

Registered Nurses' Experience of
Caring for a Dying Family Member

by

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BSN, University of Victoria, 1996

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Requirements for the Degree of

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ABSTRACT

Nurses in dual caregiving roles are at high risk for stress and burnout, which may influence nurses' decisions to leave the nursing profession. This exploratory, descriptive, qualitative study explored registered nurses' experience of caring for a dying family member. Fourteen nurses were recruited and rich descriptions of their experiences were gained through individual face-to-face interviews. Three important themes were identified through data analysis: *knowing the ropes* which captures the assets nurses brought to their family caregiving experience from their professional knowledge and association with the health care system; *caught in the middle*, which highlights tensions the nurses faced as they negotiated their professional and personal boundaries; and *gaining insights*, which describes nurses' insights about themselves and their practice gleaned from caring for a dying family member. The findings suggest that lack of support from the formal health care system may compound the stress of caregiving for nurses and may lead to health problems. Therefore, it behooves HCPs, health organizations and policy makers to individualize interventions and design palliative programs to address the unique needs of nurses caring for a dying family member.

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Praise be to the God and Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves have received from God.

2 Corinthians 1: 3&4

Thanks be to God.

CHAPTER 1: INTRODUCTION

Over the past half-century, care for the dying has transferred from institutions to home settings. There are several reasons for this change. The Canadian Institute for Health Information (2007) reports that majority of Canadian citizens wish to die in their own homes. As well, reductions in health care budgets and subsequent facility bed closures have created more demand to provide home-based palliative care services (Hudson, 2006; Morris, 2004; Stajduhar, 2002). As a result, the burden of care for the ill and dying has shifted away from the formal health care system of professional care providers towards an informal network comprised of family and friends (Canadian Hospice Palliative Care Association [CHPCA], April 2004). This trend however, is not without repercussions.

Research reveals several negative impacts on family caregivers (FCGs) who provide care to their dying family members (Perreault, Fothergill-Bourbonnais & Fiset, 2004; Zapart, Kenny, Hall, Servis & Wiley, 2007). These impacts include ill health, exhaustion, and emotional turmoil (Hudson, 2004; Stajduhar, 2003). These stressors are further compounded when FCGs are employed (Guberman & Maheu, 1999; Hawranik & Strain, 2000). Combining employment and family caregiving is challenging because of role conflicts and the need to juggle competing demands (Guberman & Maheu, 1999; Scott, Hwang & Rogers, 2006).

Family caregiving is further complicated when paid employment is also focused on the provision of care. Time and role conflicts and expectations to provide informal

¹Registered Nurses for purposes of this study, refers to nurses who are accountable to a College of registered nurses. Licensed Practical Nurses and Nurses' Aides were not included in this study.

care, have been identified by health care providers (HCPs), such as registered nurses¹, who provide ‘double-duty’ care to both their patients and their own family members (Gottlieb, Kelloway & Martin-Matthews, 1996; Grzywacz, Frone, Brewer & Kovner, 2006; Ross, Rideout & Carson, 1994; Scott et al., 2006; Ward-Griffin, 2004). These studies reveal that nurses constantly negotiate boundaries between their professional and family caregiving roles while providing care to their children or elderly relatives.

Research also reveals that providing care at work as well as to family members is associated with negative consequences such as burnout, fatigue, and emotional distress (Grzywacz et al., 2006). Additionally, work-family conflicts may hamper nurses’ ability to provide high quality care to patients (Killien, 2004). Unresolved work-family conflicts are associated with premature departure from the nursing profession, thus exacerbating the current nursing shortage (Dickerson, Brewer, Kovner, & Way, 2007; Grzywacz et al.; Simon, Kummerling, Hasselhorn & NEXT-Study Group, 2004).

Although there is a growing body of knowledge focusing on how nurses mediate professional and personal caregiving roles caring for children and elderly relatives, there is a paucity of literature that focuses on the phenomenon of nurses caring for a dying family member. The focus of this study is to explore nurses’ experiences of providing care to dying family members. Specifically, this study centres on the challenges, tensions, benefits, and opportunities associated with this experience and how nurses managed simultaneous roles of personal and professional caregiving. I anticipate that the results of the study may be used to inform HCPs, educators, and policy makers about the experiences and unique needs of nurses who care for their own dying family member.

Background to the Problem

Increasingly, family members are shouldering the brunt of care for elderly and chronically and terminally ill relatives at home (Armstrong & Armstrong, 2004; Aoun & Kristjanson, 2005; Cranswick, 2003; Hudson, 2006; Simon et al., 2004). Changes in demographics, advances in science and technology, and current economic climate are some reasons cited for the impetus toward home-based family caregiving (Aoun et al., 2005; Guberman, Gagnon, Cote, Gilbert, Thivierge & Tremblay, 2005; Stajduhar, 2003).

In the past half-century, demographic changes have increased the need for FCGs (Cranswick, 2003; Scott et al., 2006). The dramatic increase in population in the “baby boom” years during the 1950’s and 1960’s will result in more elderly people who require care (Armstrong & Armstrong, 1996). In Canada, the population of seniors aged 80 and older increased 40% between 1991 and 2001 (Cranswick). Along with an aging population comes an increase in morbidity, resulting in more seniors who require support to remain independent in their own homes (Cranswick; Chilton, 2003). In addition, advances in science and technology have enabled individuals to live longer (Brazil, Bedard & Willison, 2002), many experiencing a longer chronic illness trajectory (Perreault et al., 2004). As a result, family members may be providing care over several months, years, or even decades leading to an increased potential of stress and ill health for the caregiver as they provide care over the long term (Brazil et al.).

FCGs have taken on increasing importance as hospital bed closures and rising health care costs have prompted a shift from care that was previously provided in the hospital to care now being provided at home (Brazil et al., 2002; Stajduhar, 2003). Similarly, budgetary restraints have resulted in shortages of long term care beds, thus

leaving the vulnerable and sick waiting at home to get care that they may need. Cutbacks in professional and home support services have also placed more burden on family members to support their sick and ailing relatives (Aoun et al., 2005; Aronson, 2004). Such care has become increasingly complex necessitating family members to take on unfamiliar complex care such as administering intravenous medications and managing catheter care (Guberman et al., 2005). Research suggests that the impact on FCGs' physical and emotional health can be substantial (Given Wyatt, Given, Sherwood, Gift, DeVoss & Rahbar, 2004; Grbich, Parker & Maddocks, 2001), with one in ten caregivers reporting health problems such as sleep disturbances (Cranswick, 2002), and physical and emotional exhaustion related to the amount of care they were expected and required to do (Ward-Griffin & McKeever, 2000).

Research suggests that given a choice, most people would prefer to die in their own homes (Higginson & Sen-Gupta, 2000) because, to a large degree, the home setting evokes feelings of security and comfort (Cairns, Thompson & Wainwright, 2003; Gomes & Higginson, 2006). While many individuals would prefer to spend their dying days at home, this may not be realistic or achievable unless there is an able support person in the home. Brazil et al.'s (2002) study of factors associated with home deaths indicates that individuals who have a healthy family caregiver are more likely to achieve a desired at-home death. This study provides strong evidence that dying at home is *dependent* on FCGs' capacity to manage care.

There has been considerable research on family caregiving in the palliative phase but there has been very little research focused on instances in which the family caregiver (FCG) is also a professional care provider. No studies could be found that examined

nurses' experiences of providing care to a dying family member. Yet, combining caregiving responsibilities and employment is often difficult because of role conflicts and competing needs. The impact of caregiving is further exacerbated when the family member's paid work is also focused on the provision of care (Gottlieb et al., 1996; Mills & Aubeeluck, 2006; Scott et al., 2006; Ward Griffin, 2004). Nurses who provide care to elderly relatives report greater levels of physical and mental fatigue on paid work time compared with nurses who have no caregiving responsibility at home (Scott et al.). As well, nurses who perceive high caregiving demands at home report being inattentive at work (Gottlieb et al.) and are more likely to make errors at work (Scott et al.). Studies also reveal that nurses who provide professional and family care, view themselves as being "betwixt and between" two worlds (Ross et al., 1994; Ward Griffin). As such, nurses experience role conflicts as they mediate their professional and family responsibilities (Mills & Aubeeluck; Ross, et al., 1994; Ward Griffin, 2004). In the context of palliative caregiving, Glajchen asserts that FCGs must try to "meet the patient's needs for emotional and practical support, while grappling with his or her own impending loss and separation" (as cited in CHPCA, 2004, p. 6). Moreover, nurses may experience additional repercussions as they provide physical and emotional care not only to their patients but also to their own dying family members.

Statement of the Problem

Although there are a few recent research studies exploring nurses' experiences of caring for family members, there is a dearth of research focusing on the experience of nurses who provide care both professionally and for their dying family members. Nurses in dual caregiving roles may be additionally burdened and at high risk for stress and

burnout; some research suggests that caregiving responsibilities are a factor in nurses' decisions to leave the nursing profession (Miracle & Miracle 2004; Simon et al., 2004; Strachota, Normadin, O'Brien, Clary & Krukow, 2006). Although nurses may report similar issues of caring for dying family members, such as grappling with potential losses and communication issues, and may have more knowledge and experience in providing care and interacting with the formal health care system than those with no nursing education or experience, it cannot be assumed that nurses have fewer needs than non-nurse FCGs. Indeed, there may be issues unique to nurses, such as negotiating professional and personal boundaries. FCGs who are also nurses may have unique needs and vulnerabilities that require further exploration.

The knowledge gained about family caregiving experiences of nurses may inform health care professionals about how to better support nurses who are caring for a dying family member. It is anticipated that the number of employed Canadians balancing work and caregiving duties will increase in the future (Cranswick, 2003). This highlights the need to better understand the phenomenon of balancing paid work and caring for a dying family member in order to provide tailored and flexible support to nurses who provide 'double duty' care.

Purpose of the Study

The aim of this study is to gain understanding of registered nurses' experiences of caring for a dying family member. To explore the role of nurses as FCGs, the following research question guided this study: What are nurses' experiences of providing care for their dying family member? The main objectives of this study were to describe nurses' experiences of providing care to their dying family members and to generate knowledge

about the benefits, challenges and needs of nurses who are FCGs.

