about transitions in advanced cancer patients and their families, one limitation of this study was that the authors did not identify any differences in the period of time needed for each transition. It cannot be assumed that everyone moves through the transition process at the same rate.

2.7.3 *Transition from Home to Palliative Care Unit*

While studies have been conducted on family caregiver's experiences of admitting a family member with dementia to long term care institutions (Dellasega & Nolan, 1997; Kellett, 1999; Ross, Rosenthal, and Dawson, 1996; Strang et al, 2006; Zarit & Whitlatch, 1992), some have explored some aspect of transition in care during the end of life (Burge et al, 2005; Csikai, 2006; Dellasega & Nolan, 1997; Evans et al, 2006; Kellet, 1999; Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt & Van Den Bos, 1998; Reimer et al, 1991; Ross et al, 1997; Waldrop et al, 2005). When palliative care demands exceed what family caregivers can provide at home or the patients' disease progresses, they are often moved from home to the PCU setting for greater complex caregiving (Aranda & Hayman-White, 2001; Bowman, Rose & Kresevic, 1998; Hudson, 2003; Perreault et al, 2004; Stajduhar, 2003).

Evans et al (2006) conducted a one year retrospective qualitative study of 18 family caregivers in the United States. This study looked at admission reasons and transfer experiences from home to hospital, hospice, and nursing home. They found

transfer from home to an institutional facility was unavoidable due to the severity of the patient's condition, uncontrollable symptoms and safety concerns. When patients with acute medical symptoms were sent to an acute care hospital, family caregivers expected full treatment to be provided as these admitting symptoms were not connected to their palliative diagnosis. Conversely, patients transferred because of uncontrolled symptoms and imminent deaths were all moved from home to an inpatient hospice centre (Evans et al, 2006). They found that family caregivers' "shift in preference in site" changed when they realized the patient's symptoms and caring needs could no longer be met at home (Evans et al, 2006, p. 103-104).

In an American study, Csikai (2006) surveyed 108 bereaved caregivers' retrospective "perceptions of the communication process" from the palliative care diagnosis in the hospital through to the hospice or home transition decision. She reported that 21% of family caregivers discovered that the hospital physician did not sufficiently answer their questions when the patients were diagnosed as palliative. Consequently, caregivers chose to send the patient to hospice care in hopes of receiving greater information, emotional support and physical care for the patient. Csikai (2006) also reported that patients were less involved in palliative care decisions and that their place of care decision relied more upon the family caregiver and HCP discussions at family meetings. Half of the family caregivers made the decision for hospice because they doubted their caregiving abilities. Over half of these caregivers were only offered hospice, or less often nursing home placement, as an alternative to home caregiving. Csikai's (2006) findings revealed that: (1) caregivers were exhausted in the last week of the patient's life, and (2) both family

caregivers and patient's preferences could change based on available services and disease progression. Although caregivers identified hospice staff, nurses and social workers as the most helpful, the decision to move the patient to any palliative care setting was considered difficult and prompted anticipatory grief for all.

A Canadian study tracked palliative patients' transitions of care settings in their last four weeks of life (Burge et al, 2005). The data collections were completed of over 3700 patients chart audits regarding their transfers, reasons for referral to PCU, death location and demographic data. Their common transitions involved three care settings: acute care hospital, PCU, and home. The researchers discovered that patients within an active PC program experienced greater time at home and fewer hospital or PCU admission days. They showed that patients who had palliative care team services required only one to two transitions of care settings as their condition worsened; however, those, who lacked care from a palliative care team, experienced more transitions, were more frequently admitted to the emergency department, and had a greater likelihood of dying in the acute care hospital. These transitions caused negative impacts such as poor coordination and discontinuity of care, financial burden and psychological stress for the palliative patients and their families (Burge et al, 2005). Almost 50% of palliative patients endured one extra transition of care setting in their last four weeks of life. Another 30% experienced two or more transfers of care. The most common transition location was to either PCU or acute care hospital. Approximately 40% of palliative patients were physically moved to a new environment in their last two weeks of life. Those who had a greater number of transitions were often moved into an acute care hospital and slightly less to a PCU or

returned to their homes. Burge et al (2005) found that almost 70% of palliative patients' deaths occurred in acute care hospitals, little more than 30% at home, and less than 20% happened on the PCU. This study highlighted how palliative care services can prevent unnecessary transitions. This thesis will build upon Burge et al (2005) to provide insight into the patient's and family caregiver's experience of each transition.

2.8 *Summary*

This literature review reveals both positive and negative aspects for caregivers who have provided care to a family member with a terminal illness. Short term and the long term negative consequences of the caregiver role are well documented in the literature; however, fewer studies have focused on the positive aspects of this role. The literature review also identified factors which have contributed to many of the challenges family caregivers' face. These included limited social support, large financial expenses, progressive complex care provisions, and change of family role. The literature also suggested that although home is the preferred place of care at the end of life for the patient, uncontrollable symptoms, and lack of 24 hour support meant that for some patients it is not always possible.

Fewer studies have documented family caregivers' transitional experience of admitting the patient from home to a PCU. Burge et al's (2005) study used chart audits to gain an understanding of the pivotal, complex transitions of palliative patients from home to hospital to PCU. Other studies have collected data from retrospective interviews with bereaved caregivers. While they have offered valuable

insights, these studies have tended to rely on recalled events some time after the patient's death. McPherson and Addington-Hall (2004) found that bereaved caregivers' intense emotions, associated with grief, influenced their recollection of events. Thus, researchers are recommended to consider the timing of the interviews when gathering information retrospectively from bereaved family members because the information may change with the passage of time (Addington-Hall & McPherson, 2001; McPherson & Addington-Hall, 2004). In light of this, the researcher sought to gain a greater understanding of family caregivers' 'at the moment' experiences by interviewing participants shortly after the transition from home while the patients were situated on the PCU.

CHAPTER THREE: METHODS

This chapter will describe the phenomenological approach chosen to meet the objectives of this study. Also, it will encompass the sample, setting, data collection procedure, interview process, and approach to data analysis.

3.1 *Design*

As there remains a gap in knowledge regarding the experience of palliative caregiver's in the transitional period from home to PCU, a qualitative approach was chosen. This approach of data collection allowed for greater exploration of the phenomenon based on richer, more in-depth descriptions. As Gilgun (2006) emphasized, qualitative research findings provide insight into people's perspectives of conditions, values, preferences along with language and ethnicity. Sandelowski (1997) reminded us that "lives are lived and told in relation to other lives and in a historical and cultural context" (p. 127-128).

The researcher chose phenomenology as the specific qualitative method for this research study. Phenomenology promotes a rich understanding of a phenomenon within the real world as it is understood within the person's perspective and worldview (Polit and Beck, 2004). The person's interpretation and comparisons of what they see, hear, and feel is based on their lived experiences and how it is expressed to the researcher. As the researcher's goal was to gain understanding of the family caregivers' experiences of caring for dying loved ones from home to the PCU, this research design was appropriate. Accessing each family caregiver's everyday lived experiences allowed the researcher to accumulate greater insight into their

specific experiences; their rational of choices, included how they felt; and their collective commonalities and differences before, during, and after the transition from home to the PCU.

Heideggerian phenomenology holds assumptions that the interviewer and the interviewee each have separate worldviews as well as differing biases, but it recognizes that they are co-participants during their in-depth interaction (Loiselle, Profetto-McGrath, Polit, & Beck, 2007). This design acknowledges that the researcher has a pre-understanding of the phenomena and it can not be eliminated from his or her active participation within an interpretive phenomenology study (Benner, 1994; Koch, 1994; Loiselle et al, 2004). As participants have their own world with their own culture, language and values, meaning is understood in their interaction and interpretation of their daily events. Annells (1996) explained that "meaning lies in the individual's transaction with a situation such that the situation constitutes the individual and the individual constitutes the situation" (p. 708). Thus, the person is mentally, emotionally and physically situated in the context of their world and significant previous experiences impact how the person responds to the world they are situated within (Benner, 1994; Loiselle et al, 2007; Lopez & Willis, 2004). The Heideggerian phenomenological approach was the most appropriate research design to address this study's purpose.

3.2 *Methodological Assumptions*

Heideggerian phenomenology recognizes that the researcher's background, worldview, and biases cannot be eliminated, but rather, it be made cognizant of

during the data collection and analysis. The researcher's assumptions need to be taken into account so biases can be reduced during data interpretations (Louiselle et al, 2007). The researcher's background and biases involved: (1) being a registered nurse, worked as a home care nurse and case manager in British Columbia, (2) considering the patient and the family are a unit of care, and (3) believing that home care is the best place of care for palliative patients.

The researcher's assumptions, in relation to this study, also included: (1) family caregiving is complex, (2) PCU admission is for greater symptom management and/or family caregiver respite, (3) home to PCU transfer is a stressful time for family caregivers, and (4) the anticipated death of a family member is a sensitive topic.

3.3 *Sample*

A phenomenological approach entails a purposive sample focused on key informants (participants) and their experiences. Thus, the sample may not represent all the various cultures, ages and genders. The sample size is determined by the rich descriptions of data obtained and when the researcher recognizes repetition in narrative themes from key informants. Generally, a phenomenological study would have a sample size less than ten participants as noted by Polit & Beck (2004) and less than twelve according to Todres and Holloway (2006).

Inclusion criteria for the family caregivers in this study were: (1) age greater than or equal to 18 years old, (2) English speaking, (3) provided home caregiving to the patient for a minimum of two months, (4) patient's immediate family member such as spouse, child, same sex or common law partner, or otherwise as defined by the

patient, and (5) caregiver of a patient who has been admitted on the PCU for at least five days. By the tenth interview, rich descriptions were obtained, patterns appeared, and then data collection ceased. The total sample was ten participants.

3.4 *Setting*

This study took place in a palliative care unit (PCU) located in Ottawa, Canada. The PCU is a well recognized health care organization which promotes patient and family centered care along with teaching opportunities for all health care disciplines. The primary focus of the PCU is patient comfort care from a interdisciplinary health care team. The PCU contains 38 beds for terminally ill patients in need of twenty-four hour specialized interdisciplinary care and symptom management. The PCU is decorated in warm colours with numerous art work hanging throughout the halls which provides visitors with a cozier feeling compared to what would be found in a institutional, hospital setting.

There are 18 private one-bed, seven two-bed, and two three-bed rooms. Curtains separated each patient's bed from another patient in the same room. Patients and visitors regularly saw each other in the room, in the hallways and family rooms. Even when the curtains are closed, all conversations and sounds could be overheard. The only method was closing the doors to contain any noise. Thus, single rooms are the most private but patients are less visible to the nurses. There are large family rooms where patients and their families may watch television, listen to music, access kitchen supplies as well as just socialize and relax. Additionally, two other small, quiet family rooms are available for families to sit and talk, take a nap, or privately

meet. Evening nurses encouraged family members to stay overnight by offering, and bringing out night cots or reclining lounge chairs which could be placed at the patients' bedside. If a family member lived out of town and wished to stay overnight, a private room with a bed was available on another floor.

3.5 *Recruitment*

The researcher explained the study and its recruitment process to the PCU nursing educator, admission coordinator as well as staff nurses. Each staff member was given a copy of the study's information sheet for his/her reference. New patients on the PCU were screened by the admission coordinator or the nursing educator. If the patient was identified as coming from home to the PCU, then the coordinator would notify the palliative care educator by email. If the patient's family caregiver met the study's inclusion criteria, then the nursing educator or the staff nurses would approach the family caregiver within three days of the patient's admission to inform him/her of the study. If potential participants verbally agreed, the nurse would place their name on a formatted recruitment contact sheet (see Appendix D), seal it in an envelope, and place it into a designated mail box for the researcher. The name and telephone number of the researcher was provided to all the potential participants so they could directly contact the researcher. If the participant agreed, a meeting was scheduled. The most common time to meet was during the afternoon after lunch as the participants wanted to be present to either verify their loved one was eating or help feed them.

From January to May, only two participants were recruited. Factors responsible

for this slow recruitment included: (1) only half the beds on the palliative care unit were filled for no explainable reason during two months of this time frame, (2) patients were either dying en route to the PCU or present less than five days after arriving on the PCU, (3) majority of admissions were directly from two acute care hospitals rather than directly from home, and (4) the palliative care educator found it challenging to recruit participants within an already busy workload.

Due to the slow recruitment, modifications were made to the recruitment process. The first modification was the reduction of eligibility criterion from five days to three days on the PCU due to the number of patients rapidly dying on the PCU before five days. It was agreed that the initial contact from the researcher with the caregiver would occur at a minimum of five days post-admission to PCU, thereby, this still met the inclusion criteria as well as the research ethics boards' approvals (see Appendix A). In addition to this modification, the researcher regularly visited the PCU at varying times to talk with the palliative care nurses. If a potential participant was identified, the researcher provided the primary nurse with an information sheet and consent form (see Appendix B and C). These sheets were clipped into the patient's kardex to remind the staff to inform the patient's family caregiver about the study.

A total of 16 family caregivers were approached by the PCU nursing staff. Of these caregivers, ten participants consented to take part and were interviewed. This included two participants who were sisters from the same family. Five potential participants declined to be part of the study. The primary reasons given were: (1) being overwhelmed by fatigue, (2) concerned about the quick decline in the patients' health, and (3) complicated family dynamics.

3.6 *Characteristics of Participants*

Pseudonyms, chosen by the participants, were used to protect the identity of participants. By using their pseudonyms, the participant characteristics are summarized in the following Table I. All ten participants cared for terminally ill loved ones with some form of cancer. Eight participants were females and two were males. Four participants were older than 60 years, whereas, four of them were between the ages of 40 and 60 years, and another two were between 26 and 39 years. There was an equal number of Anglophone and bilingual Francophone participants. Two participants lived in rural areas while seven participants resided in the urban area. One participant lived two hours away in Montreal.

Most participants had resided with the patient prior to illness. One daughter moved her mother into her home when her mother could no longer live on her own. The daughter, who resided and worked in Montreal, lived with her mother during her weekend visits. This daughter, Marianne, was identified by the patient as the primary caregiver although a younger daughter lived with the patient most of the time. The younger daughter, Marianne's sister, felt emotionally unable to cope with caregiving coordination and medical appointments requiring Marianne to take primary responsibility. Isobelle, a wife who had been separated from her husband for many years, temporarily resided in the patient's apartment for a couple months during the patient's health decline and admission to PCU. One participant, Natasha, was a sister-in-law of the patient. Six participants were still working; the other four were retired. Only one participant had applied for the federal employment insurance compensation coverage.

The two most common caregiver relationships were spouse and parent-daughter. None were trained health care professionals. Three female participants identified that they had previously cared for a dying friend or family member prior to their present caregiver role. The length of the caregiving period ranged from 4 months to 15 years. Only two participants, sisters, had experienced a previous admission to PCU with their father. All other participants were experiencing their first admission to the PCU.

Table I: Participants' Caregiving Profiles

Name (pseudonym)	Age (yrs)	Gender	Taking care of	Relationship to patient	Caring duration (months)
Joe	26-39	Male	Wife	Husband	29
Natasha	40-60	Female	Brother-in-law	Sister-in-law	12
Rose	61-70	Female	Husband	Wife	6
Gerry	61-70	Male	Wife	Husband	4.5
Isobelle	61-70	Female	Husband (separated)	Wife (separated)	4
Marianne	40-60	Female	Mother	Daughter (oldest)	180 "since triple bypass"
3335*	40-60	Female	Father	Daughter (oldest)	27
Stripes*	26-39	Female	Father	Daughter (youngest)	24
Piper	40-60	Female	Mother	Daughter	21
Eva	71-85	Female	Husband	Wife	6

* notes that these two participants are sisters who expressed that they equally shared the caring for their father at home through to the PCU care.

3.7 *Protection of Human Rights*

This research study was approved by two research ethics boards: The University of Ottawa Research Ethics Board and the Sister's of Charity of Ottawa Health Services Research Ethics Board (see Appendix A). The participants were allowed time to consider their participation in this study, from the moment the nursing staff approached the potential participants, to several days later when the researcher

contacted them to discuss the study and request consent. At the first interview meeting, each participant received a written information sheet about the study, their rights as research participants and any risks associated with participation (see Appendix B). The researcher answered any questions from participants prior to offering them the written consent. Once they signed the consent form (see Appendix C), they received a copy of both the consent form and information sheet. The participants were aware of their ethical rights as research participants, such as they did not have to answer any questions and could withdraw from the study at anytime.

Prior to the commencement of the audio taping of the first interview, the participants were asked to create their own pseudonym name to ensure confidentiality. These pseudonyms as well as code numbers were used for all participants and inserted on all the study documents, such as labeling the audiotapes, transcripts and discussions with the thesis committee, to maintain privacy and confidentiality. All participant documentation, including consent forms, transcripts and audiotapes, were kept in a locked office. Additionally, the electronic files of transcripts, data analysis and the thesis document were kept secure in password protected computers.

3.8 *Data Collection*

The researcher initiated each interview by providing the consent form to each participant (see Appendix C). Once each participant had read the forms, the researcher asked if the participant had any questions. The researcher answered any questions, and re-affirmed the participant's right to withdraw from the study at any

time. Once the consent form was signed, a demographic questionnaire was completed (see Appendix D). This questionnaire was used so that the sample could be accurately described. The tape-recording was initiated once all the forms were completed. Each participant gave permission to audio tape the interview.

The researcher encouraged participants to clearly describe their caregiving experiences. Interviewing techniques included open-ended questions, paraphrasing, summarizing, prompts, and active listening. Some examples of questions asked were: What was it like looking after your family member at home? What was the move like from home to the palliative care unit? During the interview, the researcher monitored the participants for signs of fatigue, emotional distress or any other discomfort, in case reflecting on their loved ones care became too emotional for the participant. The researcher found that each participant's demeanor was open while they gave a description of their caregiving experiences of the patients from diagnosis to the current moment on the PCU. The length of the first interview varied from one hour to two and a half hours. Some participants displayed emotions of crying and anger during the interview. They were provided with an opportunity to stop, postpone or cancel the interview at any time. In addition, the participants were aware that they could request a referral to the PCU Clinical Nurse Specialist as a counseling resource if severe distress occurred.