Assumptions

My assumptions are identified as follows: (1) The experience of family caregiving is different for a registered nurse than for non nurse FCGs because the social context in which nurses' experiences are situated, influences their experiences as caregivers; (2) Nurses experience tension when mediating their professional nurse role while providing care to a dying family member; and (3) When providing care to a dying family member, nurses are vulnerable in different ways than their non-nurse caregiver counterparts.

Definition of Terms

For the purpose of this study, the following terms were defined as follows:

- *Bereaved nurses* are nurses who have lost a family member to death following a life-threatening illness. This study focused on nurses who had been bereaved for at least one year and less than 5 years. Rationale for this approach is provided in Chapter 3.
- *Caring for/cared for* is care provided or given in any of the four domains cited by Armstrong and Kits (2004). The domains are: 1) care management (e.g. finding information about resources, arranging appointments, and acting as a mediator between formal HCPs and their ill family member); 2) assisting with Instrumental Activities of Daily Living (IADL) which includes household maintenance, banking, and shopping; 3) assisting with Activities of Daily Living (ADL) such as bathing, dressing, and feeding, and 4) providing social and emotional support.
- *Formal caregiving* is defined as the paid professional care role that is the primary basis of nurses' formal employment.
- *Home* refers to the dying family member's place of residence. This study did not

exclude nurses who provide care to their family member in alternate settings such as long term care, hospice or acute care, as long as the care provided was during the dying period and the amount of care was substantial enough for the caregiver to comment on the caregiving role.

- *Family caregiver is defined as* “a family member, partner, friend or neighbour who provides care for a critically ill loved one without pay. Family is considered to include the biological family of ‘blood relatives’ as well as the “family of choice” based on close relationships with the person who is ill” (Dunbrack, 2005).
- *Palliative Care* is defined as a philosophy of care that focuses on comfort rather than cure and “stresses the relief of suffering and improvement of the quality of living and dying. It helps patients and families to address physical, psychosocial, social, spiritual and practical issues and their associated expectations, needs hopes and fears” (British Columbia Ministry of Health, 2006, p. 3).
- *Registered Nurses* is defined as “individuals employed to provide nursing care, personal care, and delegated medical care in their role as RNs” (Scott et al., 2006). For the purposes of this study, this refers to nurses who are accountable to a College of Registered Nurses. Licensed Practical Nurses and Nurses’ Aides were not included in this study.

Potential Significance of the Study

“*How* people die remains in the memories of those who live on, and for them as for the patient we need to be aware of the nature and management of terminal care and distress” (Saunders, 1989, p. 472).

In palliative care, the client and family are viewed as a single unit of care. As such, palliative care providers are directed to address emotional and spiritual needs of

both clients and their family members. This is especially warranted when family members are also assuming caregiving roles. The availability and ability of the informal support provided by FCGs is a major factor in maintaining care in the home. Therefore, *how* people die is dependent on the professional, social, and material supports available to FCGs. Findings from this study will provide knowledge to guide palliative care providers and nursing educators to more fully understand the experiences of nurse FCGs and to provide a beginning knowledge base to develop interventions to best support nurses who are in dual caregiver roles.

CHAPTER 2: REVIEW OF THE LITERATURE

Introduction

To inform this study, a review of literature was conducted to determine the existing body of knowledge and identify where knowledge gaps exist. The literature review provides a framework for the study by placing it in the context of current knowledge about family caregiving, palliative caregiving, and nurses who provide care to their own family members. In this chapter, I review what is known about family caregiving in palliative care, specifically focusing on the benefits, challenges, and health outcomes for FCGs. Then, I review the literature pertaining to dying at home, highlighting the demographic characteristics of those who die at home and of their FCGs. In this section, I will review what is known about the roles and needs of home-based palliative caregivers. Finally, studies that focus on nurses who, in addition to their formal caregiving roles also provide care to their own family members will be reviewed. Specifically, I include what is known about the benefits, tensions, and challenges nurses experience as a result of their dual caregiving roles.

Family Caregiving in Palliative Care

There is a substantive body of literature focused on family caregiving, particularly in the area of gerontology. Research on caregiving for the elderly shows that although family members derive a great deal of satisfaction from their caregiving experiences (Hudson, 2004; Lane, McKenna, Ryan & Fleming, 2003; Osse, Vernooij-Dassen, Schade & Grol, 2006), caregivers often report health problems, emotional stress and financial strain (Cranswick, 2003; Given et al., 2004; Williams, 2005; Zapart et al., 2007). Studies focused on palliative caregiving are a more recent contribution. As in research with the

seniors' population, this research suggests there are many benefits, challenges and health outcomes that are associated with caring for a dying family member.

Benefits of Palliative Family Caregiving

FCGs in several studies identify many positive aspects about their caregiving experiences. It is known that the time spent in caregiving strengthens their relationship with dying relatives (Cohen, Colantino, & Vernich, 2002; Hudson, 2006; Stajduhar, 2003; Williams, Chessie & Marche, 2003; Zapart et al., 2007). FCGs in Zapart et al.'s study had positive feelings about their caring role and derived satisfaction and a sense of achievement from their experiences.

Several studies reveal that FCGs experience a sense of satisfaction and accomplishment with providing care, especially when they have had little or no previous training or experience (Hudson, 2006; Proot, Crebolder, Goldsteen, Luker & Widdershoven, 2003; Waldrop, Kramer, Skretny, Milch & Finn, 2005; Zapart et al., 2007). Bereaved caregivers also express a sense of accomplishment and satisfaction as they successfully achieve their desired goals to make their family member more comfortable and succeed in having them stay at home as long as possible (Hudson; Koop & Strang, 2003; Williams et al., 2003). As well, caregivers express feelings of pleasure and fulfillment that they have the opportunity to reciprocate care to a dying family member (Grbich et al., 2001, Koop and Strang; Zapart et al.).

Family members also report their caregiving experience is meaningful and leads to personal growth (Brown & Stetz, 1999, Grbich et al., 2001, Hudson, 2006). Caregivers for persons with terminal cancer and AIDS in Brown and Stetz's study, for example, report that their experience deepened their compassion and produced inner strength.

The literature suggests several conditions that may promote caregivers' positive appraisal of their caregiving situations. Stajduhar's (2003) ethnographic study of home-based palliative FCGs found that caregivers who reported positive caregiving experiences felt it was rewarding because they had a choice in assuming care. As well, caregivers in this study felt they had the time and financial resources to partake in caregiving. For participants in Brown and Stetz's (1999) study, caring in the final stage of life was an "ultimate expression of love" (p. 192). Caregivers have also reported they were better able to cope with caregiving because they had good relationships with their dying family members (Hudson, 2006; Stajduhar), and they were well supported by both their social networks and the formal health care system (Hudson, 2006; Proot et al., 2003; Stajduhar).

Challenges of Palliative Family Caregiving

While it is clear that there are many benefits to palliative caregiving, several studies reveal that caring for a dying family member is imbued with challenges. FCGs frequently report challenges such as managing the complexity of caregiving tasks (CHPCA, 2004; Hauser & Kramer, 2004; Perreault et al., 2004), pain management (Osse et al., 2006), grappling with their own emotions (Grbich et al., 2001; Proot et al., 2003; Waldrop et al., 2005), dealing with conflicts with their dying family members and other relatives (Brown & Stetz, 1999; Proot et al., 2003), interfacing with the formal health care system (Hudson, 2006; Perrault et al., 2004; Proot et al.; Stajduhar, 2003; Strang & Koop, 2003), and financial burden (Proot et al., 2003; Stajduhar; Waldrop et al.; Wyatt, Friedman, Given & Given, 1999).

Complexity of Caregiving Tasks.

As more medical and nursing care is being delegated to FCGs, providing both

personal care and performing tasks such as managing pain, giving injections, and changing wound dressings is challenging both physically and emotionally (Brown & Stetz, 1999; CHPCA, 2004, Osse et al., 2006; Perreault et al., 2004, Rose, 1998). Rose's doctoral study reveals that the immediacy and complexity of personal and medical care tasks are a struggle for FCGs. Providing personal care such as bathing or toileting contributes to the burden of FCGs, as these tasks are time-consuming and perceived as "distasteful" by some carers (Rose, p.344). Further, in an Australian study using both quantitative and qualitative methods, adult children reported more discomfort in providing personal care to a parent than those who provide care to a spouse (Zapart, et al., 2007). Similarly, Rhodes and Shaw's (1999) study reveals that several bereaved adult children recalled their parents' expressions of embarrassment and humiliation when receiving intimate care from them.

Research also shows that the complexity of care tasks is a stressor of palliative caregiving (CHPCA, 2004; Hauser & Kramer, 2004). FCGs describe the last days of their family members' life as traumatic and stressful because of additional care needs caused by the increase in severity and frequency of physical symptoms (Osse et al., 2006; Waldrop et al., 2005; Wilson, 2000). Medical tasks such as managing pain and administering opioids cause anxiety and distress for some FCGs (CHPCA, 2004; Osse et al.). FCGs in several studies report feeling helpless and exhausted, especially in situations where they are unable to control pain and other symptoms (Grbrich et al., 2001; Perreault et al., 2004; Proot et al, 2003; Waldrop et al). In Osse et al.'s study, younger caregivers found it more difficult to handle the patient's pain. As well, a report from the CHPCA (2004) comments that FCGs often "struggle with a sense of guilt that something they do

for the person may hasten his or her death” (p. 15).

Grappling with Own Emotions.

Another significant challenge for many FCGs is dealing with their own personal grief and loss while adapting to caregiving roles (Brown & Stetz, 1999; Koop & Strang, 2003; Proot et al., 2003; Zapart et al., 2007). Bereaved home-based caregivers in Koop and Strang’s Canadian study report they were challenged not only with observing physical deterioration but also with facing the impending loss of their family member. The experience for family members during the final stages was described as an “emotional roller coaster” as caregivers experienced intense emotions of profound sadness mixed with anger (Waldrop et al., 2005, p. 633). Caregivers also feel anxious about the death itself and wonder how they will cope (Grbich et al., 2001). Many FCGs in Brown and Stetz’s study had never witnessed a death before and felt “emotionally unprepared...to observe someone take a final breath” (p. 191).

Conflicts with Dying Family Member and Other Relatives.