At the end of the interview, financial compensation was given to cover the cost of each participant's parking. The interviewer reminded each participant that she would contact them for a second interview once all the first interviews were completed,

transcribed and analyzed. Second interviews, completed a year after the first interviews, are consistent with the phenomenological research method.

3.9 *Data Analysis*

Colaizzi's (1978) approach guided the study's analysis. Colaizzi's seven step method of analysis included (1) reading each participant transcription to gain understanding of meanings, (2) pulling out significant statements that emphasized the experience of being an informal caregiver, (3) developing the key meanings from significant statements, (4) organizing each interviews' statements into themes, (5) comparing each theme to original transcriptions of each participant, (6) creating an exhaustive description of the themes, and (7) completing follow up interviews to validate that the researcher's findings were reflective of the participants' descriptions (Colaizzi, 1978; Loiselle et al, 2007).

First, the audiotapes were transcribed verbatim by the researcher as soon as possible after the completion of the interview. Each participant's verbal and non-verbal communication was documented in the transcripts and field notes. Common non-verbal participant behaviours, such as crying, sighing, laughter, angry tone, short and long pauses, physical pointing to an object, were included in the transcripts as well as the researcher's field notes documented the researcher's initial thoughts and observations. This information provided the researcher, as well as the thesis committee, with a greater description and enhanced understanding of the participants' words, and thus, intentional meaning.

The researcher cross-checked all transcripts against the audiotapes and ensured their accuracy. Once confirmed, the researcher began a macro thematic reflection which included reading each transcript multiple times to obtain an essence of the individual participant's interview. A phenomenology research analysis requires the researcher to be open-minded while exploring the meanings of words and phrases of each participant. The researcher found it useful to summarize each interview to grasp the essence of the interviews. These summaries began the process of pulling common meanings from the transcripts. As Todres and Holloway (2006) stated:

> The articulation and clarification of the meanings in the text, both explicit and implicit, requires a 'reading' or strategy that entails a back and forth movement between particular expressions and details within the text and a sense of the meaning of the text as a whole. (p. 233)

The back and forth movement occurred between the individual transcripts and developing themes. Each transcript was analyzed line-by-line. Two inch margins on the printed pages allowed the researcher and the thesis committee to comment on emerging data themes. This greatly assisted the manual data analysis along with the use of individual coloured file folders for each theme. As the analysis proceeded, the researcher became more immersed within the data until all sentences of the transcripts clearly fit into agreed upon themes.

3.10 *Methods to Ensure Rigour*

In qualitative research, rigour is of the utmost importance to ensure sound research. This study's rigour was ensured through the use of four accepted

techniques: credibility, dependability, confirmability and transferability (Loiselle et al, 2007).

3.10.1 *Credibility*

Credibility is developed when the data findings seem accurate, or truthful, to all reviewers. In this study, the reviewers were the researcher, the thesis committee, and the participants. The thesis committee members reviewed the interviews, and discussed their interpretations. The thesis committee members met with the researcher until full consensus on the themes was reached. This preserved the study's credibility through seeking each member's interpretation and analysis of the transcripts. During the recruitment, data collection and data analysis phases, the researcher maintained a journal which reflected decisions made as the analysis proceeded. Additionally, the researcher recorded her personal responses to the interviews in field notes which also contained the participants' non-verbal behaviour, such as emotional responses during an interview question, or an interruption during the interview.

Once an agreement by the thesis committee about the themes and framework was reached, the researcher contacted all ten participants to review the study's findings. This is consistent with Colaizzi's (1978) final step where follow up interviews with willing participants occurred. This is also known as "member checking". The follow-up interviews confirmed that the analysis and interpretation accurately reflected the participants' experiences. This second interview was completed approximately twelve months from the first interview because of the length of time it

took to complete recruitment and data analysis. Five out of ten participants reviewed the developed framework and summary of the research. They were asked if these documents reflected their experiences as informal caregivers. The interviews were completed in the participant's home with the exception of one participant who lived two hours east of Ottawa. This participant did request that the framework and summary be faxed to her and a telephone interview occurred.

The follow up interviews varied from two to three hours, but audio taping only included direct review of the study's results. This discussion was an average of one and a half to two hours. The remainder of the time was devoted to social conversation with the participants. This step verified the researcher's comprehension of each participant's experience as well as provided credibility to the researcher's interpretations. The researcher noted participants nodding their heads in agreement, and retelling parts of their stories when a quote or the description fitted closely to their own experience. Further agreement was noted when participants were able to identify their own quotes.

3.10.2 Confirmability and Dependability

Confirmability is objectivity, also known as neutrality, of the overall data. This was established when objective agreement by two or more persons was found about the meaning, pertinence and correctness of the data analyzed. This was achieved through the thesis committee meetings and member checking. Both first and follow up interviews were audio taped and transcribed verbatim by the researcher as soon as

possible after the interview. Throughout the study progression, an audit trail was completed by logging critical decisions of data analysis.

3.10.3 Transferability

Transferability, also known as applicability or fittingness, verifies if the study's findings could be transferred to other settings and populations. This is accomplished by a thorough description of the participants and the research setting. In this study, all participants were selected with the assistance of the PCU nurses. This study had enhanced transferability as participants varied in age and backgrounds although cultural mix was limited to all Caucasian Canadian born. Although the researcher maintained that recruitment be conducted on primary family caregivers of any patient with a terminal illness, all participants in this study were caring for a loved one with advanced cancer. The sample participants included both genders, a mix of white-collared or blue-collared workers as well as the retired, English and French speaking, residences in rural and urban communities, and a variety of caregiving time periods from 4 months to 15 years. According to Polit and Beck (2004), this detailed description promotes an understanding and ease of transferring this study's findings to other participant groups, settings, and other studies.

CHAPTER 4: FINDINGS

4.0 Introduction

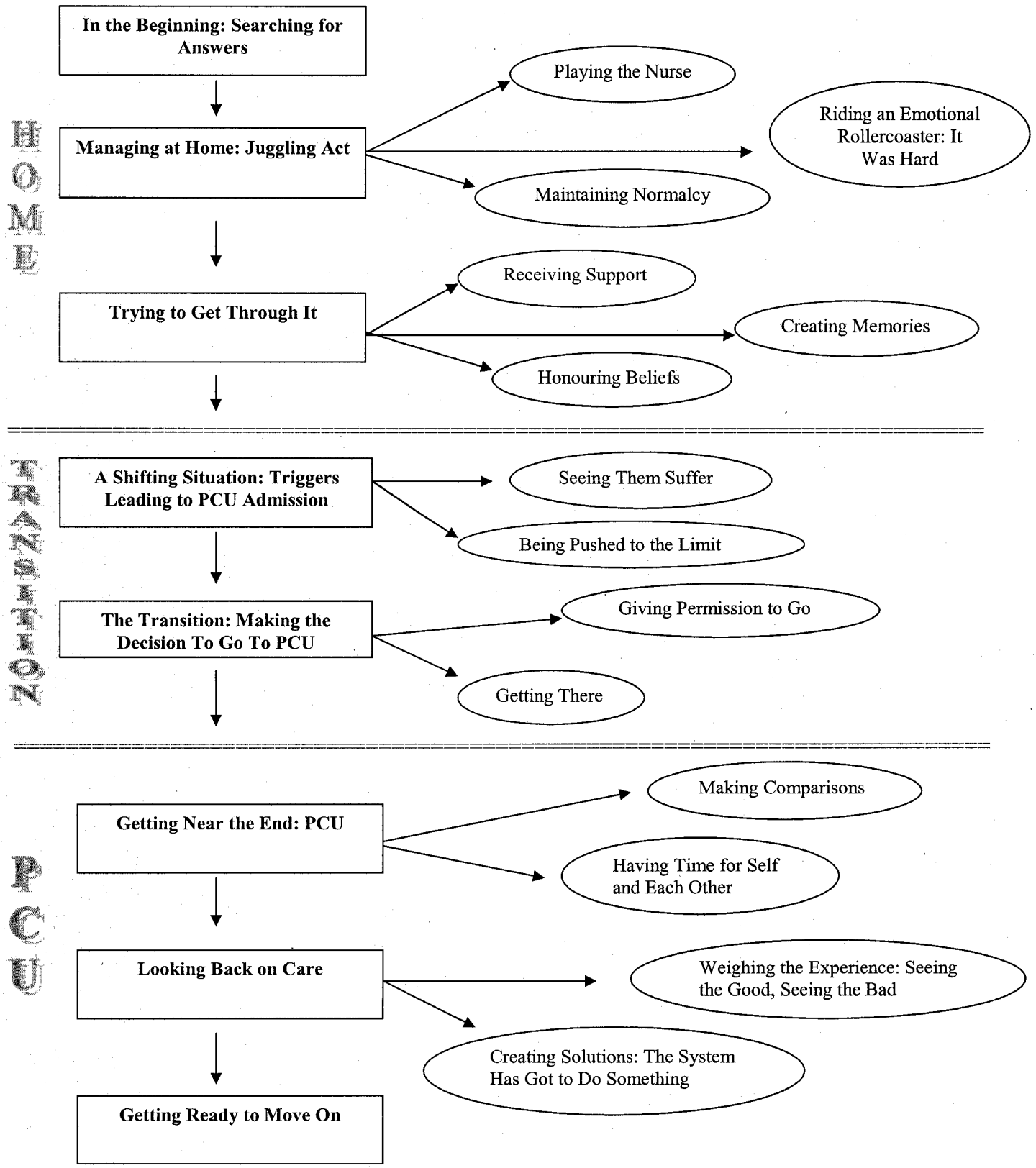
This study explored the experiences of family caregivers providing care to their loved one from the home to the PCU. The overall essence of the study was the *Transitional Experiences of Family Caregivers: A Puzzle of Care Provision.* Consistent findings were (1) providing care for a dying loved one was harder than they expected, (2) it was confusing to know where to access information and resources, and (3) there was considerable emotional significance to being the caregiver. Participants described caregiving as "*hard*", yet they managed to provide comfort care for their loved one. Albeit, when they received little help or resources, they continuously tried to access the appropriate assistance and community resources to provide quality, comfort care in the home and, later, in the PCU. When the patient was moved to the PCU, they discovered other difficulties. Overall, although palliative caregiving was not simple, informal caregivers did reflect on their experience by *"weighing the experience: Seeing the good; seeing the bad*" whilst they considered positive and negative aspects of palliative caregiving.

4.1 *Transitional Experiences of Family Caregivers: A Puzzle of Care Provision Framework*

The framework, entitled *Transitional Experiences of Family Caregivers: A Puzzle of Care Provision*, illuminates the essence of the family caregiver's journey trying to provide care to a family member with cancer from the time of diagnosis through to death (see Figure I). Eight thematic categories were identified and comprise the framework: "*In the beginning - Searching for answers*", "*Managing at home -*

Juggling act", "*Trying to get through it*", "*A shifting situation - Triggers leading to PCU admission*", "*The transition - Making the decision to go to PCU*", "*Getting near the end – PCU*", "*Looking back on care*", and "*Getting ready to move on*". The framework emerged from the participant's own words. Key participants' quotes are incorporated along with the explanation to illustrate each category and subcategory. The findings are presented as outlined sequentially in the following framework.

4.1.1 Figure I: Transitional Experiences of Family Caregivers: A Puzzle of Care Provision



4.2 In the Beginning: Searching for Answers

Participants started by describing the patient's initial symptoms, illness and diagnosis. Joe recalled how his wife was diagnosed with breast cancer:

> *She went for 3-4 mammograms and they all came back negative. She went for ultrasounds and... Everything was always coming back negative. And then.. her family doctor finally decided let's go for a biopsy. And then we will go from there. Sure enough we get the call and.. it is. And..umm. It was a shock to both of us.*

While some felt shock when they heard about the patient's diagnosis, five participants were already suspicious when the patients' ill symptoms first appeared. These participants were the motivators for the patients to visit their physician. As one participant commented, *"...Finally since beginning of April, I have been very, very involved. Taking him to the doctors and then he discovered he had cancer"* (Isobelle). Six participants attended appointments, particularly chemotherapy treatments, with the patient at some point during the disease trajectory.

Despite having had numerous questions for their family doctor, many felt that they did not receive any answers. *"At the beginning it was kind of...ok what did we do? Ahh..what pursue do we take? Ahh... who do we see ..."* (Natasha). These questions arose from limited knowledge of medical tests and available community resources. Some participants felt more investigation was required by the physicians into the cause of the disease and treatment options. Participants found they had to seek out answers related to the patients' care management in both the acute care hospital and community health settings. They turned to anyone who could help - Health care professionals (HCPs), family, and friends.

4.3 *Managing at Home: Juggling Act*

Caring for their family member meant that caregivers had to manage multiple responsibilities. Participants described how they juggled the responsibilities between (1) *playing the nurse*, (2) facing the feelings of *riding an emotional rollercoaster*, and (3) *maintaining normalcy* of every day living. Day after day, participants foresaw no relief or way to control their day beyond being extremely organized to carry out caregiving responsibilities.

4.3.1 Playing the Nurse

Participants assumed many responsibilities of a nurse. They provided hands-on care while they attempted to access help in the home. They described how these care responsibilities increased as the patients' symptoms escalated and dependency increased. When there were changes in the patient's condition and they appeared to suffer, participants attempted to access help from health care professionals to improve comfort care.

4.3.1.1 Providing care.

To provide twenty-four hour care, participants had to live with the patient. For five participants, this meant a change in living arrangements whereby either the patients moved into their homes or the caregivers moved into the patients' homes to provide care. This change in living arrangements was an adjustment for participants. One participant, 3335, described how she felt having her father living with her:

..At first.. it was like.. 'Oh my god!' Cause..you know.. we've..we've.. I've moved out of home when I was fifteen years old. Like that's.. you know.. thirty.. some odd years ago. And then.. you had a parent back in your house... It's like 'Oh my god'.

Furthermore, adult children emphasized the change in their roles when they began caregiving. Marianne pointed out:

You see your mom looking after you as a child and everything else. Then all of a sudden..the roles reverse and you see her as...that child.. role. Where you have to..to help her change. Where she is.. wearing diapers. She's got a walker. Ahh..Have to help her to the car..ahh..things like that. So I..I really really understand now..what caregivers really are.. and do.

The role change to caregiver meant participants assumed many responsibilities associated with being a nurse. They gave medications, prepared special meals, transported the patient, attended medical appointments, assisted with mobility, changed wound dressings, assessed symptoms, coordinated community HCPs, and initiated funeral plans. Natasha described her care duties in this way: *"basically.. if he needs to get up to go to the washroom. If he needs to be bathed or go to the corner store. I do all that. Uh...I pick up all kinds of medication..."* while another participant, Rose, stated *"after 4 o'clock, she (home care nurse) was gone. I did the nurse. I did the...wife, the..hahaha..whatever I needed to."* Participants' responsibilities and duties rose when the patient's symptoms escalated and functioning decreased. For example, as the patients' ability to walk declined,

participants' helped them with walking, transferring, toileting, bathing along with the assistance of medical equipment, such as walker and wheelchairs.

Participants found themselves busy with the patient's care, and many recognized that an organized routine was required to manage the 24 hour caring day of scheduled medications, treatments and health care appointments. Gerry explained:

> *You have to..you have to be very organized. Ok? Ahh.. For example, I should have been organized to do everything I had to do between 9 to 12 five days a week. ... If you are going to do groceries, you just don't do them the day you feel like it. You have to do it at a particular time because otherwise you are going to be scurrying around which is worse. OK? That kind of thing is what I mean by discipline. Plus, of course, she has got medicine to take. She has got injections that I have to give her. They are at a set time also. Ahh..I have to do the washing at the right time..and everything else. Plan the meals. The way the meals she can have. So all that has a certain amount of discipline..that you don't have and you have to acquire very quickly.*

4.3.1.2 Attempting to access help in the home.

Despite the challenges they faced in caring for the patient, many participants felt contented in being able to care for the patient. This was particularly true when they were able to provide greater comfort to the patient, such as pain control. When changes in the patients' condition occurred, such as from excessive pain and sudden falls, participants attempted to access help from HCPs so that they could maintain the

patients at home and lessen their suffering. However, many found that the community health agencies shared limited information.

4.3.1.2.1 ***Health Care Professionals.***

A variety of HCPs visited the patient at home: Physicians, registered nurses, registered practical nurses, physiotherapists, occupational therapists, CCAC case managers, and dieticians. Participants called on community nurses or physicians to guide and improve the treatment management. Often, they found themselves waiting for a physician or nurse to answer their calls or concerns. This could be hours or even days. Three participants indicated that they had to be "a pest" by continuously calling the HCPs until their concerns were recognized. Furthermore, participants expressed frustration at the inconsistency among health care professionals as well as poor sharing of information among each community service. Natasha commented *"neither of us knew exactly what to do. Even the home care, she would come in and say well "ok hi, do you know what pill to take?"* Gerry described his experience waiting for satisfactory pain control for his wife as:

> *..For example she was having bad, bad heartburn. She could not swallow. Ahh. The automatic thing is go to the doctor and say "she is having" this. And the feed back is "how long?" "One day". "Well let's see". And another day would do. And we are talking about terrible pain. Ahh. So we wait another day. Contact the doctor. The doctor sends the nurse. The nurse confirms she is in bad pain. Which is what I said three days ago. Ahh. Goes back and discusses it with the doctor and the doctor orders medicine. Takes it to the pharmacy. A day to*

deliver the medicine. She takes the medicine. It doesn't do very much. Call the doctor. Doctor says "Well, give it time". Another two days. She is still in terrible pain.

Family physicians were difficult to reach in rural regions because they rarely made home visits, even for palliative patients. Joe commented *"..because her family physician..umm.. does not go out to see his patients at home. ... ..but, we are out in the country so..a little harder to find. So there are only a few doctors that will do it."* Another patient fell and broke his arm while visiting the caregiver's country home. When the participant asked for the patient to be sent to the city hospital, where the patient was known, the paramedics denied her request. Instead, he was taken to the closest rural hospital even though it was further away from the participant's home and inconvenient for the caregiver and the rest of the family.

Accessing many key resources required a physician's approval. These resources included equipment, medication prescriptions, and referrals to PCU. Some found their family physician was not helpful. This lead to them either not obtaining the resources, or having to find an alternative method to obtain it through a different HCP or by going to the hospital. When home care services were provided, some found the services excessive, inappropriate for their actual needs, or inconvenient to their schedules. Piper explained:

We had home care. And when mom had..you know a bad few days let's say. Umm. Home care was increased to daily. But..there was nothing for this person to do. Umm...because my mom...wants company. ... She just wants...some company. Some people to talk to and hang out with.. Umm.. Not to be washed or

feed or cared for or cooked for. You know what I mean? Because at home I was there. So I did that. So we ..kinda again..we looked at each other and thought "what..what's a support person going to do?" If they come in for an hour or two hours a day. You know what I mean? It is almost... redundant. So we thought "Ok we will let somebody in to do.. something. And then.. we thought we were almost abusing the system. So the care was put back to just two hours a week .. From up to forteen hours per week.

Also, Gerry commented:

And the other thing about CCAC which comes to mind. They gave me help from 9 to 12. The unfortunate thing is here is the time that I am supposed to go out and do all these things and that is when the nurses decides to come. That's when the dietician decides to come. That's when – so..you know the time when I was supposed to be doing all these things was the time they would come. They were giving me help from 9 to 12. ... Because the nurse is coming and I want to be there when the nurse comes. The dietician – I want to be there when the dietician comes. Because I am the one who is going to give her the care. So..ahh..it was unwise on my part for not saying that nobody comes between 9 to 12 any day that I am getting help. I didn't do that. And I suffered for it. Because I had to call people in to do the things I should have done..during that time.

4.3.1.2.2 ***Resources.***

While access to HCPs was difficult, participants also found information regarding how to obtain community resources was inadequate. *"I find though.. to..is that..*

there's not enough information as to what's available out there. To help the families. To help the..the actual person in crisis. I feel there's not enough information" (Stripes and 3335). Another participant, Gerry, commented that he did not know about the CCAC or the palliative care team until reading a series of articles on palliative care in the local *Ottawa Citizen* newspaper. He said:

> *The articles that came out in the Ottawa Citizen about palliative care. A series of wonderful articles. ...We read them and all of a sudden we realized there were services that we needed. So. We went to the Cancer clinic. Ahh. We got the Community Care Access Center. We got referred to them. And we got referred to Dr. Y. Dr. Y's palliative outreach clinic.* (Gerry)

Thus, both city and rural participants frequently felt that they had to "stumble on" the needed resources. For example, Stripes, a rural participant, found it unclear to determine which community health care district she was situated in. This led to frequent miscommunications between home care nursing agencies. However, even those participants living in the city found little information on palliative care services available to help them such as Gerry described:

> *There was nobody. I called my family doctor and ok they are all the same. And I don't criticize them but they don't do house calls. So what could..the only way my family doctor could have reacted..is for me to either call him or to go down there and say. And. And it is very imprecise way of managing pain and changing drugs. But nobody would have coordinated the drugs. She was getting drugs from the Cancer clinic, she was getting drugs from the family doctor and then....*

Later, he added:

Ahh..spreading cancer is no longer the purpose. The purpose is how..amm..how much..how can we keep her (the patient)...out of pain as much as possible. Umm. Make her comfortable. And they (cancer clinic) are not in that business. ... My family doctor is not in that business. So the only one who is in that business is Dr. Y (palliative care physician) and people like her. ... I was lucky to stumble on it. And thank god. Otherwise....I..I would very much worry about the people who are being kept at home as they will be suffering more than they should. (Gerry)

As a result of limited information and difficulty accessing HCPs, participants felt both confused and frustrated while managing the care at home. They did not know where to obtain needed information, or how to access HCPs and medical equipment for the family home. They quickly learned to (1) continually ask their questions, (2) frequently contact the HCPs, and (3) become self-reliant while they waited for guidance and resources. This was something they never imagined would occur when caring for an ill loved one at home.

4.3.2 Riding an Emotional Rollercoaster: It Was Hard

Participants described the emotional ups and downs of providing care and dealing with the impending death. They frequently voice the phrase "*it was hard*" to describe this emotional rollercoaster. In addition to their own emotions, participants had to handle other family members' responses to the patient's illness as well as the patient's own negative reactions.

4.3.2.1 Handling family responses.

Participants juggled the patient's care, needs and wants. Five participants had to deal with "stubborn" patients, who refused to admit to their declining conditions and wanted to maintain their independence and control as long as possible. When describing the challenges of providing care to her mother, Marianne declared:

> *...My mother has always been a very independent lady. Umm. She does have a very stubborn streak. Ahh. Tell her to do something and it really rubs her the wrong way. You ask her to do it. She will give you the moon. So..so..it's..it's been..ahh it has been a delicate balance.*

While participants respected the patients' independence, they were concerned about the patients accident falls when they were independently moving about the house. As Rose said, "*...For that week, I slept for maybe..an hour each night. I was always listening. I was afraid he would get up..and fall. Because he was not very strong..on his legs....*" Similarly, Joe emphasized his frequent concerns about his wife's risk of falling:

> *...That was pretty much the time where she could not be left alone...for..for any period of time. Humm..before that if I had to go pick up my daughter from school, I could. I would leave half an hour and come back and she was fine. Cause most of the time she was sleeping. But towards the end, I did not want to do that because I was afraid that she would try to get up...and she had fallen a couple of times...Humm...even with me there. So, that is what worried me the most. She would try something while I was not there.*

Another issue was the variation in the patient's openness to discuss the cancer disease, deteriorating health and imminent death. When the patient was first diagnosed, all participants found that they could openly talk about their concerns and care plans. However, each participant described a period of time when the patient was distant, withdrawn, and non-responsive with them. They felt frustration when the patient closed communication with them. Participants suddenly found that they could not ask questions, obtain guidance or make plans with the patient over numerous days. Furthermore, some participants detailed how the patients distanced themselves from the caregiver. For instances, Joe recalled how he wanted to spend time with his wife during the Christmas holidays but "*...she did not want me there at Christmas. She did not want me there at New Years. She..She wanted to be totally alone.*" Participants felt emotionally rejected and stressed when they were unable to connect with the patients. Some realized that the patients were dealing with the reality of their cancer disease along with their upcoming death.

> *Umm..coming home finding him.. maybe asleep...umm..withdrawl (withdrawn). It's like "I am fine. Leave me alone". "Well do you want to eat? No. I don't want to do anything". ... As he was the type of person who would get up in the morning and do this, do that and suddenly..it is like a bomb. It just drops. ... After a length of time with all the resources that you get, you would think he would think. But some people don't think that way. Like I mean they say that.. they go into their own little world. They just..sort of just sit there and they..like will stare over there and they will say to them what is he doing? He's*

thinking..umm..he's not in his own little world because it is not the word to use but..he's like trying to like figure out what happened? How did it happen? And what do I do? He just doesn't want nobody to be in the way. He's just.. sort of..just well you can't say the word leave me alone..but..it is just like I want to be alone. But after awhile he would come back and say "I am sorry I...it didn't". Ahh..how would I say that? Ummm. "I thought I was doing best like you know not disturbing you"..like you know..umm..worrying about the problems..like you know you go through so many of them (Natasha).

Besides the patients' emotions, participants discovered that they had to handle other family members' emotional reactions as well. These family dynamics sometimes created greater anger and resentment between informal caregivers and other family members. Isobelle clearly described how she was torn between protecting her ill husband, and dealing with her sons' grieving responses to their dad's terminal illness:

And I think to.. the fact that I am having a hard time that the fact my children are having a hard..hard time with his death. Because he was never there for them. So..These... Especially one of them. The one (son) he lives in Halifax. He would like to... ..He would like to talk to him. About.. things in his head. I said 'You cannot do that. He's too far gone". You know. His mind is not a 100% and... I know that they are having a hard time... with.. their father dying. And that they cannot see him. .... That..that it is hard on many levels.

Study participants also explained how they had to protect the patient from family created tension, place limits on other family members' behaviours, and accept the

family circumstances (personalities and previous family dynamics). When other family members' reactions were unsupportive and disruptive, most participants rationalized the behaviours as the others' grieving process. For example, Marianne described how her family members were coping in different ways: *"And each one of us are handling it..in a different way. Some are in the bottle. Some are into drugs. Some are not wanting to deal with the emotions. Just can't. umm...It's my own fault."* Nevertheless, some participants wished other family members were more involved with caregiving. *"You wish you had.. more family. Or family who were.. there more often kind of thing. So that is hard" (Piper).* Whether other family members were involved or not, all participants emphasized that "it was hard" to handle disruptive family members.

4.3.2.2 Having mixed emotions.

Study participants describe a range of mixed emotions that included anger, frustration, pain, sadness, happiness, relief, and resignation. Negative feelings arose from participants' ongoing uncertainty about the care they provided, especially when they witnessed the patient suffering. When the patient suffered in pain, the participants emotionally suffered. Anger was experienced as a reaction to the patient's disease and difficulties accessing health care resources. They felt helpless and sad in their inability to control the patients' symptoms:

> *... I think that.. in a way.. it was ..rather shocking. You know. Umm..to.. to think that ..somebody could just ..almost vanish right in front of your eyes. And..and*

there's nothing you can do. There's nothing you can do. Yeah. it's..it's.. I'd..I'd say we were helpless" (Eva).

This "*emotional rollercoaster*" of emotions corresponded to the patients' "*very, very up and down*" symptoms. When asked what made it hard to be a family caregiver, Gerry stated *"Hard? Is umm... losing your partner. That has made it tremendously hard."*

Yet, positive feelings were also experienced by caregivers. When the participants were able to provide the needed care to the patient, they felt satisfaction. *"..I do a lot that I never thought I could. I'm proud. I'm proud of myself" (*Rose*).* Participants also felt fortunate to be able to spend the remaining time with the patients. They recalled quality time together as a happy memory of family caregiving and being with the patient. Time was spent on favourite past times (drinking tea, playing cards, going out for dinner) and, even, new activities (attending the theatre, and going on road trips). In addition, eight participants acknowledged that open discussions, reassurance and humour with the patient were key emotional supports for caregivers. Rose described how her husband re-enforced her support to him: "a*nd he (patient) was always telling me 'I am so proud that you can do this.'"*

4.3.3 Maintaining Normalcy

Participants talked about other responsibilities in their lives, such as young children, jobs, homes and hobbies. They strived to maintain normalcy. This was important for sustaining the home environment, their (own) lives, and those of the lives around them. They continued to meet their every day obligations of

employment, cared for their own family, and managed their own health issues as well as tried to take restful breaks (coffee break, walk). Six participants continued full time work although their ability to attend work was dependent on (1) the patient's state of illness, (2) flexible employment hours, (3) adaptability to work at home, and (4) the availability of supportive others. Natasha commented that *"it was a quite rough. Because it was meaning..like you know..leaving the office because I was the only one who would take care of him."* These participants reported talking openly with their employer with regards to their caregiving responsibilities. Two other participants clearly informed their employer that their priorities were to the patients and not to their work while they provided family caregiving. While at work, participants recognized being near a telephone as important so that they could be contacted. For instance, Natasha purchased a cellular phone so HCPs, the patient, and other family members could contact her easily. The rest of the participants were retired.

Three participants were raising young children while they also cared for the patient. Regardless of the child's age, all children were aware of the patient's illness and their parent's caregiving activities. For instance, Joe emphasized that it was beneficial for their daughter to know about her mother's cancer diagnosis and treatment so she was involved in the family situation. Two of the participants' children assisted their parents with caregiving including attending medical appointments, retrieving items, and helping with hands-on care. Despite these duties, participants recognized their need to maintain the young children's normal activities such as taking them to school, dance lessons and play groups.

Two participants protected their adult children from the patient's declining health and any disruptive family dynamics. They demonstrated protective behavior through not requesting their children's help and blocking potential escalations of unresolved family issues. Eva voiced that she wished not to disrupt her adult children's lives while her husband was dying. But overall, the participants' children were seen as a positive factor providing a distraction and happiness during an emotionally challenging period of time for both the caregiver and the patient:

> *...My daughter is an..inherent diversion. Because she is extremely active...umm. And umm...sigh... Well, it is just a busy household. Yeah. Which I think...kept mom going as well. It's..it's so alive. You know. So..so much activity going on. You know. Good and bad. Crazy..crazy household. But...she..she was right in the thick of it. It made her..it made her very much alive.* (Piper)

Four participants had to deal with their own health issues such as disabling arthritis, remission of cancer, and even, recent cardiac surgery. As Gerry illustrated,

> *...I was tied up at home near the end..with my wife twenty-four hours a day that I could not even go out and do groceries. Umm...I couldn't do exercise program as I had open heart surgery. I couldn't do my exercises. I couldn't leave long enough to do it. They (CCAC) provided (an) individual that came to the home. From 9 in the morning to 12 noon. Five days a week. Which permitted me to do my exercises and a little bit of groceries. At least do a little bit of things.*

These participants tried to manage their own health concerns without overburdening themselves at home. They recognized that they needed to take breaks such as going out for a walk or a coffee. *"..Just for me..to get out and go for a cup of coffee and*

come back and say 'ok. Pfuuu. I.. I have relaxed.' ... Like you know when you're taking care of a person...you have to take some time out" (Natasha). These breaks reduced the caregivers' frustration and stress while at home. Others talked with friends and work colleagues as well as distracted themselves with children, their own or nieces and nephews, pets, hobbies and school work all of which offered some relief from the daily caregiving stress. Overall, maintaining normalcy in the home was very important to participants' and their children's intact sense of self.

4.4 *Trying to Get Through It*

Participants used various ways to "try to get through" their day. *Receiving support*, *creating memories*, and *honouring beliefs* were helpful methods. *Receiving support* involved unsolicited help from others as well as professional support. *Creating memories* was a positive outcome of caregiving for both the participants and the patient while *honouring beliefs* motivated the participants to continue caregiving even beyond their physical abilities and daily challenges.

4.4.1 Receiving Support

Participants received unsolicited support from non-professionals, such as work colleagues or family and friends, as well as from professionals. Professional support consisted of help from employee assistance programs or elementary school counselors. Being able to openly talk about frustrations and experiences gave them emotional support. Piper remarked "w*hat helped? ... I guess talking a lot about it to a lot of people."* Joe agreed by stating *"like I would talk about it*

(to co-worker)..but I wouldn't show...how it would it effect me. Umm. Just the fact that I actually talked about it. It actually made me feel really good. Because I was actually getting some of it out."

Physical support was much appreciated by participants and often came unsolicited from friends and co-workers. It enabled them to run errands or have some time to themselves. Friends, co-workers or some family members picked up medications and groceries, and even provided substitute caregiving. Gerry declared *"then of course, I could get a family member or someone else to come and stay for other things I needed. So that was tremendous. That part of it was very good."* While many participants expected more physical support from family members than they received, they were concerned about overusing the support from friends and co-workers. Other participants chose not to request support from their family as they did not want to disrupt other family member's lives.

4.4.2 Creating Memories

A second way of "*trying to get through it*" involved participants enjoying quality of time with the patients. This time gave participants and patients the opportunity to create lasting memories together. Participants recalled positive moments with the patient, such as celebrating special dinners; creating scrapbooks; going out on road trips; attending theatre performances; preparing the patient's favorite meal; taking a walk; and openly talking about funeral arrangements, other family members, and memories of the past. For example, Marianne remembered her mother's request for a special dinner:

"You know that African dish that you make with curry, ..and meats." She said "I really would like that for supper tomorrow". I said "Mom. Mommy, it would be a pleasure to make it for you". And..and doing so..she has made me realize how she felt in doing it for us. How much pleasure it gave her. Now I can do it with...in return. In giving to her. Because she is receiving. And it is nice to be able to set her place her first. And have her sit at the front of the table as she should be..served. As a mother should be served."

4.4.3 Honouring Beliefs

Honouring spiritual beliefs and core values comprised a third way of "*trying to get through it*". Participants' beliefs compelled them to continue providing care at home. Six participants indicated that their spirituality had significantly supported them through the caregiving experience. Their faith assisted them in believing that they could continue to provide comfort care, and could get through each difficult day and night. As Rose reflected, *"will power. And praying. Every night praying, I have a Saint that I love very much. And I guess she is the one who is helping me. For me..I guess that is where I get my help."* A saint, a prayer, and a belief gave participants' will power, reassurance and faith.

Most participants expressed an inherent core value to care for the patient. They also doubted if anyone else could provide this care. Piper acknowledged that her sister had a more suitable personality for caregiving, but she rationalized that the experience would "*...perhaps it will make me a better person or a stronger person....*" There was also a sense of duty to the patient. Married participants felt a

need to look after their ill spouse whereas adult children felt a sense of reciprocity to care for their parents based on the care provided to them by their parents. While Stripes noted that it was her duty as the eldest child to care for her father, Marianne called it an "honour in a way to be able to help her…go…get there." *"Yeah.. so you know.. it's just payback. Yeah, he did a lot for us" (Stripes and 3335).*

4.5 *A Shifting Situation: Triggers Leading to PCU Admission*

As participants continued caregiving at home, they identified a shift in their ability to care for the patient. This shift resulted from an increase in the complexity of care required. Participants described two types of triggers that made them realize more care was required and something urgently needed to be done. These triggers were "*seeing them suffer*" and "*being pushed to the limit*".

4.5.1 Seeing Them Suffer

Participants witnessed the patient's increasing symptoms and assistance needs, as well as declining health and overall suffering. Increased symptoms included escalating pain, uncontrollable vomiting, poor nutritional intake, ongoing weight loss, excessive fatigue, and sudden falls. Gerry detailed:

> *Ummm. Going through the process. It got harder and harder. At the start, there was no problem because..ummm..I had to do something, I could say "stay at home and I will go do it". It was no problem as she was walking around, could go to the bathroom, I could even take her out in the wheelchair. We even went for breakfast and a few things. But as it progressed, she could no longer go out. She*

had to be inside with her walker. So that was ok. That was more difficult. But still quite acceptable. A really difficult period is when she can no longer stay by herself. Ok. That became very – we don't have any children so it is a different case. So it became very difficult. You would either have to call somebody.. or get somebody in the home.

Participants found it difficult to watch the patient's symptoms escalate to a point where they could not help them. Piper explained *"and in my heart I knew that. And a...it was just difficult to see. To see. To watch. ... Watch her suffer. Watch her suffer."* Participants observed the patients steadily worsen over a period of several weeks. *"..The weekend before..umm..or two weeks before she..or the weekend before she made the decision that she was ready to come in...umm. She was really ill. She was not keeping any food down. She wasn't keeping her medication down"* (Joe). They realized that the patient was becoming "really ill".