Research also reveals that conflicts between caregivers and their dying family member and other relatives are another source of distress. Findings from Strang and Koop’s (2003) study suggest that the relationship between the caregiver and the dying family member is an important factor in a caregiver’s ability to cope. This study reveals that the coping abilities of caregivers are positively influenced by dying family members who understand and respond to their needs. Strang and Koop contend that it is “within this profound, reciprocal, emotional, and interdependent relationship that the caregivers [are] able to continue to provide care despite their experiences of overwhelming emotional and physical strain” (p. 112).

Conversely, Proot and colleagues (2003) suggest that the vulnerability for fatigue and burnout increases when caregivers experience a lack of appreciation from their dying family member. Caregivers in this study experienced a lack of support from their dying family member when there was ambiguity in the care recipient's wishes or when they are dissatisfied with the care received from family members.

Conflicts with other family members also contribute to the distress of caregivers (Brown & Stetz, 1999; Strang & Koop, 2003). In Brown and Stetz's study, some FCGs felt unduly criticized by other relatives who felt resentful towards them because of their close relationship with the dying family member. Strang and Koop's findings indicate that some caregivers find other family members' offers of assistance and support as intrusive rather than helpful. Several studies indicate that a lack of support and appreciation from other family members increased loneliness, isolation, stress and burden in caregivers (Enyert & Burman, 1999; Goldstein, Concato, Fried, Kasl, Johnson-Hurzeler, Bradeley, 2004; Grbich et al., 2001; Proot et al., 2003).

Interface with the Health Care System.

In several studies, FCGs report a lack of support from the formal health care system and from HCPs, which adds to their distress (Hudson, 2004; Osse et al., 2006; Perreault et al., 2004; Proot et al., 2003; Stajduhar, 2003; Strang & Koop, 2003). The lack of available services, and interfacing with the health care system and formal providers, can be challenging for FCGs.

Stajduhar's (2003) study of the perspectives of family members providing at-home palliative care reveals that caregivers have difficulty accessing hospital beds for their loved one, and thus feel pressure to provide care at home. Furthermore, findings

from this study suggest that the lack of required home support help and the discontinuity of care providers also influence the experience of caregivers. FCGs struggle to maintain privacy and normalcy with the volume of HCPs coming into their home. These findings are consistent with studies by Perreault et al. (2004) and Strang and Koop (2003). FCGs in these studies report that insufficient service and long waiting periods added to their confusion, distress, and caregiving burden.

In Perreault and associate's (2004) phenomenological study, caregivers also voiced their dismay regarding the lack of follow-up from community HCPs when their family members return home. As well, caregivers in this study reveal that miscommunication and lack of coordination between health services and HCPs is a source of frustration for them. Similar experiences were voiced by FCGs in an Australian study (Hudson, 2004). The lack of continuity of palliative nurses and lack of communication between nurses and physicians led caregivers in this study to question the value and contribution of HCPs to their situation.

Research shows that the strain and distress of FCGs increase when they experience a lack of sensitivity and emotional support from HCPs (Grbich et al., 2001; Hudson, 2004; Perreault et al., 2004; Stajduhar, 2003; Strang & Koop, 2003). Caregivers in Stajduhar's study reported that some HCPs did not acknowledge their dying family members in discussions. Further, informants in another study divulged the distress they experienced as they attempted to shield their dying family members from the insensitivity of some HCPs (Strang and Koop). Studies also suggest that FCGs can experience distress when they feel disrespected by HCPs. Although FCGs feel they know their family member well and gained competency in caregiving, they sometimes perceive their

experience is minimized by HCPs (Brown & Stetz, 1999; Hudson, Aranda & Kristjanson, 2004; Stajduhar). FCGs have also reported that HCPs sometimes try and take control of decision-making about what was best for their family member, often without their input (Stajduhar). Also adding to the strain of FCGs is the lack of emotional care provided to them by HCPs (Grbich et al.; Hudson; Osse et al., 2006). FCGs in Hudson's study, for example, report that there is little time with HCPs dedicated to address their own emotional needs because much of the care is focused on the patient. Osse and colleagues postulate that caregivers may not ask for the emotional support they require from HCPs because they do not want to detract attention from the patient's problems.

Financial Challenges.

Many studies reveal that FCGs experience financial pressures related to the cost of HCPs and home care costs (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Hudson, 2003; Proot et al., 2003; Stajduhar, 2003; Waldrop et al., 2005; Zapart et al., 2007). The cost of HCP services is particularly evident in American studies. FCGs in one US study report an increase in financial strain during the end stage of life when 24-hour care is needed and they are unable to afford to pay for it (Waldrop et al.). Similarly, in Wyatt et al.'s (1999) study, bereaved American caregivers reported that during the last month of their family member's life, expenses for hospital bills, medications, physician and nursing services contributed to their financial strain. FCGs also report having to pay out-of-pocket expenses for medications and medical supplies and equipment which put a financial strain on the family (Chochinov & Kristjanson, 1998; Proot et al.; Stajduhar; Waldrop et al.; Zapart). Some Canadian FCGs in Stajduhar's study reported that they held back on purchasing essential pain medications for their family member because they

are unable to afford them.

Several studies indicate that financial strain is further compounded when family members reduce work hours or quit their job to provide care (Aranda & Hayman-White, 2001; Hauser & Kramer, 2004; Perreault et al., 2004; Stajduhar, 2003; Waldrop, et al., 2005; Wennman-Larson and Tishelman, 2002; Wilson, 2000). Quitting a job or taking unpaid leave to become full-time caregivers, coupled with the additional expense of paying for medical supplies and home help, intensifies financial strain for caregivers (Waldrop et al.; Wilson). FCGs in Waldrop and associates' study report that financial strain was evident through all phases of caregiving but especially pronounced during the final end stage when round the clock care was required and necessitated them quitting their job or taking extended time off work.

Health Outcomes of Family Caregiving

The challenging nature of caring for a dying family member has deleterious effects on the health of FCGs. Literature is replete with studies revealing physical and psychosocial impacts on family members who provide palliative care (Aranda and Hayman-White, 2001; Given et al., 2004; Grbich et al., 2001; Osse et al., 2006; Perreault et al., 2004; Rose, 1998; Stajduhar, 2002; Stetz & Brown, 2004; Zapart et al., 2007).

Physical Outcomes.

Health problems such as disturbed sleep, weight loss, fatigue, and physical exhaustion are widely reported in palliative caregiving literature, (Aranda & Hayman-White, 2001; Brown & Stetz; 1999; Carlsson & Rollison, 2003; Goldstein et al., 2004; Hudson, 2004; Hudson, 2006; Osse et al., 2006; Strang & Koop, 2003; Zapart et al., 2007). Home caregivers in Hudson's study who report illnesses such as shingles, back

pain, and emphysema, also report their ill health negatively impacts their ability to provide care. Further, physical ill health is more likely to be reported by elderly spousal caregivers who reveal that they continue to provide care in spite of and to the detriment of their own health (Davis, Cowley & Ryland, 1996).

Physical burden is also shown to be associated with disruption of FCGs' normal activities. Findings from Aranda and Hayman-White's (2001) study indicate that FCGs who report that caregiving significantly disrupts their normal activities, also report more difficulties in concentration and increased fatigue. Further, caregivers with physical problems report that caregiving impacts their health and are at risk for psychological impacts (Jepson, McCorkle, Adler, Nuamah & Lusk, 1999).

Psychosocial Outcomes.

Research indicates that emotional stress is heightened when family members provide care to a dying relative. Payne et al. (1999) found that female and younger caregivers report higher levels of psychological distress and caregiving burden. Stetz and Brown (2004) compared FCGs of persons with cancer and AIDS and found both groups had similar experiences of depression and symptoms of stress.

A few studies point to the relationship between caregiver burden and psychological morbidity (Cameron, Franche, Cheung & Stewart, 2002; Goldstein et al., 2004; Zapart et al., 2007). For example, high caregiver burden has been shown to cause depression and mood disorders in a study of FCGs of advanced cancer patients (Cameron et al.). Caregivers report bewilderment, mental exhaustion, anxiety, and depression, which were especially pronounced when their family member was experiencing multiple symptoms and in the late terminal stage (Aranda & Hayman-White, 2001; Axelsson &

Sjödén, 1998; Perreault et al., 2004; Stetz & Brown, 2004; Zapart et al.). Intensive care requirements, especially as the dying family member deteriorates, also make it difficult for caregivers to maintain connections with their social network, thus leading to feelings of loneliness and isolation (Goldstein et al., 2004; Proot et al., 2003; Strang & Koop, 2003; Zapart et al.).

The psychosocial impacts of caregiving are further compounded when FCGs are also employed. Research indicates that employed FCGs are more vulnerable to depression (Given et al., 2004; Waldrop et al., 2005), emotional distress, and social isolation than their non-working counterparts (Rose 1998; Waldrop et al.). Findings from a study by Given and associates (2004) reveal that employed caregivers of terminally ill patients, especially adult children caring for their parents, report higher levels of depression than their non-employed counterparts. Employed FCGs in Waldrop et al.'s study report the greatest strain occurred in the late terminal stage when caregiving demands were high, requiring them to ask for more time off work or give up employment to provide care (Waldrop et al.).

Competing demands of caregiving and employment also leave little time for social activities and attending to other family responsibilities, thus increasing caregiver burden (Given et al., 2004; Goldstein et al., 2004; Perreault et al., 2004). Many caregivers give up work or use up all their vacation time in order to provide palliative care (Wilson, 2000) and have less time to spend with their own family (Hauser & Kramer, 2004; Waldrop, et al., 2005; Wennman-Larson and Tishelman, 2002; Wilson). This scenario is especially common in young adults who are caring for their dying parent and also have competing family responsibilities (Given et al.; Goldstein et al.).

Dying at Home

Growing preferences for at-home deaths and cutbacks within health care budgets has led to a greater demand for at-home palliative care in Canada, Australia, and Sweden (Morris, 2004; Osse et al., 2006; Stajduhar, 2002; Wennman-Larson & Tishelman, 2002; Zapart et al., 2007). Several recent studies were aimed at expanding the knowledge about the characteristics of those who die at home and those family members who provide care to them. As well, there is a growing body of literature on the nature and extent of the role and needs of FCGs for the dying. To further inform this research project, I examined family caregiving in the context of the home setting. I briefly review literature on preferences and reasons for wanting to die at home as well as outline what is known about the sociodemographic characteristics of dying people and their caregivers. Additionally, I investigate the literature to identify the roles and needs of home-based FCGs.

Preferences and Reasons for Wanting to Die at Home

There is a plethora of international literature identifying the preference of individuals with advanced disease to die at home (Brazil, Howell, Bedard, Krueger & Heidbrecht, 2005; CIHI, 2007; Chilton, 2003; Fried, van Doorn, O'Leary, Tinetti, & Drickamer, 1999; Stajduhar, 2003; Wennman-Larson & Tishelman, 2002). Home is often idealized as the "natural" place to die as individuals are in familiar surroundings and cared for by family members who know them intimately (Stajduhar, 2002; Wennman-Larson & Tishelman; Wilson, 2000). As well, individuals who are dying and their caregivers believe the home setting offers them more privacy and autonomy than in other settings (Stajduhar, 2002; Wennman-Larson & Tishelman).

Studies reveal that this “idealization” of dying at home adds pressure to some family members to take on caregiving roles (CHPCA, 2004; Dunbrack, 2005; Stajduhar, 2003; Wennman-Larson & Tishelman, 2002). For example, some caregivers in studies by Wennman-Larson and Tishelman and by Stajduhar report that their decision to provide care at home stems from their commitment to comply with the wishes of their family member to die at home or stay at home for as long as possible rather than their own desire for the family member to be at home. Indeed, a recent study by Stajduhar, Allan, Cohen and Heyland (2008) found that patients and their FCGs only agree about half the time on where the patient should die, with FCGs preferring institutional care more often than patients. These findings are consistent with previous research suggesting that caregivers report a greater preference for an institutional death than care recipients (Brazil et al., 2005).

Several studies suggest that the primary reason for the decision to provide palliative care at home is made because of a lack of acceptable options (Aranda, 2001; Stajduhar, 2003; Wennman-Larson & Tishelman, 2002; Wilson, 2000). FCGs who have had previous exposure to acute care and long-term care facilities are sometimes left with strong negative impressions and thus, the options were viewed as unacceptable to them (Stajduhar, 2003; Wennman-Larson & Tishelman; Wilson). For example, caregivers in Stajduhar’s study reject hospital settings, describing the care as “depersonalized, paternalistic, and rule-based” (p. 29). In another Canadian study, bereaved senior caregivers revealed their belief that staying in the hospital would result in a propensity for physicians to implement unwanted life-prolonging respirator support while others observed sub-standard care in long-term care facilities (Wilson).

Sociodemographic Characteristics of People Who Die at Home

The literature indicates that the likelihood of a home death is correlated to demographic variables such as age, gender, diagnosis, socioeconomic status, and availability of informal and formal supports. With respect to age, Higginson et al. (1998) found that younger people are more likely to die at home than their elderly counterparts. Several other studies report similar significant age-related findings (Grand, Addington-Hall & Todd, 1998; Howat, Veitch & Cairns, 2007; Maida, 2002). However, Leff, Kaffenbarger and Remsburg's (2000) study of frail elders reveals that those who had planned for an at-home death were frequently able to meet their wishes. Similarly, in Burge, Lawson, Johnston and Cummings's (2003) Canadian study, elderly cancer patients were more likely to experience an out-of-hospital death.

Bivariate analyses in many studies show a strong correlation between male gender and higher probability of receiving at-home care and achieving a home death (Brazil et al., 2002; Carlsson & Rollison, 2003; Grande et al., 1998; Higginson, Astin & Dolan, 1998; Howat et al., 2007; Visser, Klinkenberg, Broese van Groenou, Wilems, Knipscheer & Deeg, 2004). Some researchers hypothesize that men more often have a spouse who can provide care (Brazil et al.; Carlsson & Rollison; Grande et al.; Visser et al.). In contrast, Gallo, Baker and Bradley's (2001) prospective study indicates that being female is associated with an increased likelihood of dying at home. Other studies show that gender is not a factor associated with place of death (Gallo et al.; Gomes & Higginson, 2006; Grande et al.). Grande et al. suggests that the cultural and family context may be more important than age or gender in achieving an at-home death.

Terminally ill persons with a cancer diagnosis were more likely to die at home

than those with non-malignant diagnoses (Howat et al., 2007; Visser et al., 2004). Visser and colleagues attribute this finding to the shorter duration of illness, younger age, and a larger social support network of cancer patients. In contrast, recent research conducted by the Canadian Institute for Health Information (2007) reveals that in Western Canada, terminally ill patients with cancer, were most likely die in hospital compared to those with organ failure or frailty. Gomes and Higginson's (2006) systematic literature review shows that a long disease trajectory is more conducive to a home death as this enables discussion and planning in regards to patient preferences. Similarly, Burge et al. (2003) postulated that a longer survival time allows for resources to be put in place to support an at-home death.

Several studies report that socioeconomic status is a factor in home death (Gallo et al., 2001; Gomes & Higginson, 2006; Grande et al., 1998; Koffman and Higginson, 2004). The probability of a home death is increased for Caucasians or those residing in high and middle-income areas, according to findings from Gallo et al.'s study of cancer patients in the U.S. Gomes and Higginson's systematic review of factors influencing death at home in terminally ill cancer patients reveals four social factors that influence the place of death: cohabitation, marital status, caregiver preferences, and number of FCGs available to provide care. Research shows that the majority of caregivers cohabitate with their dying family member or live in close proximity (Carlsson and Rollison, 2000; Visser et al., 2004).

Studies demonstrate that caregivers who live with their dying family member spend more time administering care than caregivers who do not. Visser et al.'s study of home caregivers of dying older people reveals that caregivers who live with their dying

family member provide care seven days a week whereas caregivers who are not cohabitants, provide care approximately five days per week. Further, home deaths tend to be more likely for those living with another person (Carlsson & Rollison) or who are married (Gallo et al.; Gomes & Higginson; Grande et al.; Howat et al., 2007), or for those who have people living nearby who are able to provide care (Visser et al.).

Demographic Characteristics of Home-based Palliative FCGs

Most people who die at home are primarily cared for by family and friends with support from professional services. As with the characteristics of those who die at home, the demographic features of at-home FCGs such as gender, relationship to the dying person, social support network, and support from the formal health care system is described in several studies.

Research indicates that FCGs are predominantly female and in a spousal relationship with the dying person (Brazil et al., 2001; Carlsson & Rollison, 2003; Emanuel et al., 1999; Grande et al., 1998; Howat et al., 2007; Hudson, 2003; Visser et al., 2004; Zapart, et al., 2007). It is estimated that from two-thirds (Hudson) to three-quarters (Emanuel et al.) of home-based FCGs for dying patients are women. Visser and associates suggest that male spouses may be less able to provide care as they may be older and perceive themselves to be less prepared to provide care.

Adult children, especially daughters and daughters-in-law are next likely to take on at-home family caregiving roles (Aberg, Sidenvall, Hepworth, O'Reilly & Lithell, 2004; Carlsson & Rollison, 2003; Howat et al., 2007; Visser et al., 2004). Caregivers in several studies reveal they assumed responsibility because it came as a natural extension of their family duty (Aranda, 2001; Brown & Stetz, 1999; Perreault et al., 2004; Wilson,

2000).

Several studies show that those who have more than one caregiver are more likely to achieve an at-home death (Cantwell, Turco, Brennis, Hanson, Neumann & Bruera, 2000; Maida, 2002; Visser et al., 2004). Researchers hypothesize that sharing caregiving responsibilities relieves the burden of care on one family member and caregivers can provide support to one another (Cantwell et al.; Gomes & Higginson, 2006).

Research identifies that palliative FCGs are extremely supported by the practical assistance and respite provided by family and friends. Participants of several studies exploring palliative FCGs report that practical assistance with meal preparation, household chores, shopping, and providing respite helped them to manage at-home care (Hudson, 2003; Hudson et al., 2004; Perreault et al, 2004; Proot et al., 2003). Moreover, in a study by Perreault and colleagues, Canadian FCGs report that the contribution of a support person is pivotal to their ability to continue in their caregiving role. Caregivers in this study express gratitude for assistance from family and friends with practical help such as providing meals or doing household chores.

Several studies indicate the importance of caregivers' own social support networks to meet their emotional and social needs (Cantwell et al., 2000; Maida, 2002; Proot et al., 2003; Perreault et al., 2004; Strang & Koop, 2003; Visser et al., 2004; Zapart et al., 2000). For example, FCGs in studies by Perreault et al. and by Strang and Koop comment on the strength they received from having a support person to talk to about their experiences. Similarly, FCGs in a Canadian study, report that they are able to cope with caregiving demands because they had support from family and friends who provided emotional support and acknowledged the care they were providing (Stajduhar, Martin,

Barwich & Fyles, 2008).

Research also indicates that FCGs who have access to formal palliative care services are likely more able to support their dying family member at home (Brazil et al., 2002; Burge et al., 2003; Gallo et al., 2001; Gomes & Higginson, 2006; Howat et al., 2007; Maida, 2002; Proot et al., 2003). For example, Proot et al.'s study shows that daily assistance with patient care and respite options such as overnight companionship decreases FCGs vulnerability to fatigue and burnout.

Several studies also demonstrate the need for skilled professional support to provide appropriate information to FCGs (Brazil et al., 2005; Hudson, 2004; Maida, 2003; Proot et al., 2003; Stajduhar et al., 2008; Waldrop et al., 2005). Several studies indicate that FCGs need information that is specific and timely to their needs. For example, palliative FCGs report feeling better prepared when they received detailed information early on in their caregiving role about the patient's condition and prognosis, and what to expect during progression of the disease (Stajduhar et al.; Zapart et al., 2007). As well, palliative FCGs in other studies report they depend on health care professionals to provide information about how to develop competency in caregiving tasks, particularly related to the dying phase (Stajduhar et al.; Visser, 2004; Waldrop et al.; Zapart et al.).

FCGs also report that timely response and appropriate symptom management provided to their family member gave them a sense of security and positively influenced their ability to provide care at home (Brazil et al., 2005; Stajduhar et al., 2008). For example, palliative FCGs providing care in the home in Stajduhar and associates' Canadian study report feeling a sense of security knowing that they could call health care

professions when they were unable to manage sudden exacerbation of symptoms.