In an attempt to deal with these issues, participants tried to give breakthrough pain medication, encouraged the patients to eat, and monitored their nutritional intake. They finally realized the patients were severely ill when they first showed excessive pain. Later, they noted that the patient had no appetite, showed no interest in eating or were unable to keep digested foods down (non-stop vomiting). The patients' increased weakness and sudden falls were the final indicators for them that the patients were severely ill. At this point, several participants questioned if they would be able to lift the patients without injuring themselves. They began to feel overwhelmed and doubted they could handle the escalating complex care as Gerry emphasized *"...and I was not meeting the goal of care. Keeping her comfortable."*

4.5.2 Being Pushed to the Limit

Along with the decline in effective management at home, participants felt "*being pushed to the limit*" of their capabilities which led to their realizations that home was not the best place to provide care. Rose explained *"For that week, I slept for maybe..an hour each night. I was always listening. I was afraid he would get up..and fall. Because he was not very strong..on his legs."* Constant worrying, sleeping very little at night, increasing physical care needs along with safety concerns of injuring themselves if the patient fell were frequently on participants' minds. Isobelle reflected:

> *Because I knew I could not take care of him. I mean if he falls how do I get him up? Although he's... He only weighs a 150 pounds, but he still will be a dead weight and I..I am nearly 70 years old. Boy. There are somethings I cannot do anymore.*

The final triggers that pushed the participants to their limit were: (1) a lack of additional help (professional and family), (2) the presence of medical equipment which overtook the home, and (3) the degree of the patient's suffering which they recalled as the "worst weekend" ever experienced at home.

As the patients' condition deteriorated, HCPs still relied on the participants for 24 hour care in the home even when the family support and health care services were limited. Patient care had become more complex; nonetheless, participants were still the primary caregivers at home. The amount of equipment and medical supplies in the home grew as the patient's further health declined. Participants described medications, needles, diapers, commodes, hospital beds, walkers, and wheelchairs in

their homes. Commodes and hospital beds were placed in living rooms. Needles and medications were added to bathrooms or kitchens. Equipment spreading throughout the home caused anguish for some participants. Their house was no longer their "home" as it had transformed into a medical like setting. Also, the patient's and participant's privacy and quality time together lessened as participants shared their home and their loved one with numerous HCPs. Rose stated:

> *That was the worst part. Having a hospital bed.. in the living room. Changed all my living room...completely because to put..ahh..a bed. A hospital bed takes room. A commode. A table. And then...all the supply that we need when the VON was coming to change his ahh ..ahh..his tube here (gestures to left abdomen) for a pump. So. Really the the. It is only a living room. ... It is like someone..had take a armrior and knocked me down. It really, really make me down. Having all the...the house all upside-down like that.*

While the participant's home felt smaller with increased medical supplies, numerous HCP visits caused additional stress and inconvenience. Participants were uncomfortable spending quality time with the patient when a HCP was present as they often felt they were physically in their way.

Participants typically described their worst experience as the last weekend at home that pushed them to their limits: Joe remarked *"that..that weekend was actually, probably the worst one. Umm..For her pain just became unmanageable. You know... Every couple of hours she would wake up yelling and screaming..at night. That was probably the roughest weekend I had."* Furthermore, Gerry added his reflection:

Very, very difficult. That was the most.. traumatic part for me. Ahh. I could stand the work. I could stand being there 24 hours. I could stand having to call someone to come in to do something. I could not stand...seeing her in pain day after day. This happened to her on two to three occasions. One was her leg. She had complained for god who knows how long about her leg. Ahh.. It took along time before we resolved the problem. Eventually, it was resolved. But she still had to suffer for about a week. Which really..that was the most tension that I had. To see her in pain. And I think I realized that was the worst for me. The rest of the stuff I could handle pretty well. It would go away. That. That was the worst part.

When the patients required total care, yelled in pain, or were completely confused, participants knew that they were pushed to their limit. They knew that they could no longer provide care to the patient at home.

4.6 *The Transition: Making the Decision to Go to PCU*

Participants placed significant meaning on moving the patient from home to the PCU. *The Transition: Making the decision to go to palliative care unit* was the first step towards the actual transition of care which involved both "*giving permission to go*" and "*getting there*". This transition of care forced participants to acknowledge the extent of the patients' illness and the impending death. They believed that once the patients left home, they would never return.

4.6.1 Giving Permission to Go

The decision to move from home to PCU was not made by the participants in this study. Instead, the patient and a HCP typically decided on the move. Joe emphasized:

> *..When she made the decision..like she said it herself..umm..she said she felt relieved and it was a load off her shoulders. She made the decision. It..it was done. She said 'there is not turning back. I am definitely going in on Monday.'*

Also Marianne commented, *"It was hard for her (the patient). Like I said..it was a very surmountable decision. For her to decide to go to palliative care."* The care transition was usually recommended by a HCP, such as the home care nurse or physician, because the patient's symptoms were uncontrollable and beyond the practitioner's expertise to manage the patient's care in the home. Isobelle recalled that "*the nurse.. said 'hey, this man has to be in the hospital. There was no two choice(s) about that.'*"

When the HCP offered admission to institutional care, the patient either gave permission (agreed) or negotiated more time at home. Two patients requested extra time at home prior to being admitted to the PCU. Patients' requests were respected even when it was against the participants' own judgments and capabilities to continue caregiving at home. Participants felt a sense of relief once the decision was made, but they neither told the patient that they could no longer provide care, nor raise the suggestion for PCU admission. This was clearly indicated in several participants' comments. Rose recalled:

I said "well. It is not me who told him" I want you to go. You see..for me. I was ahh...glad that it was coming from him. Not from me. Because I..I wouldn't..I couldn't do that. I wouldn't tell ahh..one morning well that's enough. You have to go to the hospital. I always said no, keep him as long as he wants to be here. And even if it is hard..for me..having all those people in the house..ahh..no, I will keep him here. I always told him "I will keep you here as long as I want as I long as I can and as long as you want to stay". It is because it was his decision. Other than that he would be at home again. Still at home. So..ehh.. I said well that is what he wants. I am happy with that. If..if that is what he wants. And..I guess..that was his wish. So...ok then.

Eva added her reflective thought:

No, no. It was taken out of my hands... .... Somehow or other.. I would've kept him at home. You know. .... Yeah. I..I think.. somehow or other. You know.... I would've. .... Ahh.. Just the fact that I don't want him to go.

4.6.2 Getting There

Getting to the PCU involved both physical and emotional acceptance of a change in the patients' condition and impending death. The actual transfer to PCU was directly organized by either the home visiting nurse or the physician. As Joe illustrated, *"..I spoke to the Doctor on the Sunday night and he said he would call again at the (PCU) on Monday morning to make sure everything is set. And...the home care were trying to set up an ambulance...."* Six patients were directly

admitted to the PCU by a physician's referral. Those without referrals ended up at the only point of entry into institutional care: a hospital emergency department.

While direct referrals led to a one-step transition, four patients experienced a two-step transition, by first being admitted to the emergency department and later to the PCU. Three patients were admitted to an acute care unit for up to a week while further medical investigations were performed. Once the full diagnosis was determined, patients were offered comfort care measures and transferred to the PCU when a bed was available. Only one participant noted the transition to the acute care hospital as a benefit. It prompted the patient to recognize her circumstances and ask for palliative care measures. Conversely, two participants acknowledged that they had to demand answers and request a transfer to PCU from acute care hospital physicians and administration. Eva, for example, expressed frustration with the ongoing tests and discomfort her husband experienced while at the acute care hospital. She was dismayed at the lack of information that was provided to her. Eva did not receive her husband's diagnosis and prognosis until her son demanded a family meeting which stimulated answers and the patient's move to the PCU. Similarly, Isobelle had to request several different HCPs' assistance until she received a very empathetic and helpful social worker, who understood Isobelle's concerns.

For most participants, the physical transition went very smoothly but emotionally it was very difficult. *"I thought it was going to be extremely difficult. Umm..But I found it extremely easy. Umm. The people we were talking to..umm the home care, the nurse, the doctor and the people here we were talking to just.. made it so easy" (Joe).* Gerry described the transition of care as *"emotionally very difficult. But*

physically it was easy. ... For me, very difficult. ... Emotionally very difficult. Because..umm..for both of us we knew it was the end. Ok? She leaves the home and will not come back. OK? So. Emotionally very difficult."

Six patients moved to PCU by ambulance. Two participants reported the transfers as negative experiences. Eva stated "I felt it was mean" when she observed how the paramedics restrained her husband to prevent him from removing the intravenous in his arm. Piper declined the ambulance transportation because neither she nor her mother were ready to recognize the significance of the disease by seeing an ambulance in their driveway. Piper emphasized:

> *Her doctor umm..and everyone else insisted on..on an ambulance. And you know.. There was no way in hell Mom was going to come here (PCU) in an ambulance. As far as she was concerned. And me. There was just no way. So she packed up some stuff and I drove her in. Got her here and got her settled. And that was fine.*

4.7 *Getting Near the End: PCU*

Once on the PCU, the study participants began *making comparisons* between the PCU and the family home. There were both positive and negative aspects to being on the PCU.

4.7.1 Making Comparisons

Participants recognized that the patients were now being "*cared for properly*" as their symptoms improved. However, they also indicated that the PCU setting was "*it's not home*".

4.7.1.1 Cared for properly.

Participants typically admitted "*it's a relief*" that the patient was finally cared for properly once on the PCU. The PCU staff's swift reaction time meant that the patients' symptoms were rapidly relieved. Another positive outcome for the caregivers was "*I can get knowledge*".

4.7.1.1.1 ***It's a Relief.***

The participants felt "a lot of relief" when the patient was admitted to the PCU. HCPs on the PCU were viewed as knowledgeable, experienced and able to provide quality care. Joe reflected:

> *Well, just knowing she would be well taking care of..umm..because there are a lot of things I can't do. I am not a nurse, I am not a doctor..so..umm. There is just a lot of relief that..somebody was there that knew what to do.*

Natasha added *"less stress. Less worrying because I knew he was here and I was not at home saying 'ok, fine - did I miss a pill, was he supposed to do this?' It is like. It was put into a level for me."* Rose acknowledged that having home nursing services during the day was not equivalent to 24 hour PCU care. One of her concerns had been what to do if

the patient's symptoms escalated during the night. This concern had impacted her ability to sleep at night. As Rose described:

> *So I prefer seeing him here. I know if there is something there is always professional help. They can call the doctor. If the nurse cannot do anything, they call the doctor. Asking the doctor what they got to do...with the patient. So..at least..at least I don't..I prefer coming here...seeing him here and coming here everyday than being at home and wondering what to do at home. At least here I know there is someone. Professional people I can ask for help. .... It is the best thing for me. That's how I feel.*

Gerry explained that it took seven days in the community to respond to his calls of concern, whereas, the PCU staff responded immediately and controlled the patient's pain within one hour. He said "*that is the difference between home care and care in an institution. As soon as a patient starts getting terrible pains, which has to be controlled, there comes a time when (its) the reaction time (needs to be quick)*" (Gerry).

Patients improved on the PCU to the extent that they were able to enjoy meals and quality time with their family again on the PCU. Marianne stated *"for the first time in my life..my..like I can say my mom is well."* Consequently, participants were pleased with the PCU care. They found that they could return home and get caught up on some sleep with the reassurance that the patients would receive proper care. Participants felt reassured that the PCU staff would call them if any significant changes occurred with the patients.

4.7.1.1.2 ***I Can Get Knowledge.***

Participants also appreciated the ease of access to knowledge from PCU staff about the patient, the dying process and available community resources. For example, Stripes and 3335 compared their searches for information in the community versus the PCU:

> *It's..it's almost like... you gotta dig, and dig and dig (for information when at home) and you feel bad. Like we were lucky because:..ahh.. you know we dug and plus.. we had more information from here, from (PCU). They (PCU staff) were quite helpful...you know..to get us the information. But people out there... who ahh.. it's their first time... it's harder for them. So.*

Information was offered and questions were answered by palliative care nurses and social workers. Eva stated *"and.. I thought that.. the nurses who were.. so good. You know..to say this is the (dying) stage that he's in ..and you know breathing is going to change...and the coloring you know in the feet..in the fingernails...."* The PCU staff were the first HCPs to advise participants in this study about the community pain and symptom management team and hospice services. They were also given pamphlets about the dying process. Overall, participants were satisfied with greater understanding of the patient's condition and the care provided.

4.7.1.2 ***It's not home.***

Although participants appreciated the improved care, there were negative aspects to care in the PCU versus the comforts of their own home. Both participants and patients needed to adjust to a new setting and to feeling like a guest on the PCU.

They had to conform to the routine of the unit. Participants indicated a greater degree of adaptation than the patients.

4.7.1.2.1 *I'm a Guest.*

The PCU did not offer the comforts and familiarities of home. Thus, participants and patients had to adjust to being "*guests*" on the PCU where they were required to follow the routine and rules of the unit. One aspect of feeling like a guest was that participants had to rely on the PCU staff for updates on the patients' conditions by sudden telephone calls or discussions on the unit. A few participants recalled situations in which communication was vague when they were called about a change in the patient's symptoms. This caused anxiety for three of them who had to quickly return to the PCU to find out what had actually occurred.

> *I still..still..you know that the phone will start ringing and I get jumpy. But at midnight. I just have to go downstairs. So then I do not get woken when I am in bed. I can check to see if they phoned. My son does have a phone in his bedroom. Ok? So that I..I feel better. I can ignore. Not so anxious. Still stressed out, but not so..as stressed. As I as stressed out. It was not easy.* (Isobelle)

Care on the PCU meant that participants had to travel there from their home. Once there, they experienced challenges in eating proper meals during their visits due to limited cafeteria services in the building. Many felt guilt at no longer having the patients at home in familiar surroundings. Piper clearly described her mixed feelings of relief and guilt:

It is good..because of the care. Umm.. It's umm...it's not good because it is not like a home like environment. Umm...I know that...mom loves the people..and just thinks the world of the doctors, the nurses, the social workers and the volunteers. The whole thing. It is fantastic! She cannot say enough about them, but it is still not a...it is very clinical. Because it is a hospital... ummm... and... a...there is not too much you can do about that. I think..ummm... Paint the wallpaper, but..I am sure that would not help either. .... Yeah. Because of the clinical place of it. Ummm.. Yeah. It is just not her stuff. You know. She is not surrounded by her stuff.

Furthermore, many participants found it difficult to observe and overhear other patients dying on the unit. In shared ward rooms, the awareness of other dying patients was visually and audibly could not be avoided. Even patients in private rooms could not be isolated from others' deaths, they heard the talk and noticed who was missing on the unit. In particular, some participants described seeing bodies moved into the hallways reminding them of the reality of their loved one's impending death. Thus, participants tried to protect the patients from these sights, and from the news of other patients' deaths. As Stripes said,

I'll tell you that it's not easy... always... in a hospital cause you know... you're..you're always here and you see lot of sick people... And... You don't want to get sick yourself or anything like that. You know. That's.. the hard part too! You know. And for us too. And you see more and more of that...then you are going to go down too. .... Yeah. Cause just like the other day.. we were.. I came in and I see, I see people dying. .... He(the patient) used to count how

many people... ... I used to go into the room and he would say "Four guys died today" And then I would say "Let's go play cards." Let's do something.

Participants also discovered that they had no ability to manage their own family members' reactions as they once had in their own home. Many found that their own family members as well as other patients' visitors were disruptive with their loud arguments and late visiting hours. Several participants were surprised that the PCU staff were unable to restrict any disruptive visitor behaviour as there was no unit policy. Natasha explained her experience:

...What happened is they (extended family) start to come around. And they were..sort of disturbing everyone. Like they would come here and they would stay past 11, 12 o'clock at night. It was like..hello? There are lots of patients on this floor. That are trying to relax. So when I spoken to one of the nurses and said 'Can we do nothing about that?' She says 'Nope. Not really. This is palliative care..and people can come and they go as they please and they do what they want.'

Consequently, she and many others were dismayed at the commotion and limited privacy in shared ward rooms. Many avoided the PCU for periods of time when these disturbing visitors visited.

4.7.1.2.2 ***How Long Is Palliative Care?***

During the time on the PCU, the participants found that they waited and observed the patients' changing conditions. Symptoms increased, improved, and slowly worsened again with the disease progression; consequently, participants

were not certain if their loved ones' death would occur sooner or later. Piper described it as:

That's another thing that is very, very hard is...to keep thinking that it is the end. And then she bounces back. Which on one hand it is wonderful! You know. It is fantastic! We would rather have her around..but ummm...on the other hand it is scary too.

When patients improved, participants wondered if they should make other arrangements for care. Six participants thought the patient might be discharged home once re-stabilized. For example, Piper voiced uncertainty about where her mother belonged as she knew she was dying, but recognized that she was not actively dying compared to other patients on the PCU. This same uncertainty led Rose to comment:

But I don't know how long they will keep him here. If...it is too long I guess..it is not a hospital here. As a...it is not a home. I should say. It is palliative care. But how long is palliative care?

Later, she added:

But hopefully he will be able to stay here as long as... But I guess it won't be too long now. Because if he is starting to lose..ahh..his mind. It cannot be very long. And being weak like that. Not moving. It is hard to say. No one can – I guess even the doctor can't won't be able to tell me that.

Participants expressed difficulty witnessing the patients' deterioration during the active dying process. They observed the patients slowly dying. Rose stated:

It seems like it is me that is losing with him" while Marianne explained *"because I think we have all come through reality. We all look at our mother as if she is still 40 years old..and capable. But now..I think reality is slowly..setting in. And we are starting to see her as 77....and terminally ill.*

Eva described how she felt while she sat, waited, and watched her husband: *"I..I just thought.. that it was such a morbid.. experience. To.. to sit.. and.. wait until somebody drew their last breath. I just.. I just thought it was terrible."* Participants also found that witnessing other family members' responses was emotionally stressful for them. For example, Joe expressed concerns about his wife's parents' reactions while on the PCU:

And I still tried to get them some help...umm..like I knew they were both on antidepressants..and I was trying to avoid them overdoing it. Umm..the last three or four days..when Jane was alive..that's what they were living on. And..uhh..it was to a point where we had to take their keys away because.. I was afraid that..you know..they might just decide 'well I need some air' and decide to go driving...and I was afraid for them because..that's all I could see them.. taking. Taking a little bit of water... and their pills. They were not eating.