Studies also demonstrate that emotional support from HCPs is vital to meet the psychosocial needs of FCGs (Payne et al., 1999). Caregivers in Proot et al.'s (2003) study felt emotionally supported when HCPs were respectful of their wishes regarding involvement in care, provided guidance in decision-making, and listened to their concerns. Similarly, Canadian caregivers in Stajduhar's (2003) study report positive experiences when health care professionals expressed empathy and when the caregivers felt their expertise was respected.

Several caregivers in Perreault et al.'s (2004) study reported they could have cared for their family member at home for a longer period if the caregiving load had not become so burdensome. Findings from Goldstein et al.'s (1999) study suggests that it is not so much the actual caregiving activities performed but the perception of providing such care that contributes to feelings of burden. Visser et al. (2007) found that caregivers' perceived burden of care is the most compelling reason for admissions to institutions before death. As demonstrated above, FCGs felt better able to support their dying loved one at home when they had practical and psychosocial support from formal and informal sources. Studies such as these highlight the importance of providing support to meet the psychosocial needs of palliative FCGs.

Nurses and Caregiving

The complexity of family caregiving is increased when the focus of employment also centers on the provision of care. This is the case for registered nurses who simultaneously provide care to clients and to their own family members. There is a small body of knowledge related to nurses who provide care to family members such as

dependent children and elderly parents. Only one published study was found which explored the experiences of nurses who care for family members with a life threatening illness (Mills & Aubeeluck, 2006). There were no published studies found which focuses specifically on the experience of nurses who provide to a dying family member.

To understand the phenomenon of nurses who provide care to dying family members, I draw from Mills and Aubeeluck's study as well as literature related to nurses' experiences of providing care to their dependent children and/or to frail elderly family members. In this section, I will begin by providing an overview of the social context of nurses' work to illustrate demands of professional caregiving. Secondly, I will report on the current state of knowledge about nurses who provide care for their own family members. I will highlight the perceived benefits of providing care at home and at work. As well, in this section, I will report on the challenges expressed by nurses who provide care to their family members, focusing on the tensions reported by participants as they negotiate between their professional and family caregiving roles.

Social Context of Nurses' Work

Reductions in health care budgets over the past decade have led to hospital downsizing and restructuring, which in turn has resulted in nurses providing the same level of services with fewer resources (Burke & Greenglass, 2001; Dickerson et al., 2007). With staff shortages, many nurses report that their work environment is fast paced, and mentally and physically exhausting (Dickerson et al.; Simon et al., 2004). As a result, nurses report they are hampered in being able to deliver safe quality care (Dickerson et al.; Oberle & Hughes, 2001). For example, nurses in a study by Dickerson and colleagues

voiced concerns that with their heavy workload, more frequent errors occurred which compromised patient safety.

Staffing shortages and heavy workloads also impact nurses' health. Personal impacts of heavy workloads are well described in a study investigating the association between perceived stress and work supports and burnout. Cancer nurses in this study report they become distressed when their workload exceeds their ability to complete their work (Barnard, Street & Love, 2006). Further, work absences are attributed in part to work-related injuries resulting from providing heavy care without additional help needed.

The work of nursing also has deleterious effects on nurses. For example, in their professional work, nurses are frequently exposed to multiple deaths (Sherman, 2004). In several studies, nurses report an increase in stress when caring for and bearing witness to the suffering of seriously ill and dying patients (Dickerson et al., 2007; Ross et al., 1994; Vachon, 2007). As well, nurses in Ross and associates' study who describe their working conditions as high pressure characterized by dealing with death and dying, managing critical situations, and constant change, also report high levels of stress in their work lives.

Nurses' professional work is also characterized by conflicts with other health care team members, particularly physicians. Nurses in several studies report feeling undervalued and sense a lack of respect from physicians (Barnard et al., 2006; Dickerson et al., 2007; Oberle & Hughes, 2001; Sherman 2004). In Barnard et al.'s study, nurses rated conflicts in values and decision making by physicians as a high source of stress. Similarly, in a study by Oberle and Hughes, nurses express feeling subordinate to physicians because they often did not have input into decision making but were left

having to carry out decisions they did not agree with or that were contrary to their own values. As well, with medical advances in the past decade, nurses are faced with many ethical dilemmas as they seek to manage the consequences of treatment decisions not previously existing (Pendry, 2007; Schwarz, 2003). For example, palliative care nurses in Schwarz's study exploring ethical decision making, acknowledge that they struggle with issues such as finding acceptable ways to respond to patients who request assistance with dying.

Nurses working in health care facilities, such as hospitals, are often required to work evenings and night shifts, and mandatory overtime. Studies show that shift work impacts nurses both professionally and personally (Burke & Greenglass, 2001; Dickerson et al., 2007; Simon et al., 2004). A study investigating work-home conflicts among European nurses, Simon et al. reveals that work-family conflict increases when nurses work both day and night shifts. The irregularity of work hours interfered with amount of time nurses were able to spend with their families.

Nurses Caring for Their Own Family Members

Nurses in several studies reveal that caring for their own family members engenders positive benefits to themselves personally and positively contributes to their paid professional work. Reciprocally, studies show that being in the nursing profession is beneficial to family caregiving roles. Nurses report having medical knowledge, skills to provide nursing care and connections with the health care system. While nurses find their nursing background an asset, they also report unique challenges and tensions whilst providing care to family members that are associated with their professional role.

Benefits of Being a FCG.

Nurses in several studies reveal that many positive benefits are derived from providing care to their family members (Macdonald, 1998; Mills & Aubeeluck, 2006; Ross, et al., 1994; Rutman, 1996; Walters, Lenton, French, Eyles, Mayr & Newbold, 1996). The benefits arising from family caregiving experiences are shown to have positive effects both personally and professionally. Personal benefits derived from family caregiving are well described in Walters and colleagues' study of 2288 male and female RNs and LPNs. They explored the links between nurses' health and features of their paid and unpaid caregiving and found that having children at home significantly decreases the likelihood of health problems. These researchers postulate that parents derive intrinsic rewards from their children.

Mothers who are also RNs in Macdonald's heuristic study report that their parental role increases their awareness and understanding of others who have children. As a result they felt better able to support their colleagues who were going through similar experiences. Further, they felt that their personal experiences in caregiving roles made them a better professional caregiver. This is reflected by one participant in Mills and Aubeeluck's study of six British nurses caring for a relative with a life threatening diagnosis who felt she became more reflective in her professional practice as a result of the experience as a FCG.

Benefits of Being a Nurse.

Participants in a several studies also report that being in the nursing profession is beneficial in terms of monetary rewards, personal and family growth, and to their family caregiving role (Macdonald, 1998; Mills & Aubeeluck, 2006; Ross et al., 1994; Rutman,

1996; Ward-Griffin, 2004). In regards to monetary benefits, Ross and associates explored the feelings associated with providing care and perceived tensions and benefits of combined caregiving roles of 40 full-time hospital and community-based nurses who also provide direct care to either or both their own children and elderly parents. They discovered that for some nurses, combining a career with family responsibilities was not an option. However, the majority of participants chose to combine work and family responsibilities because the financial benefits from their paid work allowed them to be self-sufficient and afforded them the freedom of making financial decisions independently.

Personal and family growth is well reported in the same study. Participants also report increased confidence, self-worth and powerfulness, which they attributed as an outcome of their professional caregiving role (Ross et al., 1994; Rutman, 1996). Intrinsic rewards, such as increased self-esteem and self-worth stemmed from the perception of nurses that they were making invaluable contributions to society in their dual caring roles.

Further, participants in Ross et al.'s (1994) study also report that combined caregiving roles enhanced relationships with their own family members and moreover, provided opportunities for the personal growth of their children. For example, nurses felt that the diversity of their professional role made them more interesting and they believed that they had more to bring to their relationship with their spouses. As well, nurses felt they were positive role models for their children because combined roles encouraged their children's independence and adaptability.

Also described in literature are the benefits of nurses' professional caregiving role

to their family caregiving experiences (Macdonald, 1998; Mills & Aubeeluck, 2006; Ross et al., 1994; Ward-Griffin, 2004). Nurses in a study by Ross and colleagues shared that providing care in their formal roles enhances their understanding of others and in turn, helps them work through their own family caregiving issues. As well, these participants voiced that better understanding of older people helps them deal with emotional issues within their own family.

Several studies indicate nurses felt they were able to use their knowledge and skills to effect positive change for their ill family members (Macdonald, 1998; Mills & Aubeeluck, 2006; Ward-Griffin, 2004). For example, participants in Ward Griffin's study of 15 community health care nurses in Ontario report that they naturally drew on their nursing knowledge and skills in their family caregiving roles to assess their family members' health status and make decisions for further care requirements. Similarly, in a study by Mills and Aubeeluck respondents report their nursing knowledge and skills enabled them to provide a positive contribution to practical and emotional aspects of care to their ill family member. As well, they voiced confidence in providing physical and emotional care to their family members with life threatening illnesses, as they possessed nursing knowledge and skills to do so effectively.

Inherent in nurses' professional work is their familiarity with and connections within the health care system. Nurses also report their knowledge of and association with the health care system as extremely beneficial in several studies. For example, a study by Ward-Griffin (2004) reveals that nurses are able to access information, resources, and expertise not normally available to other FCGs. Similarly, participants in Mills and Aubeeluck's (2006) study reported that their familiarity with the health care system

allowed them to influence and facilitate the care required at time of their relative's death.

Challenges of Dual Caregiving.

Literature also reveals that while possessing nursing knowledge and skills, and connections with health care system is beneficial, nurses also experience challenges and tensions of providing care to their own family members typically not faced by non-nurse FCGs. The uniqueness of nurses' experiences of family caregiving is embedded in the duality of caregiving roles. Ross et al. (1994) and Ward-Griffin (2004) use the metaphor of "torn between two worlds" to describe the challenges and tensions nurses experience while assuming both professional and family caregiving roles. Inherent in these challenges is the difficult issue of separating and negotiating boundaries between the two identities of nurse and family member.

Although nurses view their family caregiving roles as natural extensions of their formal caregiving, many feel they have no choice in assuming care but rather, feel obliged to use their nursing knowledge and skills (Ward-Griffin, 2004). Nurses also experience considerable pressure from other family members and HCPs to assume care. As they view themselves as the "nurse in the family", they felt they had no other options but to assume care.

Nurses voice distress in situations in which HCPs discuss care with them as if they were in their professional nurse role not as a family member. Studies suggest that while HCPs view nurses as professional colleagues, nurses felt they could not maintain a clinical persona when discussing the health of their family members (Mills & Aubeeluck, 2006; Ward-Griffin, 2004). For example, nurses in Mills and Aubeeluck's study perceived that HCPs assume they have up-to-date clinical information about their family

members' illness when in fact they did not. As a result, they missed obtaining explanations they felt they needed. Moreover, expectations from other family members that nurses have information about the illness and care of their family member left some nurses feeling inadequate as a professional and as a family caregiver (Mills & Aubeeluck). Similarly, in other studies, participants express feelings of guilt when they are unable to provide all facets of care and while nurses see themselves as competent professional caregivers, they questioned their ability to provide care to their family members (Ross and associates, 1994; Ward-Griffin).

Similarly, several nurses in Ward-Griffin's (2004) study voiced concerns and feelings of guilt about making poor clinical assessments and decisions for their family members. Nurses in this study were concerned about losing objectivity and clouding their clinical judgment because of the emotional attachment that comes with familial relationships. Furthermore, nurses expressed concerns that they were expected by HCPs to take on more responsibility of the care for their family member than they felt comfortable providing. Feelings of distress were particularly pronounced in situations where nurses felt that they did not have the necessary knowledge and skills to provide required care.

Although nurses benefit from their knowledge of disease in their caregiving role, participants in Mills and Aubeeluck's (2006) study found that knowledge of diseases and access to information vaulted them into uncomfortable situations. For example, one nurse knew that her family member had a poor prognosis before the family member was aware. Another nurse FCG recognized signs that death was imminent before any other family member.

This 'knowing' was an awkward place for nurses because they found themselves jumping ahead and anticipating what the next stage would be before their dying family member or other relatives were prepared. Nurses often did not share this information because they feared being perceived as pessimistic and non-supportive to their dying family member and other relatives. In the same study, nurses' ready access to information raised ethical issues pertaining to confidentiality. Nurses grappled with whether or not speak with their family member's physician prior to gaining consent and accessing information available on medical databases. As a result, they felt torn between wanting the information but not wanting to overstep boundaries and influence treatment decisions. As well, nurses also report discomfort when exposed to details about their family members that they perceived to be beyond the boundaries of their familial relationship (Ward-Griffin, 2004). In particular, this was the perception of nurses caring for a frail elderly parent.

Impact of Dual Caregiving.

Several studies reveal significant negative impacts for nurses who provide care in both work and personal life (Gottlieb et al., 1996; Mills & Aubeeluck, 2006; Ross et al., 1994; Scott et al., 2006; Walters et al., 1996). These impacts stem from the burden of care associated with each role and the tensions associated with negotiating the boundaries between the roles. Findings in a study by Ross et al. reveal that most nurses experience high levels of stress associated with combining caregiving roles in their professional and private lives. The heavy burden of care required by young children and ill elderly parents contributed to the high level of stress experienced in home life. Nurses in this study felt pulled in many directions due to the complexity and multiplicity of both home and work

life demands. Likewise, in a study measuring the impact of multiple caregiving roles on nurses' work performance by Scott and colleagues stress and fatigue was significantly higher among nurses who simultaneously care for both children and elderly family members at home and patients at work.

As with non-nurse caregivers, juggling work and family demands negatively impacts nurses as they provide care in their professional role. For example, in Mills and Aubeeluck's (2006) study, nurses expressed guilt feelings of 'cheating the system' or letting other colleagues down when they took time off to care because often they were leaving understaffed and busy units. Gottlieb and peers (1996) reveal that the more nurses perceived their employer as supportive of their home life situation, the less conflict they experienced.

In the same study, nurses who perceived higher caregiving demands at home reported being inattentive at work. Similarly, Scott et al. (2006) found that nurses who provide care to elderly relatives were more than twice as likely to make medication-related errors, and procedural and transcription mistakes. Scott and colleagues postulate that work performance is related to sleep loss as they found that nurses who care for elderly family members are more sleep deprived.

Summary of Literature Review

Literature sheds light on the dichotomous nature of caring for a dying family member. Although FCGs face significant challenges in their roles, they report that caregiving has many benefits. Research findings also highlight many physical and psychosocial impacts experienced by FCGs when caring for a dying family member. FCGs commonly report anxiety, sadness, and depression. Moreover, literature indicates

that being employed compounded with providing care impacts FCGs both financially and socially, as well as physically and emotionally.

While research reveals the preference of dying individuals to die at home, in actual practice, most deaths occur in institutional settings, primarily due to caregiver burnout and lack of resources available to support FCGs. Characteristics of those who are likely to die at home include younger age, male, and those with lung, colorectal or genitourinary cancer diagnosis. Terminally ill individuals who are married and those who have more than one caregiver also have a greater likelihood of achieving an at-home death. Literature indicates that females, particularly those in a spousal relationship are most likely to take on caregiving roles. At-home FCGs are also likely to maintain their roles if they have a strong social support network. Palliative care in the home setting is complex because caregivers are responsible for managing an array of symptoms. As such, caregivers need physical and psychosocial support from family and friends, and skilled, compassionate HCPs to ease caregiving burden and enhance the probability of an at-home death.

In addition, literature reveals that nurses experience unique tensions and challenges as they mediate between their professional and personal caregiving roles. While nurses are able to capitalize on their nursing knowledge and connections with the formal health care system to affect positive outcomes for their family members, having knowledge and connections is also sometimes problematic as HCPs and other family members expect nurses to take on care that they do not feel adequately prepared to do. As such, the expectation that nurses provide competent care while functioning in the role of family caregiver places them in a “no-win” situation (Ward-Griffin, 2004, p. 109). The

impact of family caregiving is compounded with the stresses related to providing care in a professional role. Nurses report mental and physical exhaustion, burnout, injuries, and stress symptoms which they contribute to heavy workloads, caring for seriously ill patients, and lack of respect from other team members (Dickerson et al., 2007). Literature reveals that stress and fatigue are significantly higher among nurses who simultaneously provide care to family members at home and to patients at work.

There is a substantial body of literature on family caregiving, most of which is focused on caring for elderly family members. Studies focused on FCGs of the dying are a more recent contribution. There is a growing body of literature on the nature and extent of the role and needs of FCGs for the dying. As well, recent research is also focused on expanding current knowledge about the characteristics of those who die at home and those family members who provide care to them. In relation to nurses as FCGs, there is a small body of knowledge mainly focused on the care of dependent children and elderly parents. Only one small study was found that explored the experiences of nurses who care for family members with a life threatening illness (Mills & Aubeeluck, 2006). There were no published studies found that focused specifically on the experience of nurses who provide care to a dying family member.

This reported study offers an important contribution to the body of knowledge about the experience of registered nurses providing palliative care to their family member. Caring for a loved one who is dying adds complexity to caregiving because of the emotional nature associated with coming to terms with impending death and loss of their loved one. Furthermore, the emotional strain of caring for a dying family member

may be compounded for nurse FCGs because they bear witness to pain and suffering on a daily basis in their professional role. This study sheds light on the emotional affects of providing care both personally and professionally.

This study also adds to the existing body of knowledge about the unique challenges and tensions nurses face being both professional caregiver and family member caring for a dying loved one. In particular, this study shows how having nursing knowledge, while beneficial, influenced the expectations nurses have of themselves as FCGs and of the care given to their family member by HCPs.

CHAPTER 3: RESEARCH METHOD

The purpose of this study was to explore the experiences of nurses who cared for their own dying family members. Although many aspects of palliative caregiving have been studied, there is a dearth of literature focused on nurses' personal experiences of caring for a dying relative. In this chapter, I provide an overview of the study design chosen to explore this phenomenon and describe the research processes undertaken including participant recruitment, sampling, data collection, and data analysis procedure. As well, I will outline how rigor was maintained and describe how ethical considerations were managed during the study.

Study Design

As there is little known about the experience of nurses who provide care to a dying family member, a qualitative exploratory descriptive study seemed an appropriate design. A qualitative exploratory approach is useful when little is known about the phenomenon (Morse & Field, 1996) and the focus is on the subjective experience of informants (Munhall & Boyd, 1993). As such, this approach was suitable to obtain narrative descriptions of nurses living through the experience of caring for a dying family member and establish baseline knowledge of this phenomenon.

Initially I intended to use an ethnographic approach as this method is focused on the work of describing and analyzing a culture, ethnic group, or subculture (Burns & Grove, 2005; Morse & Field, 1996). Although ethnographic approaches traditionally examine the behaviours of ethnic groups, this method is also used to examine the beliefs and practices of cultures within a culture and groups of individuals with common

experiences (Morse & Field). I view nurses as inexplicably interwoven in several subcultures including their professional culture, health care culture, and the culture of their families. And as such, are continually informed by these cultures as asserted by Agar (1997):

We have learned that a person we work with [the subject] is not a simple representative of some single comprehensive and coherent culture; rather, that person draws from a mix of identities, running from local to global, sometimes conflicting and contradictory, that one uses to craft different selves at different moments (p. 1159).

However, using solely an ethnographic approach was not feasible in this retrospective study as an ethnography generally employs participant observation as the main means of data collection (Burns & Grove, 2005; Wolf, 2007). Therefore, I used a qualitative exploratory approach guided by ethnographic principles. This allowed me to elicit rich, detailed descriptions revealing the meaning of the experience for nurses. As well, this approach helped to uncover beliefs and implicit and explicit behaviours that influenced the experiences of nurses who 'live' within a health care culture and within their own family culture.

Participants

Participant Recruitment

Participants were recruited in a variety of ways. After obtaining ethical approval (see section on "Ethical Considerations") and receiving permission letters from health authority managers and directors to post and email information about the study, information posters (Appendix A) outlining the proposed study were placed on bulletin boards in acute and long term care facilities and home care offices. As well, an information letter about the study (Appendix B) was sent out through email to nurse

managers, leaders, and educators requesting distribution to registered nursing staff.

Nurses were invited to contact me directly by phone or email to indicate their interest to participate in the study. A pre-interview contact by telephone was made to discuss the scope of the study and to determine if the eligibility and inclusion criteria for the study were met (see “Sampling” section following). During the initial contact, potential participants were screened to determine if they were willing and able to describe their experience. See Appendix C: Script for the Initial Phone Contact.