As the patients' health declined over their estimated last few days on the PCU, the participants waited for their deaths. They portrayed increased acceptance and readiness for their loved one's death. Joe acknowledged "so *I knew it was coming ..and ...I was getting ready for it. I was trying to get her parents to get ready for it."* These participants were preparing to move on with their lives without their ill loved ones.

4.7.2 *Having Time for Self and Each Other*

The resolution of the patients' discomfort on the PCU facilitated quality time for the participants and other family members. For patients, better symptom control meant that they could focus on other things. Many patients came to terms with their disease and inevitable death; they reflected and accepted the end of their lives. Marianne described how she observed her mother's acceptance changed:

> *..But no-w...in her own way..she is coming out. That little bud is opening up into a flower. Because..she she says to me..' you know. Helen brought me this..this little prayer book..."and she said "I don't know why but I decided to start reading it. And I have been reading it every day and I just love it.' ... So the light is starting to come through. And she is accepting it. That priest she just loves to speak to. And..umm..and it is nice to see my mom...umm.. She..she knows now...that she only has 3 months to live. So she is taking the time to have the quality of care..she wants and needs...very much.*

Two participants accepted apologies from patients, related to emotional and physical pain they had inflicted on them in the past. Isobelle described in detail how her separated husband apologized for being an alcoholic, a neglectful husband, and a poor father.

Participants initially used this spare time to catch up on their sleep. Later, they completed errands, spent time with valued family and friends, and visited the PCU when they chose. They fulfilled errands such as cleaning their homes, and attending medical appointments about their health problems. Release time was important as

participants were able to spend guilt free time going out for dinners and movies with other family members. When the participants visited the patients, they preferred to appear during meal times so they could assist and ensure that the patients ate. Letting go of some caregiving responsibilities meant that the participants had time to sit as a spouse or daughter while visiting the patient. Piper emphasized:

> *I'm..I'm glad.. other people are doing it. So now I do get to sit. And..and. Well..as much as I can with my daughter around. Sit and talk with mom. I mean when I was at home that was one thing that..umm..that was difficult. It might sound strange. But.. Because you have been busy with..with life. You know. It's..it's often difficult to sit down and spend quiet time talking together. And..and.. No. No. It's good..that umm.. other people are..are caring for us. I mean. It is a benefit.*

This positive time together was valued for talking, playing cards, eating meals as well as making funeral arrangements. Participants still valued opportunities to give hands-on care to the patients. They fed, shaved, physically transferred, and toileted the patient on the PCU. One participant still changed, and taught the PCU nurses how to change the patient's wound dressing when he visited. Participants appreciated that they were able to help the PCU nurses while still able to provide some care to the patient.

4.8 *Looking Back on Care*

As the death of their loved ones approached, participants reviewed their journey as caregivers. They *looked back on the care* in both home and PCU settings to weigh

between what they saw as "the good" and "the bad" of their experiences. Many offered clear recommendations on how the health care system could improve palliative caregiving.

4.8.1 Weighing the Experience: Seeing the Good, Seeing the Bad

When asked what helped Marianne to be a caregiver, she reflected: *"It's.. it's not what's helped but..it's what..it's what you assess your journey as a daughter."* Participants specified the positives of home caregiving as spending time together, and being able to provide care to the patient in their home. Receiving support from friends and co-workers significantly helped. Rose described how she felt pride and found personal growth in learning how to take charge of the situation and make decisions.

However, the caregiving experience was hard for most due to their inexperience. Two participants compared the care of their children to caring for a dying loved one. For example, Eva commented:

> *"I..I couldn't have coped.. if..if he'd ..stayed in the house. I couldn't have done it. I know I couldn't have. .... I..I just wasn't..prepared for it. And I.. you know..ah-hhh.. I took care of six children but.. it's a lot different when.. you're.. taking care of.. of somebody (who is terminally ill)...."*

Participants recalled the patients' suffering and their own limitations in providing the necessary comfort care. Lack of information about available community resources and difficulty accessing health care professionals were key hindrances. Also, caring for the patient became more complicated in the home when other family

members interfered and exacerbated family dynamics. This amplified stress and emotional pain to both the participants and the patients. Interestingly, participants also discovered that family dynamics further escalated at the PCU, where participants were unable to neutralize the disruptive behaviour due to the unit's lack of visitation policies to control such behaviours.

The overall caregiving experience was viewed as both good and bad, based on the advantages and disadvantages of their circumstances. Stripes and 3335 remarked *"so..we've seen the bad, we've seen the good. And.. for dad too! Seen bad and good. But mostly good...."* Most participants appreciated the time with the patient when he/she was independent at home. However, they agreed that the PCU was the best place for the patient to receive care when the patient became dependent on greater physical care. Gerry reflected on the best time to send his wife to the PCU in saying: *"So there comes a time where, you know, you have to weigh the two sides. And to me there was a couple of ways, a couple of weeks before the end. And I think I gauged it right (sending my wife to pcu)..in the end."*

4.8.2 Creating Solutions: The System Has Got to Do Something

Participants clearly identified problems in the health care system and offered solutions to improve family caregiving. Their primary concern was the difficulty accessing information about community resources. They found that they had to 'stumble on' resources to find the correct answers and services that they needed. Participant 3335 stated *"Yeah, I still feel like there's not enough information out there for the public."* Participants recommended the development of a caregiver

information booklet on available community resources. They also suggested improvements to the medication delivery methods from pharmacies to reduce wait times and lessen urgent runs to pick up medications. Gerry recommended that HCPs increase their trust in the family caregiver's assessment of the patient's increased symptoms. Isobelle re-enforced Gerry's suggestion, by voicing that family caregivers should not be treated like children and should be respected for the knowledge they possess. Two participants recommended more consistency in primary home care nurses to avoid the need to repeat information as Stripes explained,

> *When you have a sick person at home, please try to have the same nurse. Don't give... different nurses. ... And the story over, and over, and over. Do you know how tiring it is for someone who's dying to say over and over and over and over?*

Continuity and consistency in HCPs would provide continuity of care in the home. It would allow the HCP to be familiar with the patient, his/her condition and changing symptoms, the caregiver's abilities, and the home layout.

Although the participants' recommendations mainly focused on the improvement in home care, they also made two suggestions for the PCU. First, all patients should have a private room in the PCU, to promote privacy and reduce disruptions that occurred in shared rooms. Second, the PCU should develop visitor regulations to reduce disruptive behaviour when it occurs.

4.9 *Getting Ready to Move On*

Even while the patients were still alive on the PCU, participants began to make plans to move on with their lives as they anticipated the imminent death of the patient. Gerry described his manner of moving on in this way:

> *In the way that it is becoming a little easier to talk about it. Ahh.. A little easier to accept. You know since she has left (the home). And the separation. It is still hard but it is a little easier. Now I am doing a few things. Uhh..I go to a restaurant with my nieces now and then. I played a few games of golf and get out for a few hours. So..I am starting to do more normal things. So that is my way of saying the grieving process is in. And slowly I will (do) so more and more like that.*

Participants also began re-organizing their home, enjoying hobbies and considering what they would do with their time. While some talked about becoming a palliative care volunteer in the future, others relinquished the patients' belongings and moved to a new home. Eva, for example, explained how she discarded her dying husband's belongings at home:

> *We've - between my daughter and I - we have umm.. well I moved and that..so we just gathered up his clothes, or.. she gathered up his clothes. We've donated everything that we can and ..ahh.. That's..that's it! I.. I...umm as I say there is nothing I can do. He's gone.*

4.10 *Follow Up Interviews*

The follow-up interviews were conducted with available participants to verify the accuracy of the researcher's interpretation. The follow up interviews confirmed that the analysis and interpretation accurately reflected the participants' experiences. They expressed positive comments such as "*This is really well done*" (Isobelle), "*(this) sentence goes very well. That's what we go through*" (Rose), "*You describe it very well. There is not a thing I would change in this model (framework and summary). You have done it well*" (Marianne), and "*I think you did, I, I think you did cover everything very well*" (Eva).

Two participants reflected a greater positive perspective about the patient and providing his/her care compared to their first interviews. For example, Eva expressed less anger at her husband regarding his neglect to inform her about his cancer diagnosis. Joe did not express frustration about the patient's need for control which he previously had. While these participants did recognize the challenges of the patient's behaviour during the caregiving experience, they did not express the same degree of emotions in the follow up interviews, approximately a year after the first interviews. Hence, the importance of research "at the moment" transition from home to PCU admission.

CHAPTER 5: DISCUSSION AND RECOMMENDATIONS

5.0 Introduction

This study explored 10 participants' caregiving experiences before, during and after the patients' transition of care from home to a PCU. They described complex, stressful, and helpless caregiving experiences. Their experiences are displayed in the *Transitional Experiences of Family Caregivers:* A *Puzzle of Care Provision framework* with eight themes of (1) "*In the beginning - Searching for answers*", (2) "*Managing at home - Juggling act*", (3) "*Trying to get through it*", (4) "*A shifting situation - Triggers leading to PCU admission*", (5) "*The transition - Making the decision to go to PCU*", (6) "*Getting near the end – PCU*", (7) "*Looking back on care*", and (8) "*Getting ready to moving on*". This framework was the foremost diagram where the complex journey from becoming a family caregiver, challenges faced when providing care at home, the triggers that stimulated the transition of care, family caregivers' feelings of handing of the care, and being present during the patients' last days of life on the PCU was thoroughly illustrated. This chapter will integrate the key findings with the current literature and raise points for further inquiry. The discussion begins with an exploration of the family caregivers' roles and responsibilities as they relate to how the participants managed at home. The transition to a palliative care approach, as well as the PCU move and adjustment, will be further examined prior to a summary of the transitional experience. Finally, recommendations for practice, education, and research will be presented as well as implications for advanced practice nursing.

5.1 *Becoming a Family Caregiver*

In this study, all participants shared similar caregiving functions such as: (1) chauffeuring the ill family member to and attending medical appointments; (2) coordinating physicians, and other HCPs; (3) providing medications; (4) preparing meals; (5) assisting with dressing, bathing, and physical transfers; and (6) obtaining multiple medical supplies and services. These caregiver functions are common "caregiving skills" when a person is caring for an ill family member at home, according to Health Canada's national profile of family caregivers (2003), and Schumacher, Stewart, Archbold, Dodd, and Dibble (2002).

Initially, participants offered assistance to the patient during the onset of symptoms (weakness, pain, poor appetite, and skin changes) or when a diagnosis was received. Friedrichsen, Strang, and Carlsson (2001) found that family caregivers began their role in a similar manner to this current study. Although participants in this current study did not directly state that they 'transitioned' into a new role, they acknowledged that the family caregiver role was naturally expected of them by the HCPs, the patient, and other family members. Other studies have found that similar expectations are placed on family members to take on the caregiver role (Aranda & Peerson, 2001; Duke, 1998; Kristjanson & Aoun, 2004; Stajduhar, 2003; Wennman-Larsen & Tishelman, 2002).

Dunbrack (2006) as well as Aranda and Peerson (2001) indicate that family members may take on the caregiver role because of how dying at home can be portrayed in an idealized way without an understanding of the responsibilities and challenges involved in caregiving. According to Aranda and Peerson's (2001), the

bases for accepting the caregiver role was the personal relationship (such as spouse or adult child) as well as social and emotional bonds to the patient. In this study, caregivers 'stepped into' the caregiver role because of : (1) perceived expectations of who would be the caregiver; (2) proximity to the patient's home; (3) close relationship to the patient; (4) incompetence of other family members; (5) personality characteristics; and (6) greater flexibility in their lives to provide care. There were no references to a "promise" of providing care to the patient as identified by Stajduhar (2003).

Friedrichsen et al (2001) found that family caregivers were still expected to be key supporters and communicators as the patients' health declined. Participants in this study described how they took on greater responsibility as the patients' illness progressed along the illness trajectory. Sometimes, this caregiving went beyond their capacity. Further work is needed to reassess the needs of caregivers as the ill family members' health continues to decline.

5.2 *Managing at Home: What Helped Them Get Through It*

Participants in this study identified three factors which helped them provide care to the patient: (1) *receiving support*, (2) *creating memories* and (3) *honouring beliefs*. These three factors greatly assisted them to continue coping with the complexity of daily home caregiving.

5.2.1 Receiving Support

Receiving support was a significant factor in participants' ability to cope with the daily caregiving challenges. There is extensive literature on the value of social support for family caregivers (Duke, 1998; Kramer & Lambert, 1999; Perreault et al, 2004; Stewart et al, 2006; Stoltz et al, 2006; Strang & Koop, 2003; Waldrop et al, 2005). While social support encompasses emotional, informational, affirmation, and practical support according to Stewart (1989), emotional support was the most valued by participants in this study, defined as the ability of the participants to openly talk about their caregiving concerns and frustrations to another without judgment. Stoltz et al (2006) found that active listening created a sense of trust between the family caregiver and the supportive listener. Similarly, talking to others promoted positive feelings, increased sense of support, and lessened stress for the participants in this study. Emotional support positively assisted them to continue facing the daily struggles of caring for an ill loved one at home.

Although most participants in this current study expected physical assistance from family members, such as brothers, sisters, and mothers, this rarely occurred. Instead, they described how their young, school-age children notably assisted them in providing care to the patient. These young children gave considerable practical support to the participants. These occasions permitted quality time and bonding between the participants, the patient and/or the young children. Stoltz et al (2006) have described this as a "sense of togetherness". The patients themselves formed another source of practical and emotional support through active listening, complimenting the participants' efforts, and having a sense of humour. Participants admired the patient's ability to endure, maintain control and sustain both the patient's

and the participant's dignities throughout the daily home care routine. This finding complemented Strang and Koop's (2003) research where they identified that a supportive, dynamic relationship between the family caregiver and patient permitted greater ease in home caregiving. This quality time offered further emotional and affirmation support to participants.

Outside the home, participants in this study received additional social support from two sources: non-professional and professional. Unsolicited support from close friends and co-workers was not expected, yet valued and greatly appreciated by participants. Active listening, completing errands, and providing short-term substitute caregiving were the most appreciated practical supports that enabled them to persist in providing daily complex home care. All agreed that support was beneficial when they faced uncertain, complicated palliative home caregiving. Being offered support was a positive aspect of caregiving. According to Stoltz et al (2006), it facilitated a sense of networking and building trust, as well as, a feeling of being heard and responded to. This study compliments Stoltz et al (2006).

While co-workers and friends offered emotional and practical supports, professionals offered informational support, reassurance, and guidance. The employment assistance program, mental health, and elementary school counselors were common professional support sources named in offering information on available resources, as well as, providing reassurance, and guidance. In contrast, neither physicians nor home care nurses were identified as offering any emotional, informational, and affirmational support to participants. This contradicts an earlier study by Duke (1999) who found that nurses took an interest in and provided great

assistance to caregivers. This finding is important in light of the practice expectations set by the Registered Nurses Association of Ontario (RNAO) *Nursing best practice guideline: Supporting and strengthening families through expected and unexpected life events* (2006), which recommends registered nurses assess and offer support such as information sharing, and communicating with families. In addition, although Dunbrack (2006) mentioned volunteers as a useful resource, none of the participants in this study mentioned any awareness or usage of the two local community hospice volunteer programs.

5.2.2 Creating Memories

The creation of memories helped participants in this study. All recognized the limited period of time left with their loved ones; therefore, they tried to take advantage of any special moments. Special events included hosting parties, having dinners at local restaurants, and attending theatre performances. They recalled everyday routines which they enjoyed with the patients: drinking tea, playing cards, and even watching television together. The creation of special memories has not been previously documented in literature, yet it was clearly beneficial to participants in this current study.

5.2.3 Honouring Beliefs

Honouring beliefs, based on the participants' spirituality and core values, was another factor that facilitated caregiving at home. These beliefs assisted participants to drawn upon their inner strengths. Caregivers' personal values and spiritual faith

have been identified in maintaining the care commitment (Strang and Koop, 2003; Stoltz et al, 2006). Participants in this study repeatedly emphasized their fundamental personal value, that providing care to the patient was important to them. Many referred to the fulfillment of a perceived duty or "*payback*" to the patient. These participants were giving back, or reciprocating, to their parents for the care they had received as children.

5.3 *Managing at Home – The Challenges*

Family caregivers became the "medical team representatives in the home" who provided complex care, assessed symptoms, made decisions, and coordinated services to patients throughout the day and night at home (Rabow et al, 2004, p. 488). As a result, several participants expressed challenges in providing home care. These related to: (1) communication concerns, (2) handling emotions, and (3) watching their loved one suffer.

5.3.1 Communication Concerns

5.3.1.1 Trying to obtain information and services.

As an untrained caregiver, participants did not fully understand the patients' conditions, treatment options, or available hospital and community services. Dunbrack (2006) reported that family caregivers have common informational needs related to: (1) pain management, (2) health care system navigation, (3) bereavement support, (4) respite services, (5) practical caregiving, (6) patient's illness progression, (7) various HCPs' roles and responsibilities, (8) legal and financial considerations, (9)

emotional and spiritual support, (10) cultural services, and (11) alternative therapies. Participants in this current study frequently emphasized their need for information. They described how they relentlessly inquired how to (1) obtain a home visiting physician, (2) access home care nursing, (3) receive medical supplies and equipment, and (4) pick up prescription medications. Most of their inquiries focused upon the patients' disease symptoms, as well as, the available community and hospital resources. This information was essential to guide and support participants in their care provision.