Sampling

The qualitative principle of adequacy was used to determine the sample size. Adequacy is defined as enough data to develop a full and rich description of the phenomenon under study (Morse & Field, 1996). To gain maximum variation, purposeful sampling was employed (Morse, 1991). Purposeful or purposive sampling allows for a greater insight and in-depth understanding into a phenomenon which is not well known and complex (Burns & Grove, 2005). Knowing that participants with a variety of demographic and phenomenal variation (Sandelowski, 1995) would be best able to inform a researcher about the phenomenon under study, I attempted to recruit a diverse sample of nurses. For example, I recruited both female and male nurses, nurses who worked in different clinical areas, and with varying years of experience as a nurse. As well, I recruited participants with varying lengths of family caregiving experiences and with varying relationships with the care recipient.

Demographic data (Appendix D) were collected on all participants. Participant demographics included gender, relationship to the dying family member, length of family caregiving experience, number of years bereaved, level of education, years of nursing

experience, and area of professional practice during caregiving experience. Demographic data were used to describe the sample and used to highlight variation in perceptions and experiences. For example, information about the nurse's relationship to the dying family member helped in understanding how filial relationships influenced the experience of caregiving.

To allow for reflections and ensure accurate recall on the experience, I sought participants who were bereaved for more than one year and no longer than 5 years. To balance ethical considerations of interviewing participants too soon after their family member's death, nurses who have been bereaved for a less than a year were screened during the pre-interview contact to determine if they were fit worthy for an interview. Nurses who have been bereaved for longer than 5 years were excluded from the study. It is known that broader economic, social and political contexts shape the provision of palliative care services and the relationship between family member and formal providers (Ward-Griffin and McKeever, 2000; Wiles, 2003), thus nurses whose experience occurred longer than 5 years ago, may not be reflective of current realities.

Description of Sample

A sample of 14 registered nurses who had provided care to a dying family member were recruited for this study. All participants were English speaking and resided in the study region, a mid-sized city in Western Canada. Two male and 12 female registered nurses were interviewed. The number of years of nursing experience ranged from 20 to 43 with an average of 28.7 years. Most participants were employed on a full time basis (n=7) during their caregiving experience, while others were employed part time (n=6). One nurse was on maternity leave. Most participants were practicing in acute

care (n=9) with the remaining working in home care (n=2) mental health (n=1), hospice (n=1) and Senior's health (n=1). The majority of participants were direct care providers (n=11) with the remaining 3 in senior educator or clinical leader positions (n=3). The length of time bereaved ranged from 10 months to 5 years. Although one nurse was bereaved for less than a year (10 months), a decision was made to include her in this study because it was the participant's desire to share her experiences. I had a pre-interview conversation with that participant and determined that she was emotionally able to participate. As well, the bereavement period was nearing a year (i.e. 10 months) and I determined that the participant's experience of caring for her husband with a non-malignant diagnosis would add diversity to the sample.

The majority of participants cared for a parent (n=7). More specifically, there were daughters caring for a father (n=4), daughters caring for a mother (n=2) and son caring for a father (n=1). Relationship to dying family member also included: wife (n=3) with one spouse who was separated from the care recipient, sibling (n=2), cousin (n=1), friend (n=1) and daughter-in-law (n=1). Four nurses had more than one experience of caring for a dying family member within the past five years. During their interview, these nurses shared excerpts from these additional experiences however, only the demographic information related to the caregiving experience that was the main focus of the interview is reported here.

The length of time of caregiving ranged from one day to 7 years. Seven participants traveled out of town to provide care while others lived independently in the same town/city (n=4) or shared the same household (n=3). One participant lived in the same town but moved to his dying family member's home temporarily for a month to

provide care.

Most of the care recipients had a diagnosis of cancer (n=11) while 3 had a non-malignant diagnosis. The majority of care recipients died in their home (n=7), while others died in an acute care (n=3), hospice or palliative care unit (n=3) or a long term care facility (n=1). Detailed demographic characteristics of the 14 participants are given in Table 1.

Data Collection Procedure

Consistent with exploratory descriptive methods, the experiences of bereaved nurses was gained through one individual face-to-face interview with each participant. Interviews took place at a time and place of the participant's choice and convenience. The length of the interviews varied between participants and ranged from 40 minutes to 140 minutes with an average length of approximately 90 minutes. With consent, all interviews were audiotaped and transcribed verbatim.

The interviews explored nurses' experiences of providing care to dying family members. Prior to commencing the interview, I ensured informed consent was given by reviewing the Consent to Participate form (Appendix E) and answered any questions raised by participants with regards to their participation in the study. I gave a brief overview of the research study and gained permission to audio record the interview. Participants were then invited to reflect and describe their family caregiving experiences to the researcher. An interview guide (Appendix F) was used to elicit detailed descriptions of nurses' experience of the phenomenon to be explored. Most interviews were initiated by asking participants to provide the context of their experience (relationship to caregiver, diagnosis) and to describe their caregiving role. Descriptive

Table 1

Demographic Profile of Nurse Family Caregiver Participants

Gender	Female	n = 12	Male	n = 2
Age	36-40	n = 2	55-60	n = 3
	46-50	n = 3	60+	n = 2
	51-55	n = 3	no data	n = 1
Number of years of Registered Nurse experience	11-20 years	n=1	30+ years	n=5
	21-30 years	n=8		
Employment status at time of caregiving experience	Employed full-time	n=7	Employed part-time	n=6
	Maternity leave	n=1		
Area of professional practice during caregiving experience	Acute Care	n=9	Home Care	n=2
	• Emergency	n=2	Mental Health	n=1
	• Radiology	n=1	Hospice	n=1
	• ICU	n=3	Seniors Health	n=1
	• Medical/Surgical	n=2		
	• Pediatrics	n=1		
Role of employment during caregiving experience	Direct Care (one on maternity leave)	n=11	Nurse Leader Position	n=3
Level of education	Nursing Diploma	n=9	Baccalaureate	n=4
			Masters Degree	n=1
Number of years bereaved	< 1 year	n=1	3 years	n=2
	1 year	n=2	4 years	n=4
	2 years	n=3	5 years	n=2
Relationship to dying family member*	Daughter caring for father	n=4	Wife	n=3*
	Daughter caring for mother	n=2	Cousin	n=1
	Son caring for father	n=1	Friend	n=1
	Sister caring for brother	n=1	Brother caring for brother	n=1
			*One spouse was separated	
Diagnosis of dying family member	Cancer	n=11	Other	n=3
Length of caregiving experience	Less than 1 year	n=8	4 months	n=2
	• < 2 weeks	n=4	1-2 years	n=2
	• 6 weeks	n= 1	2-3 years	n=3
	• 2 months	n=1	7 years	n=1
Status of residence at time of caregiving	Shared the same household as the dying family member	n=3	Lived independently in same city/town	n=3
	Moved to Family member's residence in same city/town	n=1	Traveled to another city/town to provide care	n=7
Location of death	Home	n=7	LTC Facility	n=1
	Acute Care	n=3	Hospice/Palliative Care Unit	n=3

questions were designed to obtain information about the participant's view on the phenomenon (Merkle Sorrell & Redmond, 1995) and help to position subsequent questions (Wolf, 2007). For example, I asked participants to describe their caregiving situation and what a typical day was like for them. Further prompting questions were used as needed for clarification and to encourage the interviewee to elaborate on particular aspects of the phenomenon under investigation. For example, to understand what it was like as a professional caregiver to provide care to a family member, I inquired about participants thoughts and feelings about their role as a both a nurse and a FCG.

Field notes recorded during and after the interviews also comprised another source of data (Emerson, Fretz & Shaw, 1995, Wolf, 2007). Key words, ideas, and phrases were noted during the course of the interviews. For example, ideas such as "suspended emotions", "parked my emotions" & "double-edged sword" were noted. Immediately after each interview, non-verbal observations about the participant such as silences, hesitations, tone of voice, and body language were noted. After each interview, full field notes were written, providing an overview of the nurses' experience, documenting my initial impressions and interpretations of the interview (Mason, 2002) and noting preliminary findings which related to current literature. Personal notes (Wolf) were also recorded throughout the data collection and analysis process, noting my reflections, feelings, and intuition about tentative categories and patterns. For example, after the first few interviews, I recorded thoughts about the high expectations nurses had of themselves to provide the best possible care and as a result seemed to put their emotions aside to attend to the needs of their dying loved one and other family members.

Data Analysis

Data analysis began at the onset of data collection. The audiotaped interviews were transcribed verbatim as soon as possible after the interview by the researcher or hired transcriptionists. Transcribed texts were produced in both electronic and hard copy formats. Personal details were removed to prevent identification of participants and any third party names used.

All audiotaped interviews and transcriptions were reviewed in their entirety numerous times to gain a sense of the whole interview. This helped me to understand the essence of the phenomenon under investigation. A computerized program, NVivo qualitative data analysis software (QSR International Pty Ltd., Version 8, 2008) was used to store, sort, and code data. Each transcript was coded by reading transcribed texts line by line to identify key words, patterns, or codes. During this process I read and reviewed transcripts and audiotaped interviews several times in order to immerse myself in the data to identify items which were relevant to the research questions (LeCompte, 2000). Passages of data that seemed relevant to the research question were coded.

Data analysis involved content and thematic analysis (Morse & Field, 1996; Wolf, 2007). During this process, data was sifted and sorted to identify frequency of occurrences, omissions of expected codes, and declarations by study participants (LeCompte, 2000), as well as inconsistencies and contradictions (Thorne, 2000). Codes were repeatedly compared and contrasted to identify similarities in description (LeCompte). Codes which were similar or which appeared to be related were clumped into broader categories. For example, codes such as “delayed grief” and “shelved emotions” were combined to form a broader category of “suspended emotions.”