Participants in this study were keen to have information to prepare for the patients' home care requirements when their caregiving role commenced. This finding complements Kristjanson and Aoun's (2004) study and Dunbrack's (2006) report where family caregivers highlighted the need for information to make informed decisions and adapt their current situation. However, information was not easily obtained by anyone in this current study. Frustration and confusion were felt with unclear, inconsistent information, and vague answers. Consequently, participants continued to search for alternative answers, more succinct information, and more guidance. The searching for answers and care services consumed a significant amount of time and energy. As Rabow et al (2004) found, "at times, families may feel as if they are 'reinventing the wheel,' with each individual family trying to identify local services even though many in their community have struggled with the very same issues" (p. 484). Since all participants received some home care nursing services, they were connected with a Community Care Access Centre (CCAC) case manager for allocation of community palliative care services. As all patients required

a reason for home care services, the CCAC would likely have known that the patient was palliative and eligible for palliative care program services. However, participants in this study were not aware that patients were automatically accepted into a palliative care program when they began receiving home care nursing services from CCAC. This information was not fully explicated when they were first introduced to the community care services.

Several studies have reported that family caregivers commonly retrieve community services and caregiving information through secondary sources such as books, pamphlets, internet, videos, audiotapes, volunteers, telephone services, support groups and family and friends (Andreassen et al, 2005; Dunbrack, 2006; Hudson et al, 2004; Kristjanson et al, 2004; Waldrop et al, 2005). Yet, Hudson et al (2004) remarked that secondary information sources for families were very few, focused primarily on the patients, and contained questionable intervention effectiveness. Family caregivers need to ask more specific questions and obtain further information from physicians and other HCPs when secondary sources are used according to Andreassen et al (2005). For example, the CHPCA website (www.cpca.net) provides easily accessible information for family caregivers about care for a dying person along with a specific community agency resource list. However, no participants mentioned any usage or awareness of secondary source information from websites, books or even videos in this current study. A few, however, did mention the *Ottawa Citizen's* week long newspaper series on palliative care in March 2005. This series described the city's palliative care program, acute care, and community services, such

as CCAC. Participants who read this newspaper series expressed great appreciation for such useful information, which was so easily obtainable.

5.3.1.2 *Challenges in communicating with health care professionals.*

Challenges in communicating with HCPs began with the disclosure of the patient's diagnosis and prognosis and continued as the illness progressed, all participants expressed great displeasure at how the physician communicated the diagnosis. Several cited the physician's words verbatim, while many quoted physicians' comments with strong emphasis on statements, content and/or behaviour. This had significant impact upon them. The timing of the physician's communication of the diagnosis, prognosis and hospice care referral was judged as poor by several participants. After multiple physicians' visits and numerous medical tests were completed, their dismay, doubt and anger grew about the physician's inabilities and the slowness of the health care system as they waited for answers. Many questioned the numerous medical tests and procedures needed for an accurate diagnosis. This finding supports studies by Andreassen et al (2005) and Kirk, Kirk, and Kristjanson (2004). Kirk et al (2004) stated "the exact words used by doctors were vividly remembered" by subjects in their study (p. 4).

Many in this study voiced that the patient's diagnosis was confirmed too late for early cancer treatment. A previous study discovered that most family caregivers received the diagnosis only one month prior to the family member's death (Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hureler & Bradley, 2005). Furthermore, a few participants in this study only learned about the patient's diagnosis and

palliative prognosis when the severely ill patient was admitted to an acute care hospital. According to Murtagh, Preston, and Higginson (2004), physicians' reluctance to provide estimations was related to their own preference of not wanting to diminish any patient and families' hopes, such as a cure for the cancerous disease. As well, Murtagh et al (2004) state "physicians' cancer estimations are known to be inaccurate and over-optimistic, but they do appear more accurate closer to death" (p. 42). Murtagh et al (2004) surmised that being open about the uncertainty of diagnosis and treatment can contribute to trust among patients, family caregivers, and HCPs.

Kirk et al (2004) showed that trust is not built upon the initial disclosure, but through repetitive interactions between HCPs and family caregivers. Some participants in this current study acknowledged that HCPs, particularly specialized physicians, ignored their concerns regarding the patients' escalating symptoms. They felt disrespected, frustrated, and angry when their verbalized worries were "not taken seriously". Participants felt belittled by the HCPs during office meetings, telephone discussion and home visits. Dunbrack (2006) similarly expressed concerns that family caregivers may feel frustration and fear when trying to get their observations and worries acknowledged by HCPs. Participants in this current study, who experienced inconsistent information and mistrust of HCPs, especially with physicians, recognized that their lack of trust would remain an issue for the rest of their care provision with subsequent HCPs. As a result, a few participants sought a new physician in hopes of re-establishing trust. Limited research has documented the effect on family caregivers when their concerns and expertise related to the patients'

escalating symptoms are overlooked and the compounding effect on present and future HCPs interactions.

5.3.1.3 *Communicating with the patient.*

Both Kirk et al (2004) and Hinton (1998) found that communication changes between the family caregiver and the patient were related to the patient's (1) personality or attitude, (2) illness progression (weakness, sudden falls, and increased pain), (3) limited information requests, and (4) care information differences. This was congruent with findings in this current study. Sometimes, patient – caregiver communications changed as the disease progressed. Patients' refusal to accept additional assistance from the participants, from other family members, and even from HCPs caused significant distress for participants. The patients were described as self-reliant, refusing help, even when safety was a concern. Despite this, participants tried to negotiate with the patient and the physician to acquire greater support in the home. Open discussions helped the patient and family caregiver to collaboratively, accomplish the daily care as well as plan for the future.

Nonetheless, many participants acknowledged a period of time when they had to cautiously talk about the patient's deteriorating condition, transfer to PCU and death. Communication with the patient became restricted. When patients suddenly closed communication, it caused all participants further emotional stress. They could no longer talk openly about their thoughts and feelings with the patients. Consequently, superficial conversations dominated the daily communication between them. This finding supports results of studies by Duhamel and Dupuis (2003) and Kirk et al

(2004). The new communication style is thought to mask the persons' fear and distress (Duhamel & Dupuis, 2003; Kirk et al, 2004).

Duhamel and Dupuis (2003) highlighted that family caregivers initiated new communication styles when faced with a loved one's terminal illness. Kirk et al (2004) specified that when the patients' symptoms escalated their conversations focused on 'at moment' symptom management. However, participants in this study specified that the patients were the ones who suddenly modified communications. This sudden communication change happened when symptoms became more complex and personal care needs increased. Several participants noted that the patients were "deep in thought" during this period of time. It was difficult for participants to continue caregiving because the patients required their physical assistance, and yet, they were neither emotionally nor mentally engaged with participants.

5.3.2 Handling Emotions

There is increasing recognition of high level of emotional strain to family caregivers (Health Canada, 2003; Kramer & Lambert, 1999; Rabow et al, 2004; Singer et al, 2005; Stajduhar, 2003; Yates, Aranda, Edwards, Nash, Skerman & McCarthy, 2004). While providing care to their ill loved ones, all participants experienced difficulty with negative emotions. Participants in this study repeatedly described their experiences as "*it was hard*" when (1) dealing with other family members who were unhelpful, in denial, aggressive, or unable to cope with the patient's illness, and (2) when the patients refused help. Many recognized the "*ups*

and downs of their mixed emotions" and some felt they were on an "*emotional rollercoaster*". Grbich et al (2001) also used the term "emotional rollercoaster" to describe the positive and negative mixed emotions of caregiving for a dying loved one. These emotions required participants to manage their own feelings as well as others.

Emotional stress was related to how other family members reacted to the patient's illness and physical decline. Most participants indicated that there had been previous family tension between one or more family members prior to the patient's illness. Many expected greater support and consideration from other family members, regardless of the individual issues within the family. All participants in this current study confirmed that they lacked any understanding and awareness of how encompassing and intense the caregiver role would be for them. They had expected supplemental support and physical help from other family members, which supports Stajduhar and Davies' (2005) finding about caregivers' expectations of family assistance. While Strang and Koop (2003) found that external family members' support was often sporadic and excessive, the current study participants' frustration and anger escalated because other family members neither visited nor offered to help with the patient.

Another significant influence on participants' emotions was the patients' refusal of any assistance in caregiving by others. Participants described greater difficulties in providing care and accessing services when the patients would not permit helpful services or assistants in the home. While the literature agrees that caring for patients at home is emotionally difficult (Harding, Higginson & Donaldson, 2003; Grunfeld,

Doyle, Whelan, Clinch, Reyno, Earle et al, 2004), this current study uncovered two additional factors contributing to the complex negative emotions felt by family caregivers: (1) the lack of family support and (2) the patients' refusal to accept help.

5.3.3 *Watching Their Loved One Suffer*

The most difficult aspect for family caregivers was watching their loved one suffer. Several studies have observed family caregivers' emotional tension escalate when patients experienced pain or appeared to be suffering (Aoun et al, 2005; Mehta & Ezer, 2003; Stoltz et al, 2006; Yates et al, 2004). All participants in this current study thoroughly described watching their loved one suffer with uncontrollable, escalating pain, moaning and yelling in discomfort, vomiting all weekend, having progressive weakness, sudden confusion, poor appetite, and nonstop weight loss. Participants felt helplessness, sadness and frustration when they observed the patient suffer with these severe symptoms while they waited for the HCPs to return their calls for help. Mehta and Ezer (2003) indicated that spouses' felt stronger emotional pain when they watched their loved ones' pain and suffering while Yates et al (2004) warned that family caregivers may become emotionally charged when observing a loved one suffer. Participants in this study attempted to manage escalating discomfort by providing additional medications to the patient. Most found that they waited hours to days for HCP's to either return their phone call or visit them at home.

5.3.4 *The Changing Home Environment*

As the patient's condition worsened, the home care needs and services rose. Participants lost their sense of home identity when the number of HCP visits increased along with the amount of medical equipment and supplies. Their houses were no longer their "homes" but transformed into medical-like settings. Participants felt obligated to accommodate and work around visiting HCPs. They altered their schedules and tried to not get "in the way" of HCPs during the day. Consequently, participants had difficulties when they planned their day as HCPs visiting times varied. A Health Canada (2003) report discovered that caregivers receiving home care services had higher reported stress levels than those who did not have any formal (HCP) assistance; however, no explanation was provided for this finding. Dunbrack (2006) and Stajduhar (2003) findings suggested that increased HCPs presence led to greater caregiver distress in the home environment. Dunbrack (2006) commented that family caregivers no longer felt "at home" whereas Stajduhar (2003) discovered that family caregivers worried about "preserving their core identity within the family".

Stajduhar (2003) recommended that HCPs schedule visits during certain times so family caregivers can balance the visits with medical appointments and personal time with the patient. While this appears like a reasonable suggestion, one participant found that designated respite times did not co-ordinate well with the range of HCPs' schedules. This participant regretted that he accepted other HCPs visits during his (CCAC designated) home care respite period because he neglected his own cardiac rehabilitation to be present for the visiting HCPs. In light of this, Stajduhar's

recommendation may work at the beginning of the caregiving phases, but it is difficult to maintain designated respite times once the patient has multiple symptoms that require numerous HCPs.

Employed caregivers juggled their fears of losing their jobs, traveling to multiple medical appointments, and fulfilling other family responsibilities. All described difficulties in juggling the demands of multiple daily responsibilities that included the patient's care, their family's (spouses and children) needs, and their employment demands along with their daily household tasks. Waldrop et al (2005) found some parallel results when family caregivers handled multiple responsibilities along with family and work conflicts. In Waldrop et al (2005) study, the family caregiver's exhibited elevated stress response as the patient's condition severely declined and led to conflicts with other responsibilities.

Aranda and Peerson (2001) found that participants who were retired or had flexible work hours, and considered themselves in good physical health were more capable of juggling both their own responsibilities and the patient's care. A Health Canada (2003) report found that employed caregivers benefited from flexible work hours since they experienced frequent work disruptions due to home caregiving. Although Health Canada's (2003) report found that half receive modified work hours, one in five caregivers quit their job or retired early to provide family caregiving. In this current study, only one participant quit her job while caring for the patient; four participants had already retired, consequently, they did not have to juggle employment with home caregiving responsibilities. Another five participants' negotiated either their employment hours or location with their employer. They

recognized that flexible working hours, as well as empathetic employers, and colleagues were a benefit while home caregiving.

5.4 *Transitioning to a Palliative Care Approach: Trying to Access Resources*

Lack of knowledge about what was entailed in the transition from curative to comfort care impacted participants in this study. Knowing where to go, what to get, and who to call was unclear for everyone. One participant acknowledged that there was no longer any reason to access the Cancer agency when his wife was deemed palliative, even though they had been the primary care provider since the cancer diagnosis. As a result, he was uncertain which services and HCPs to contact next for information and resources. As Dunbrack (2006) highlighted, cancer agencies are common organizations which family caregivers rely on; however, they later feel abandoned by, once the patient is deemed as palliative. All participants in this current study had to find a new interdisciplinary team who could provide guidance, support, and resources. Most expected to get information on palliative care from their family physician. Yet, no participants in this current study were referred to a community palliative physician by their family physician. Only patients who were admitted to the emergency department for symptoms received referrals to PCU and later obtained a palliative care physician specialist. Although a multidisciplinary pain and symptom management team was available to Ottawa's palliative home care patients, only one participant received this service.

Effective communication between the family caregiver and the physician is required for effective care management according to Rabow et al (2004). However,

this relationship did not exist for this study's participants. Only one participant expressed appreciation for the home visiting physician. Those who did have a community palliative care physician still encountered long waiting periods for expected home visits and telephone guidance from both nurses and physicians. Although participants with specialized palliative care physicians reported greater satisfaction with home care, they still found problems when they needed to coordinate and access equipment, information, and medication. There were long delays when trying to obtain new or additional medications from their community pharmacies in both urban and rural communities.

5.4.1 Challenges of Rural Settings

It is recognized that Canadians living in rural areas have limited access to palliative care services compared to those residing in urban centres (CHPCA, 2006; Carstairs and Beaudoin, 2000). Study participants, who lived in rural settings, expressed greater problems than their urban counterparts in obtaining a family physician to visit the patient at home, as well as, accessing specialized services, such as chemotherapy treatments and specialist physicians. All (2) rural participants reported difficulty in finding services, and expressed confusion over regional service boundaries, and limited community services. Trying to identify services was time consuming and took time away from caregiving. This finding contradicts Hugh et al (2004), who indicated that urban and rural family caregivers' concerns and needs were equal in palliative home caregiving.

5.5 *The Actual Transition: Moving to PCU*

Several studies have explored family caregivers' responses when admitting their loved one from home to a nursing home (Dellasega & Nolan, 1997; Kao, Travis & Action, 2004; Kellett; 1999; Ross et al, 1997; Strang et al, 2006; Zarit & Whitlach, 1992). Yet, Burge et al (2005) is the only Canadian study which has focused on the actual transition to palliative care settings. They discovered that almost 50% of patients experienced at least one transition of care setting within four weeks of death. Researchers in Italy highlighted that patient referrals approximately one month prior to the patients' death is too late for useful palliative care services (Costanitini, Toscani, Gallucci, Bruneeli, Miccinesi, Tamburini et al, 1999). In this current study, many potential patients died too soon after arrival at the PCU making their family caregivers ineligible to participate in this study.

When directly asked about the move, participants described how the transition of care setting had considerable significance to them. All focused on navigating the path from home to PCU, and in some cases via a local hospital. After further exploration, many acknowledged that the move had a special meaning. They were aware that once the patients left for the PCU, they were unlikely to return to their homes again. The participants became highly aware of the patients' imminent demise and a future without their loved one. Participants had recognized a need for institutional care for several weeks prior to the move but with the actual move came the reality of losing their loved one. Further studies are needed to fully understand family caregivers' experience once their loved ones are situated on a PCU. In the meantime, community

and hospital HCPs need to recognize the significance and meaning of the transition of care settings for the family caregivers by helping to prepare them beforehand.

The patients' transition of care setting was more complicated for those without a PCU referral. Participants had to call the emergency number (9-1-1) as it was the only option that they knew to initiate the patients' admission process to institutional care. Consequently, the patient arrived via an ambulance at the emergency department of their local acute care hospital. As Stajduhar (2003) points out, the emergency department was considered the only "point of entry into the system" (p. 31). Stoltz et al (2006) further added that family caregivers' only way to draw attention to their concerns and overall home care situation was to move the patient to the emergency department. In this current study, two of the three patients who went to the emergency room were admitted to the acute care hospital for further medical investigation that lasted up to two weeks. The third patient was admitted to the emergency department for less than twenty-four hours. Although these patients were admitted to the acute care hospital, caregivers still described how they had to "fight" to get full answers and appropriate health care services for the patient; this included referral to the PCU. The needs of these family caregivers continued to be overlooked by community and hospital HCPs. Both Andreassen et al (2005), and Duhamel and Dupuis (2003) identified comparable findings, where family caregivers often felt 'invisible' when HCPs focused on the patient and 'ignored' the family and their concerns. Similarly, family caregivers in Stoltz et al's (2006) study also indicated how they continued to feel "disregarded and overlooked" by HCPs in the emergency department (p. 601).

5.6 *The Palliative Care Unit Transition*

Participants were the first to recognize the need for the patients' transition of care. Recognition began as concern about: (1) their inability to manage the patients' symptoms, (2) observations of the patients' dramatic physical weakness, (3) fears of further injury to the patients and themselves, and (4) uncertainty about prompt access to community HCPs assistance. As Mehta and Ezer (2003) showed family caregivers understood that the progression of the pain was a constant reminder of the cancer disease and impending death. Caregiving at home had become too complex for participants in this study to safely manage. They described their feelings of helplessness as they searched for HCPs guidance and additional resources to rectify their uncontrollable and unsafe situations. They were the first to identify when providing care was beyond their abilities and safety. Likewise, Perreault et al (2004) found that family caregivers felt helpless when their caring abilities were hindered by their own physical and emotional limits.

Studies have recognized that family caregivers often jeopardized their own health when the patient's needs amplified (Aoun et al, 2005; Kristjanson & Aoun, 2004; Hudson, 2003; Shyu, 2000). Health Canada (2002), Kirstjanson and Aoun (2004), and Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt, and van den Bos (1998) acknowledged that family caregivers sustained poor physical health through their own worsening chronic illnesses, or by developing poor health and psychological difficulties. Participants in this current study began to question whether they could

continue to physically, mentally and emotional provide the necessary caregiving at home.

The last few days at home, often on a long weekend, pushed the participants in this study to their emotional and physical limits. All expressed emotional and physical discomfort while they tried to sustain the patient's care at home. It was described as "the worst weekend" and "the hardest thing" for family caregivers to experience. Like a study of patients with dementia who made transitions to a nursing home, Evans et al's (2006) described how the transition was unavoidable when the patients' disease caused extreme safety concerns and uncontrollable symptoms.

Family caregivers' lack of training was prevalent in this study. Untrained family members were often expected to provide increasing physical care to weakened, deteriorating patients which placed them at higher risk for their own physical injuries. This lack of training has been documented by Rabow et al (2004), and Waldrop et al (2005). Furthermore, Ferrell et al (1999) indicated that a family caregiver's quality of life was most affected by: (1) physical disruptions - sleep disturbances, and pain, (2) psychological disruptions - difficulty coping, increased anxiety and depression, (3) social disruptions - isolation, disruption in home activities, and financial burden, and (4) spiritual well-being disruptions. They reported negative impacts as patients became weaker, suffered with worsening symptoms, progressed to complete dependence, could not safely be left alone at home. In this current study, patients' declining health caused greater dependence on the participants along with enhanced safety concerns. Further researcher is needed on safety concerns for both the patient and the caregiver in the home.

In the decision to go to the PCU, the caregivers were neither given any decisionary power nor did they voice any preferences. Many did not want to tell their loved one that they could not look after them any longer. They waited for permission to let the patients go to institutionalized care. Previous studies have found that family caregivers were more proactive in initiating this transition. For example, in Perreault et al's (2004) study, family caregivers were assertive in moving the patient to institutional care as soon as they had reached their maximum caring abilities. Csikai (2006) found that physicians were the primary persons to discuss PCU admission when the patient was in hospital; however, family caregivers were not provided with any alternatives to PCU so they indifferently agreed to the suggestion. In the current study, home care nurses or physicians only suggested that the patient could be moved to PCU and waited for the patients' to agree or refuse. Further understanding is needed about the process of communication about the transition of the patient to a PCU.

5.6.1 The Advantages of the PCU

All felt an immediate sense of relief once the patient was transferred into the PCU. Participants knew the care setting change was the "best decision" for both the patients and themselves. They recognized that their loved one would receive proper professional care from trained palliative HCPs. They were no longer alone at home in their isolated, 'shrinking world' as many previous studies had documented (Aoun et al, 2005; Kristjanson & Aoun, 2004; Perreult et al, 2004; Stajduhar, 2003; Strang & Koop, 2003; Syren et al, 2006). Evans et al (2006) found that family caregivers were

satisfied that the new setting provided apparent goals, efficient personalized care, clear communication, and effective symptom management. Continuous nursing care and effective symptom management provided on the PCU was a positive outcome also recognized in Brazil, Howell et al's (2005) study. For caregivers in this current study, "it was a relief" to no longer care for the patient alone or worry about the patient dying in their presence. All participants could get a full night's sleep without having to provide medications, or monitor the patients or worry about sudden death. Participants in this study observed the patient's pain decline within a few hours on the PCU. This was in contrast to trying to manage uncontrollable pain at home for days and even weeks. This positive reaction to PCU is noteworthy as it does not reflect the reported preferences for palliative care at home by organizations such as CHPCA (2002). Participants in this study based their preferences on (1) the rapidness of the patients' symptom management, (2) the effortless access to information, and (3) the efficiency of HCPs responses.

With less time spent on providing physical care, participants were able to refocus on their own personal concerns and enjoyments. They could let go of some caregiver responsibilities to the PCU staff allowing them to, finally, be seated beside the patient as a spouse or a child; no longer a care provider. This finding was similar to results of Perreault et al (2004)'s study where family caregivers were able to "change their caregiver role into being simply a husband/wife, child ... again" when on the PCU (p. 142). However, participants did not fully give up their family caregiver role. They continued to provide some hands on care, including shaving, transfers to the bathroom, and feeding. Several described contentment in completing these physical

tasks because (1) they could spend quality time with the patient, (2) continue to create memories, and (3) assist the PCU nursing staff with their work. This was the first time participants felt they were collaborating with the health care team.

Once the patient was situated on the PCU, participants had the time to assess their journey. They reflected upon their palliative caregiving experience. They weighed the good and the bad aspects of their experiences. This complements Waldrop et al's (2006) findings where family caregivers reflected on "meaning making" of their experience of being a caregiver, and prepared for a future without their loved one while they waited for the patients' death to occur.

5.6.2 The Disadvantages of the PCU

Participants also identified challenges on the PCU such as: (1) less of a homey environment, (2) feeling like a guest, and (3) uncertainty about how long the patient would stay on the PCU. All acknowledged that they felt guilty for taking their loved one from their home to the PCU. While they described relief in receiving caregiving information, many mentioned their change in role when they had to ask HCPs, mainly nurses and doctors, for updates. The phone was their only immediate link to the PCU and the patient. Yet, communication over the phone was frequently perceived as vague and unclear.

Caregivers observed their loved one's condition improve, decline and improve again. All participants became fatigued while they patiently waited not knowing how many days the patients had left on the PCU. Participants and patients were aware of other patients dying on the PCU, especially those who shared ward rooms.

Participants often tried to protect the patient from seeing the bodies of neighbouring patients in the hallways. Participants' greatest challenge was coping with inappropriate behaviour by their own family members as well as those of other families. Several were surprised that the PCU staff had no control over these disruptive behaviours.

5.7 *Final Thoughts: The Family Caregivers' Summary*

This study gave participants a voice. They were able to make suggestions for home caregiving and felt strongly about the changes needed. They were able to summarize their experiences as a family caregiver providing insight into this challenging role. Hudson (2003) found that family caregivers to palliative patients verbalized the positive benefits of being involved in a research study. Involvement gave them an opportunity to verbalize their thoughts and concerns. Verbalizing their thoughts led to increased validation of their caregiving role, coping, and decreased feelings of caregiver isolation. Tod (2006) adds:

> Interviews may provide the only method of eliciting the views of people who are often 'hard-to-reach' in terms of research and who would be reluctant or unable to participate in research using other methods. There is some indication that, while not intentionally having a direct therapeutic effect, people do find the experience of being interviewed a positive one (p. 348).

Likewise, as Hudson (2003) found, participants in this current study concluded that there were positive benefits to participating in a study. This was observed when each participant left the current study's interviews with a relaxed posture and a smiling

face. Several participants said that the interviews were very therapeutic for them to fully reflect on their caregiving experiences. In addition, follow up interviews permitted participants to confirm that the study's framework reflected their lived experience and offered an accurate visual layout of the experience to future caregivers.

5.8 *Summary*

This study provided new information in the area of palliative care and family caregiving research. In particular, it provided greater awareness of the family caregiver's transitional experience from home to the PCU than previous literature has offered. *Transitional Experiences of Family Caregivers: A Puzzle of Care Provision* framework provided a visual schematic of family caregivers' experiences of caring for a loved one from home through to the PCU. Hudson, Aranda, and Kristjanson (2004) emphasized "until researchers and HCPs develop and validate a framework for family caregiving that is directly applicable to understanding the family caregiver experience, there will continue to be difficulties for practitioners in applying a suitable framework for guiding their care decisions" (p. 21). It is important for clinicians and frontline practitioners to be aware of family caregivers' intense physical and emotional challenges experienced in the home setting. This understanding has implications for HCPs assessments and family caregivers' care provisions in both home and PCU settings.

All participants in this current study voiced positive and negative experiences when caregiving for an ill loved one from home through to the transition to the PCU.

The actual transition from home to PCU was significant to both patients and family caregivers. For patients, it meant leaving the familiarity of home, whereas for caregivers, it meant facing the inevitable death of a loved one. Once the move was completed, all agreed that PCU was the best place to receive care given their circumstances. Participants recognized the difficulties of home caregiving; nevertheless, most stated they "would do it all over again". Participants persevered with little information and few community resources to provide palliative home care, to support the patient's care needs, and to uphold personal values to the best of their abilities. Their final hope was the Canadian health care system would improve community and palliative care services to better support family caregivers. There are several implications for practice, education, and research resulting from this study.

5.9 *Implications for Practice, Education, and Research*

5.9.1 *Practice*

The current study was unique in exploring family caregivers' transitional experiences of admitting ill family members from home to a PCU. Interpretation of participants' experiences of the transition revealed a complex and often stressful journey, as depicted in the *Transitional Experiences of Family Caregivers: A Puzzle of Care Provision* framework. The findings touched on several bodies of literature in family caregiving and relevant concepts such as "caregiver burden" (Pearlin, Mullan, Semplet & Skaff, 1990; Zarit & Edwards, 1996) and "caregiving skill" (Schumacher et al, 2000). However, the findings are new in capturing the dynamic process from the initial diagnosis to the last days on the PCU. Thus this study offered insight and

raised awareness of, not only, the challenges family caregivers faced as they care for their loved ones, but also how the decision to initiate the transition of care was triggered and how they felt about handing over the responsibility of care.

As a result, these findings are important in raising awareness of the needs of family caregivers, which are often overlooked by HCPs who are focused on patient-centered care. Insights are offered into strategies to help HCPs support family members during the challenging family caregiver role and the transition of care process. There are eighteen recommendations for practice related to the challenges of caregiving at home during the transition to PCU and on the PCU:

1. There is a need for consistency in HCPs visiting the home. Lack of continuity in care led family caregivers to providing repetitive explanations of the patient's history, present condition and required care needs;

2. HCPs visiting the home need to thoroughly assess the support provided by family members and not make assumptions that it is available;

3. HCPs' need to reassess the information needs of family caregivers as they move through the illness trajectory. One example of these needs is community resource information;

4. HCPs need to recognize safety concerns more fully in their assessments of the home for patient and family caregivers as the patients' health worsens;

5. HCPs in the home need to re-evaluate on a regular basis the caregivers physical and emotional capacity to continue caregiving;

6. Physicians and other HCPs should acknowledge the caregivers' expertise regarding patient's escalating symptoms and request for additional medications as the family caregiver has the most contact with the patient;

7. Equipment in the home needs to be introduced in a way that anticipates patient's needs rather than responding only in crisis;

8. Pharmacy services available 24 hours are required to deliver around the clock medications to patients' homes in order to lessen problems, such as escalating pain, and long waits to receive appropriate treatment;

9. Consideration needs to be made between rural and urban family caregiving experiences. For example, rural participants expressed difficulty in finding a home visiting physician and in obtaining medications. Lack of information on community resources as well as difficulties getting to the city hospitals due to distance created further obstacles for rural family caregivers. Greater case management and home care resources are required for patients living in rural areas;

10. CCAC case managers should make regular home visits and telephone contacts to guide and offer the patient and family caregiver available community and hospital resources;

11. HCPs should promote a regular palliative volunteer to telephone and/or visit the patient and caregivers so that this service is seen as an additional resource;

12. There needs to be enhanced communication among HCPs, the family caregiver, and the patient regarding the possibility of the transition to a PCU;

13. The interprofessional team needs to re-examine the process for admitting a patient from home to the PCU in order that patients and family caregivers can access

these services in a timely and efficient manner so that patients are not admitted hours or days before they die in a crisis state;

14. Community HCPs should promote and transition the patient's PCU admission sooner in the illness trajectory, rather than the last few days of life or during symptom crises as the PCU has a positive benefit for patient and family caregiver for more efficient symptom management;

15. PCU should consider the establishment of rules of etiquette to lessen disruption on the unit from family members;

16. Single rooms should be available in PCU to improve privacy and lessen disturbances from other families;

17. PCU staff need to be aware that family caregivers begin to feel like "*I'm a guest*" on the PCU. Further work is needed to examine the factors contributing to this "guest" feeling; and

18. PCU nurses need to examine the intent of their phone calls to family. An examination of issues such as when to call and how to relay information is required so that families do not receive phone calls with vague information related to their loved ones conditions.

5.9.2 *Education*

Participants in this study emphasized that they did not receive appropriate palliative caregiving education and guidance until the patient was situated on the PCU. Participants felt distressed about the limited support received, increased home isolation, watching their loved ones' suffering escalate, and dealing with safety issues

while caregiving at home. Education of future HCPs, current HCPs, and family caregivers needs to include more content on palliative home caregiving. This study suggests the following recommendations for education:

1. All undergraduate students in the health professions should have content on palliative care as well as have opportunities to collaborate with other HCPs in clinical rotations. For example, nurse educators should incorporate aspects of palliative care and interprofessional practice throughout the curriculum in core nursing courses and clinical rotations. This would enhance interprofessional communication and team work;

2. CCAC should initiate public information sessions where people could gain greater understanding of family caregiving and palliative care, as well as, available information on community resources;

3. Local information booklets need to be developed to provide community resource information, such as CCAC and PCU, with particular attention to weekend and evening periods. This information would provide family caregivers additional knowledge as well as easier access to support services at any time. This booklet would be available at cancer centres, physicians' offices, community health centres and CCAC offices where interdisciplinary HCPs would provide the information to family caregivers or individuals could chose to pick it up on their own initiative;

4. Family caregivers should be provided accurate information about the reality of caregiving at home. The *Transitional Experiences of Family Caregivers: A Puzzle of Care Provision* framework exemplified the realities of caregiving as experienced by

the participants. It could be shown for future family caregivers to help them prepare for the journey of caregiving;

5. Family caregivers should be taught safety techniques such as transferring the patient from bed to chair, fall prevention methods, and who to call when they are unable to lift the patients off the floor;

6. Education needs to be provided to patient and family caregivers regarding the entrance and usage of the PCU. For example, patients and family caregivers need to be aware that the PCU is a resource, accessible for symptoms management, and not only utilized as a last resort for patients' last days of life; and

7. Opportunities should exist for former family caregivers to facilitate others in the journey of caregiving by providing a form of mentoring orchestrated through hospitals and community agencies.

5.9.3 *Research*

The following recommendations are suggested for future nursing research:

1. Since little research has been conducted in the present, or 'at the moment', caregivers' experiences, further research needs to focus on present time experiences of caregiving such as following family caregivers in their homes over time;

2. Greater exploration of how family caregivers step into their role is needed in nursing research. For example, do family caregivers accept to provide care out of obligation from family or patient expectations, or their own personal values?;

3. Further examination of how community support services impact the family caregiver and the patient's sense of home;

4. Investigation of patient and family caregiver's safety issues in the home is required to prevent injuries;

5. Further research is needed to gain greater understanding of the role of HCP including physicians in the palliative home care setting as well as the role of the volunteers;

6. Further exploration of how HCP's respond to family caregivers' assessments of the patients' symptoms and needs;

7. Examination of how HCPs approach patients, family caregivers, and other family members about transitional care decisions such as the admission to PCU; and

8. Further exploration upon the meaning of the transitional move between care settings for patients, family caregivers, and HCPs.

In the next section, the role of the advanced practice nurse (APN) will be highlighted to exemplify how changes can be made in the provision of services to patients and family caregivers across settings of care.

5.10 *The Role of the Advanced Practice Nurse (APN)*

An APN can learn by just listening to those persons who are involved with the health care system (Shilbeck & Payne, 2003). In this study, the family caregivers were the barometer of the health care system's ability to provide palliative care in the home. The participants' collective suggestions will be woven into the five Advanced Practice Nurse (APN) roles: Expert practice, research, consultant, education, and leader (Hamric, Spross & Hanson, 2000).

5.10.1 *Expert Practitioner*

The palliative care APN is considered an expert practitioner as well as a role model to other HCPs. Skilbeck and Payne (2003) emphasize that all APNs work with more complex client situations and thus this role can influence daily palliative care practices in both community and hospital settings. This study has demonstrated that further improvements to palliative care practices are required to promote quality home and palliative experiences for family caregivers. The palliative care APN is the ideal practitioner to implement the following suggestions:

1. Support interdisciplinary team members, patients and their family members to promote the best comfort care for complicated palliative care situations in all care settings;

2. Advocate for an APN as a case manager to follow patients from active cancer treatment through to end of life care. This role should initially begin at the Cancer Agency where a patient's first transition occurs, and later include visits to patients and family caregivers in their home to ensure continuity of care between cancer centre, community and PCU services, appropriate access to community services and supplies, and greater support to family caregivers;

3. Encourage greater interdisciplinary and interagency communication in order to share information (review patient's condition, future concerns of patient and family), and organize thorough home care (present and future) health care resources;

4. Promote community HCPs attendance at regular patient care management meetings such as grand rounds. The APN can provide expert knowledge to frontline HCPs along with promoting problem solving of home care challenges; and

5. Develop assessment and intervention strategies for HCPs in the home to facilitate caregiving such as clinical pathways;

5.10.2 *Researcher*

The APN is also a researcher who promotes the integration of evidenced based practice into care provision as well as development of new research ideas. The following suggestions are posed to encourage the APN role in palliative care and family nursing research:

1. Enhanced research is needed on how caregivers access resources once the patient is deemed palliative and no longer connected with oncology services;

2. Further research is required about how information sources are accessed and utilized by family caregivers;

3. Additional research is needed regarding ways to reduce HCPs' impacts in the home related to, for example, scheduling of visits;

4. Facilitate research projects with rural hospitals to help identify specific care provision issues;

5. Conduct focus groups with family caregivers to identify local community needs in the home;

6. Identify gaps in palliative care delivery and family caregivers services and facilitate strategies to narrow those gaps (for example pilot projects);

7. Further research is needed to understand the extent that caregivers' personal health is affected by their family caregiving role; and

8. Greater understanding is needed regarding how HCPs communicate and work with patients, family caregivers and other family members when decisions are made about transitions to a PCU.

5.10.3 *Consultant*

The goal of an APN clinical consultant is to support and strengthen the consultee's decisions while improving patient care through expert knowledge (Hamric et al, 2000). Thus, the palliative nursing consultant teaches, advises and updates other HCPs on current palliative care literature and best practices to enhance comfort care for patients in all care settings. The consultee is often a family physician, oncologist, a staff nurse, or a CCAC case manager. These HCPs require informational and emotional support when caring for more complex palliative patients as well as for palliative patients' with more disruptive family behaviours. This study makes the following recommendations for the APN consultant role:

1. Evaluate how home care agencies implement care to palliative families. Within the aspects of palliative care provision, the consultant should monitor and foster a comprehensive palliative care program that links community and institutional settings. With greater resources and access to information along with smoother transitions from home to PCU, family caregivers and the patients will experience improved caregiving;

2. Advocating at the local committee level for changes in policy related to employee supports while caregiving; and

3. Act as a consultant in the hospital setting for complex patient and family situations where palliative care is required.

5.10.4 *Educator*

This study suggests the following recommendations for the APN educator role:

1. Conduct a needs assessment in community to determine the available resources and information;

2. Work with rural hospitals and community agencies about issues related to medication access;

3. Identify learning needs for nurses providing care in the home related to palliative care. For example, assessments of family caregiver support and abilities;

4. Provide educational sessions on palliative care and family caregiving for community and hospital staff;

5. Promote staff nurses' participation in conferences, grand nursing rounds, and journal clubs for increased understanding of patients' and families' needs related to palliative home caregiving; and

6. Provide opportunities for nursing staff to present challenging patient situations in order to improve care practices and reflect on how members of the interprofessional team collaborate with patient and family.

5.10.5 *Leader*

The APN is well prepared to lead interdisciplinary teams within community and hospital care settings, along with advocating safe and appropriate practices to patients

and their family caregivers. This study's findings have clearly demonstrated that further collaboration and cooperation of community home care services is required.

The nursing leadership recommendations are:

1. Enhance communication between community health agencies, cancer clinics and PCU staff to further promote collaboration and cooperation of community home care services. The focus would be on enhancing coordination of the services as well as improving interagency communication related to patient care and symptom tracking. All agencies should be notified when clients require palliation services. This mode of communication could become a network between the interdisciplinary care team of CCAC case managers, home care agencies, pharmacist, family physician as well as APNs and Social Workers in the acute care hospitals. Such an initiative would reduce service duplication, improve updates on individual patient's condition and prognosis along with improve smoothness of resource allocation and transition of care to any setting;

2. Advocate for increased community service providers and consistency among HCPs to reduce time pressures during palliative care home visits. By promoting adequate time for staff to sit down with family caregivers, this would lead to greater awareness of the home caregiving situation, needs for education, additional physical assistance, and emotional support. This encourages information exchange, builds trust and value of each others role (HCP and family caregivers). It is likely that family caregivers would not feel intruded upon when the patients' medical care needs escalate in the home as there would be a greater level of comfort with the HCPs; and

3. Lobbying for flexible workplace arrangements and funding for employees who are providing family caregiving in the home setting. This initiative includes openness to family caregivers having to leave the workplace on short notice, promotion of extended work hours and work from the home. Both HCPs and employers should encourage family caregivers to access employee support services such as employment assistance program, and counselors.

5.11 *Study Limitations*

There are several limitations in this current study. The first is that it was conducted in one institution within a Canadian city. The second limitation was the sample's homogenity. While this study did not narrow its participants to family caregivers of cancer patients intentionally, all participants were caring for family members with end stage cancer. Cancer patients are the most prominent population receiving palliation services (Murtagh et al, 2004; Carstairs & Beaudoin, 2000). Consequently, this study did not represent family caregivers caring for patients with other terminal illnesses, such as heart failure. Additionally, there was no cultural diversity as participants were all Canadian-born and Caucasian.

5.12 *Conclusion*

While published research has been based on interviews with bereaved palliative caregivers, this study offered the only 'at the moment' insight into the family caregivers' transitional experience of moving a patient from home to the PCU. The *Transitional Experiences of Family Caregivers: A Puzzle of Care Provision*

framework illustrated the complexity of the caregivers' experiences from the cancer diagnosis (home) through to the *getting ready to move on* (PCU). This study discovered that both home care and PCU have positive and negative aspects for family caregivers.

While home was the preferred place of care when the patients were still fairly independent with their personal care, it was limited in the ability to support both the patients and caregivers as the patients' health declined. Family caregivers commonly expressed challenges of sustaining the caregiver role due to lack of health care knowledge, inability to obtain essential resources, difficulty accessing HCPs', feeling helpless when watching the patient suffer, and intrusion of medical equipment. They were physically "pushed to their limits" with multiple responsibilities. Family caregivers sustained the patients' care beyond their own emotional and physical abilities.

Participants compared the differences between the home and PCU settings. All participants felt guilty for moving the patient from the home; however, they were relieved to receive information, rapid medication management, and easier access to HCPs. They finally felt supported within an interdisciplinary team approach. It was evident that further enhancements to community services are required to improve palliative home caregiving. Studies have indicated that greater services and resources are needed in palliative home care. Recommendations from this study are made in the hope that palliative caregiving will improve in the future. The participants clearly stated "*the system has got to do something*" so future caregivers can have greater positive experiences of caring for a dying loved one.

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Appendix A: Research Ethical Board Approvals

December 2, 2004

Dr. F. Fothergill-Bourbonnais
School of Nursing
Faculty of Health Sciences
451 Smyth Road
Ottawa, ON
K1H 8M5

RE: The Informal Caregiver's Transitional Experience of Admitting a Family Member from Home to the Palliative Care Unit.

Dear Dr. Fothergill-Bourbonnais,

Your letter of November 19, 2004, in response to the conditional letter of November 10, 2004, answered all the issues raised by the Research Ethics Board reviewers.

It is therefore with pleasure that the SCO Health Service Research Ethics Board (REB) gives ethical approval for one year to proceed with the above titlé study.

Please note that any future changes to the protocol must be submitted to the REB for approval. You are also expected to provide notification of the termination of the study.

We wish you the best of luck with this study,

Best regards,

Richard Blair, C. Psych.
Chair, Research Ethics Board
SCO Health Service

RB/lgr

Université d'Ottawa · University of Ottawa
Services universitaires de recherche et déontologie Research Grants and Ethics Services

September 30, 2004

Dr. Frances Fothergill-Bourbonnais
School of Nursing
University of Ottawa
451 Smyth Road
Room 3237
Ottawa, ON K1N 6N5

Dr. Christine McPherson
Élisabeth Bruyère Research Institute
43 Bruyère Street
Room 272J
Ottawa, ON K1N 5C8

Ms. Kelly N. Kilgour

RE: The Informal Caregiver's Transitional Experience of Admitting a Family Member from Home to a Palliative Care Unit (file H 08-04-07)

Dear Researchers,

You will find enclosed the Health Sciences and Science REB ethical clearance for the abovementioned research study.

Please note that it is the responsibility of the Researchers to:

a) Inform the ethics office of any changes in the research project; and
b) Fill out an annual status report to be sent to the Protocol Officer for Ethics in Research. Such report can be found on the ethics web site at: http://www.uottawa.ca/services/research/rge/rebs/download/rapport_annuel_projets_anglais.doc

A copy of this approval will be sent to Research Services, if necessary.

If you have any questions, you may contact me at the number 562-5387.

Sincerely yours,

Rita D'Alessandro
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the Health Sciences and Science REB

Université d'Ottawa · University of Ottawa

Cabinet du vice-recteur à la recherche
Office of the Vice-Rector, Research

HEALTH SCIENCES AND SCIENCE RESEARCH ETHICS BOARD

CERTIFICATE OF ETHICAL APPROVAL

This is to certify that the University of Ottawa Health Sciences and Science Research Ethics Board has examined the application for ethical approval for the research project entitled **The Informal Caregiver's Transitional Experience of Admitting a Family Member from Home to a Palliative Care Unit (file H 08-04-07)** submitted by Kelly N. Kilgour, of the School of Nursing, Faculty of Health Sciences, who is supervised by Dr. Frances Fothergill-Bourbonnais, of the School of Nursing, Faculty of Health Sciences, and Dr. Christine McPherson, of the Élisabeth Bruyère Research Institute. The Board found that this research project met appropriate ethical standards as outlined in the Tri-Council Policy Statement and in the Procedures of the University of Ottawa Research Ethics Boards, and accordingly gave it a Category 1a (approval). This certification is valid for one year from the date indicated below.

Rita D'Alessandro
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the
Health Sciences and Science REB

September 30, 2004
Date

550, rue Cumberland
Ottawa (Ontario) K1N 6N5 Canada

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(613) 562-5270 • Téléc./Fax (613) 562-5271

Université d'Ottawa University of Ottawa
Services de subventions de recherche et déontologie Research Grants and Ethics Services

October 25, 2005

Frances Fothergill-Bourbonnais
School of Nursing
University of Ottawa
451 Smyth Road
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Christine McPherson
Élisabeth Bruyère Research Institute
43 Bruyère Street
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Ottawa, ON K1N 5C8

Kelly N. Kilgour
212-169 Lees Avenue
Ottawa, ON K1S 5M2

Object: **The Informal Caregiver's Transitional Experience of Admitting a Family Member from Home to a Palliative Care Unit (file H 08-04-07)**

Dear Drs. Fothergill-Bourbonnais and McPherson and Ms. Kilgour,

You will find enclosed the Health Sciences and Science Research Ethics Board renewal certification for your research project above-mentioned.

During the course of the study, any modifications to the protocol or forms may not be initiated without prior written approval from the REB. You must also promptly report to the REB all adverse events or experiences encountered by participants.

The renewal certification is retroactive to September 30, 2005 and valid until September 30, 2006. Please submit an annual status report to the Protocol Officer in September, 2006 to either close the file or request a renewal of ethics approval. This document can be found at: http://web9.uottawa.ca/services/rgessrd/ethics/application_dwn.asp

A copy of this renewal approval will be sent to Research Services, if necessary.

Please do not hesitate to contact me at extension 5387 if you should have any questions.

Sincerely,

Rita D'Alessandro
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the Health Sciences and Science REB

Université d'Ottawa University of Ottawa
Service des subventions de recherche et déontologie Research Grants and Ethics Services

HEALTH SCIENCES AND SCIENCE RESEARCH ETHICS BOARD

CERTIFICATION OF ETHICS APPROVAL

This is to certify that the University of Ottawa Health Sciences and Science Research Ethics Board (REB) examined the application for extension of ethics approval for the research project **The Informal Caregiver's Transitional Experience of Admitting a Family Member from Home to a Palliative Care Unit (file H 08-04-07)** submitted by Kelly N. Kilgour and supervised by Frances Fothergill-Bourbonnais of the School of Nursing and Christine McPherson of the Élisabeth Bruyère Research Institute. This project received initial ethics approval on September 30, 2004 by the REB as meeting appropriate ethical standards set out in the Tri-Council Policy Statement and in the Procedures of the University of Ottawa Research Ethics Boards. The University of Ottawa REB members accordingly gave it a one-year extension of ethics approval. This ethics renewal certification is retroactive to September 30, 2005 and valid until September 30, 2006.

Rita D'Alessandro
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the
Health Sciences and Science REB

October 25, 2005
Date

550, rue Cumberland 550 Cumberland Street
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

Appendix B: Study Information Sheet

Title of the study: The informal caregiver's transitional experience of admitting a family member from home to a palliative care unit

Researcher: Kelly Kilgour, RN, BScN
University of Ottawa MScN student
Tel:

Thesis Supervisor: Frances Fothergill-Bourbonnais RN, Ph.D.
Full Professor, School of Nursing University of Ottawa
Tel: (613) 562-5800 (ext. 8423)

Thesis Co-Supervisor: Christine McPherson RN, Ph.D.
Adjunct professor - University of Ottawa
Research Scientist – Élizabeth Bruyère Research Institute: SCOHS
Tel: (613) 562-0050 (ext. 1451)

Funding: University of Ottawa School of Nursing and Élisabeth Bruyère Institute fellowship in palliative care nursing

Purpose: You are being asked to take part a research project conducted by Kelly Kilgour, Registered Nurse. The study is being completed for completion of the Master of Science in Nursing program at the University of Ottawa. The purpose of this study is to explore an informal caregiver's experience of recently admitting a family member to a Palliative Care Unit.

Procedure: You are invited to participate in two tape recorded interviews. Your participation is entirely voluntary and there will be no adverse consequences should you decide not to participate. Both interviews will be conducted in English. The first interview will be conducted at the Palliative Care Unit, Élisabeth Bruyère Centre with a pre-arranged time convenient for you. During the first interview, you will be asked to fill out a short questionnaire about your experience as a caregiver before and after admission of your family member to the palliative care unit. The recorded tapes will be type out word for word. This will help the researcher to recall the details of the interview and make sure her understanding is correct. A summary will be developed by comparing your responses to other participants' responses. A second interview will be arranged at a convenient time and place for you once the researcher has completed the analysis. If your family member has passed away during this study, your participation is still requested. You will be given the opportunity to withdraw from the study or the researcher may postpone the meeting up to four weeks. During the second interview, you will be asked to review the analysis of this study. The

second interview is to determine whether you agree with how the researcher has understood your experience.

Duration of Participation: The first interview will take approximately 60 minutes of your time. The second interview will take place approximately 2-3 months after the first interview. The second interview will take approximately 30 minutes.

Confidentiality: The information collected during this study will be kept confidential. A fake name will be used to recognize your information and you may choose your own fake name. Only the researcher and research committee will see the information, which will be kept in a locked filing cabinet at the University of Ottawa. The data will be stored for five years after the study completion. The study results will be published and quotes may be included using the fake names. No personal information will appear in any presentations or the published reports.

Risks: The interview process may raise sensitive thoughts and memories for you. You may feel fatigued during or after the interview due to the discussion of these sensitive thoughts and memories. The researcher conducting the interviews is a Registered Nurse, who has experience talking to caregivers caring for terminally ill family members. She is prepared to provide support during the interview and will suggest a counseling resource if you show severe emotional distress. The researcher may phone you after the interviews as a follow up to see how you are managing.

Benefits: You will have the chance to talk about what it has been like to be a caregiver. Your information may help future caregivers and health care professionals develop a better understanding of the resources required for caregivers.

Rights of a Participant: You do not need to take part in this study and you may withdraw from this study at any time. If you find that you would like to stop the interview at any time, please let the researcher know. You can refuse to participate or to answer individual questions without any impact to yourself or the care that is provided on the Palliative Care Unit.

Compensation: Your parking will be reimbursed the day that you are at Élisabeth Bruyère Health Centre for the interview. No other compensation will be offered.

Other Information: If you have any questions, please contact the researcher at

Thank you very much for taking the time to consider helping with this study.

Appendix C: Consent Form

Title of the study: The informal caregiver's transitional experience of admitting a family member from home to a palliative care unit

Researcher: Kelly Kilgour, RN, BScN
University of Ottawa MScN student
Tel: (
Email

Thesis Supervisor: Frances Fothergill-Bourbonnais RN, Ph.D.
Full Professor, School of Nursing University of Ottawa
Tel: (613) 562-5800 (ext. 8423)
Email: fbourbon@uottawa.ca

Thesis Co-Supervisor: Christine McPherson RN, Ph.D.
Adjunct professor - University of Ottawa
Research Scientist – Élizabeth Bruyère Research Institute: SCOHS
Tel: (613) 562-0050 (ext. 1451)
Email: cmcphers@scohs.on.ca

Purpose of the study: The purpose of the study is to explore a caregiver's experiences of recently admitting a family member from home to a Palliative Care Unit.

Participation: My participation in this study will consist of attending two interview sessions conducted in English. The first interview will take approximately one hour and has been scheduled at Élisabeth Bruyère Centre. During the first interview, I will be asked to fill out a short questionnaire. The second interview will take approximately half an hour and will be arranged at a convenient date, time and place for me in two to three months. Both interviews will be tape recorded.

Risks: I understand that my participation will involve discussing some sensitive thoughts and memories for me. I may feel tired and emotional during or after the interviews. I have received assurance from the researcher that every effort will be made to minimize such risks.

Benefits: My participation in this study will allow me to discuss my experiences of being a caregiver. My information will help future caregivers and health care professionals through a greater understanding of caregiving experiences.

Confidentiality: I have received assurance from the researcher that the information I share will remain strictly confidential. I understand a fake name will

be used to recognize my information. Only the researcher and thesis committee will see the original study information. The data will be stored in a locked cabinet at the University of Ottawa for five years after the study completion. Confidentiality will only be broken if I become emotionally distressed and the researcher may contact a counseling resource on my behalf.

Voluntary participation: I am under no obligation to participate and if I choose to participate, I may withdraw from the study at any time. I may also refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, none of my interview data will be utilized.

Acceptance: I, , agree to participate in the above research study conducted by Kelly Kilgour of the Nursing department, Faculty of Health Sciences, University of Ottawa, whose research is under the supervision of Dr. Frances Fothergill-Bourbonnais and Dr. Christine McPherson. I have had all my questions satisfactorily answered about participating in this study. I understand that by accepting to participate that I still may withdraw from the study at any time.

If I have any further questions about the study, I may contact the researcher or her supervisors at the numbers mentioned above.

If I have any ethical concerns regarding my participation in this study, I may contact Dr. Richard Blair, Chairman of the SCO Health Service Research Ethics Board, Élisabeth Bruyère Health Centre, 43 Bruyère Street, Ottawa, ON, K1N 5C8, (613) 562-6292 or rblair@scohs.on.ca.

There are two copies of the consent form, one of which is mine to keep.

Participant's name: Date:
Participant's signature: Date:

Witness's signature (if applicable): Date:

I confirm that I have explained the nature and purpose of the study to the named participant and that I have answered all questions.

Researcher's signature: Date:

Appendix D: Caregiver Recruitment Contact Sheet

Study: "The Informal Caregiver's Transitional Experience of Admitting a Family Member from Home to the Palliative Care Unit"
Principle Investigator: Kelly Kilgour, RN, BScN

The following informal caregiver

_____ has agreed to be contacted to discuss taking part in this study.

His/Her home phone number is (_____)_____

Additional relevant information (optional):

Thank you

Appendix E: Caregiver Demographic Questionnaire

Caregiver Demographic Questionnaire

1. What is your gender?

☐ Male ☐ Female

2. Which age category fits your approximate age?

☐ 18 -25 yrs ☐ 26 -39 yrs ☐ 40-60 yrs ☐ 60-70 yrs ☐ 71-85 yrs ☐ 85+

3. Are you retired?

☐ Yes ☐ No

4. If no, are you working from your home or outside of your home?

_____

5. Have you applied for compassionate leave? If so, please approximate how long ago you applied.

_____

6. What is your relationship to the patient?

_____

7. Do you live with the patient in the same home?

☐ Yes ☐ No

8. If no, how far away do you live from the patient's home?

_____

9. How long have you been caregiving the patient?

_____

10. Have you previously or are you currently providing care to someone? If yes, please explain your experience.

_____