Thematic analysis involved identifying common threads that extended throughout a set of interviews. Preliminary categories and themes were shared with a subset of participants who were interviewed in the latter part of the study. After interviews were completed with four of the participants, preliminary analysis took place by reviewing each interview audiotape and transcription several times. Preliminary categories were identified. For example, the concept of “suspended emotions” and “knowing ahead” were identified among the first four participants and were tested in subsequent interviews with other participants. Subsequent participants were invited to give their thoughts on these preliminary conceptualizations and were encouraged to provide feedback as to the accuracy of the findings based on their experiences. Preliminary categories and conceptualizations continued to be developed and refined based on subsequent interviews. As well, additional categories were developed from subsequent interviews which, in turn, were tested in subsequent interviews. Data were then reviewed again and reflected upon as a whole and themes were identified and refined based on the thoughts and suggestions from subsequent interviews. Preliminary concepts and themes were more fully developed and by the twelfth interview, I reached data saturation (Polit & Hungler, 1995). Preliminary concepts and themes were discussed with participants in the last two interviews and again, these were refined based on the participants’ experiences and suggestions.

Rigor

To ensure trustworthiness of a study, the methodological decisions and process used should be made explicit (Lincoln, 2000). Lincoln and Guba (1985) suggest four criteria to establish trustworthiness of a qualitative study: credibility, transferability,

dependability, and confirmability.

Credibility refers to the truth value of a study – or how a study demonstrates confidence and believability in the findings (Lincoln, 2000; Lincoln & Guba, 1985). In this study, criteria used to strengthen the truth value or credibility of the results involved member checking and peer debriefing. In terms of member checking, the researcher is responsible to obtain participants' perspectives of the phenomenon under study. This involved returning to participants with preliminary results and refining these according to participants' responses. Preliminary categories and themes were shared with a subset of participants in the later part of the study, as previously described. These participants were asked to comment on whether preliminary findings resonated with their experience. Categories and themes were reworked based on their feedback. Lincoln and Guba suggest peer debriefing as another technique to establish credibility. Some of the findings were discussed with a student cohort who provided me with feedback.

Transferability refers to the applicability of the descriptive account of the findings to other contexts. This involves including thickly contextualized descriptions that represent multiple layers of realities and observations so that the reader can make inferences to other instances of the same phenomenon (Denzin, 1994). In this study, the descriptive account includes extensive quotations gathered from participants' narratives. Transferability was also demonstrated by informally sharing some of the findings with both a social work and an occupational therapist colleague.

Dependability refers to the internal consistency of the data to ensure that the findings can be repeated (Lincoln & Guba, 1985). Lincoln and Guba suggest that records stemming from the inquiry be available for inquiry audits. In this study, dependability

was applied by keeping an audit trail, which included field notes recorded during and after each interview, reflexive notes, and process notes. These notes outlined how I developed and structured codes, categories, and themes and the rationale for decisions made during the data analysis phase.

Confirmability is establishing the neutrality of the data (Lincoln & Guba, 1985). In this study, confirmability was maintained in several ways including keeping a record of the research process. An audit trail was established by documenting my decisions, choices, and insights during the data collection and analysis process. As well, some of the data was co-coded with one of my academic supervisors. I also had regular consultation about the research with both co-supervisors. Confirmability was also maintained as much as possible through a process of reflection and recording personal journal notes during the course of the study. Through this process, I sought to identify my biases and assumptions prior to and during the process of data collection and analysis. See following section: “Reflexive Process”.

Reflexive Process

Reflexivity is a continuous, active process of self-appraisal researchers employed to identify personal values and beliefs that may influence the research process (Dowling, 2006; Kingdon, 2005). My decision to research this topic was based on professional and personal reasons. I have been a registered nurse for over 20 years and have cared for many palliative patients in my former role as a home care nurse. In this role, I have witnessed the burden placed on FCGs caring for dying family members. Also, I have had discussions with colleagues who were providing care to their ill family members and with nurses caring for patients whose FCG was a HCP (physicians and nurses).

Personally, I have had two significant caregiving experiences with chronically ill family members. One occurred during my mid-teens as the main caregiver for my mother who had chronic renal failure. My experiences of caring for my mother strongly influenced my decision to pursue a nursing career. I also was the sole caregiver for an older brother with a mental illness that began before I entered nursing school and continues presently but to a lesser degree. My caregiving role with my brother focused on providing emotional support and health advice, and advocating for care during several hospitalizations. Both professional and personal experiences have informed my understanding of the role nurses play as FCGs.

Throughout the data collection and analysis process, I remained aware that my formal role as a registered nurse and previous family caregiving experiences might influence the entire research process. I recorded reflexive journal notes my assumptions about and reactions to the research throughout the research process. Kingdon (2005) contends that reflexivity “enables researchers to acknowledge the socially situated nature of their projects” (p.627). During this research study, a close friend was diagnosed with cancer and receiving treatments. I recorded my thought and reactions to my experience of being a nurse and providing support and advice as a friend.

Ethical Considerations

Researchers have an ethical responsibility to recognize and protect the rights of human research subjects and ensure that studies are conducted in an ethical manner (Burns & Grove, 2005). Moreover, research involving dying patients and their FCGs who are particularly in a vulnerable state, must be ethically sound (Seymour & Ingleton, 1999). Prior to conducting this study, I obtained approval from the University of Victoria

Human Ethics Research Board and the Health Authority Ethics Review Committee. In this study, protection of human research subjects was achieved by ensuring informed consent was obtained and confidentiality was maintained.

Informed consent

Consent to participate in the study was explained and obtained from all informants prior to each interview. Participants were asked to sign a consent form outlining the purpose and nature of the study, procedures to be followed, and the risks and benefits of participating in the research (Appendix E). All participants were given a copy of the consent form for their personal record.

Due to the sensitive nature of the topic, it was recognized that the interviews have the potential to cause distress. To mitigate potential distress, participants were reassured at the time of recruitment, when they signed the consent form, and at the beginning of and during each interview, that they may choose to stop the interview at any time.

Although I am a novice researcher, I have extensive clinical experience in palliative care. During the course of the interview, I observed for any cues of discomfort or distress. During those times, I asked the participant if he/she would like to pause or stop the interview and did so if requested. As well, I exercised discretion during each interview as to how and when to use probes to focus the interview.

Confidentiality

Confidentiality and anonymity were maintained during the course of data collection and analysis and will be maintained in any subsequent peer reviewed journal submissions. Anonymity was maintained by ensuring that any audiotaped interviews and subsequent transcriptions did not identify any participants. Each interview was assigned a

code letter (e.g. Participant A) and only I had access to a list of participants' names. Both transcriptionists signed a confidentiality agreement (Appendix G). Transcriptionists were asked to erase digital recordings and/or returned the CD to me to be destroyed. As well, once an electronic transcript was received from the transcriptionists, they were asked to erase any electronic versions they had. Transcriptions were made available to my thesis committee members and myself only.

All data was kept in a locked cabinet. Demographic information was stored separately from the interview data to ensure information was not linked to participants. Any future published findings will not include any information that could identify participants.

Summary of Research Methodology

To explore the experiences of nurses who provided care to a dying family member, a qualitative exploratory descriptive methodology informed by ethnographic principles was the study design chosen. A purposeful sample of 14 registered nurses were recruited. Variations in the sample included nurses of different gender and clinical areas of professional practice and those who had varying relationships to the care recipient. Rigor was maintained by attending to issues of credibility, applicability, consistency and neutrality. As well, methods of attending to ethical considerations of informed consent, confidentiality and anonymity were described.

One individual face-to-face semi-structured interview with each participant was the main means of data collection in this study. Each interview was audiotaped and transcribed. Data analysis involved content and thematic analysis. Thematic analysis involved searching and identifying common threads that extended throughout the set of

interviews. In the following chapter, I will describe the four main themes arising from the analysis of interviews of the fourteen nurses who provided care to a dying family member.

CHAPTER 4:

FINDINGS

Introduction

The purpose of this study was to examine the experiences of nurses who have provided care for a dying family member. Three main themes were identified: 1) knowing the ropes; 2) caught in the middle; and 3) gaining insight (see Figure 1).

In this chapter I will begin by first describing the theme of knowing the ropes. *Knowing the ropes* relates to the gifts nurses brought to their family caregiving situation. Many participants revealed how their familiarity with and connections within the health care system, combined with their nursing knowledge and experience, allowed them to orchestrate a positive death and dying experience for their ill loved one and other family members. Next I describe the second theme, *caught in the middle* which highlights the tensions nurses experienced feeling caught between their professional and FCG roles. Consequently, the tension between these dual roles resulted in high expectations of the care they and others provided. As well, in order to focus on the provision of care, some nurses found themselves juggling caregiving demands with work responsibilities. In addition, several nurses suspended their emotions in order to cope with the caregiving expectations they placed on themselves. Finally, I describe the theme, *gaining insight*, which captures the insights nurses gleaned from having “walked” through the experience of caring for a dying family member and how this experience subsequently informed their professional practice and role.

FIGURE 1: Outline of Themes and Sub-themes of Nurses' Experience of Caring for a Dying Family Member

Knowing the Ropes

1. Knowing and Having Connections with the Health Care System
 - Skillfully Navigating
 - Relationships with HCPs

2. Having Nursing Knowledge
 - Knowing How to Provide Care
 - Knowing How to Provide Palliative Care
 - Knowledge of Death and Dying
 - Knowing How to Advocate for Care
 - Knowing Ahead

Caught in the Middle

1. Conflicts with HCPs
 - Expectations of HCPs
 - Communicating with HCPs

2. Having Knowledge
 - Burden of Knowing Ahead
 - Expectations of Self
 - Suspended Emotions

3. Juggling Paid Work and Family Caregiving Responsibilities

Gaining Insight

1. Increased Awareness, Understanding and Empathy

 2. Increased Legitimacy

 3. Supporting FCGs Who Are Nurses: Advice for HCPs
-

Knowing the Ropes

All participants asserted that the knowledge and skills gained from their professional nursing role was extremely beneficial to their personal experiences of caring for a dying family member. Several nurses referred to their nursing roles and experiences as “gifts” and “blessings” they were able to offer to their dying loved one and their family. For example, a home care nurse used the metaphor of *knowing the ropes* to describe how her nursing knowledge and experience was instrumental in providing care for her elderly mother:

I think [it's] easier...I kind of knew what to do. I think, what would it be like if I wasn't [a nurse]...at least I kind of knew what to do. I always have found that to be a real blessing for me [to be a nurse]...you kind of know the ropes you have to take and you have to do it.

Two sub-themes were identified with *knowing the ropes*. First, knowing of and having connections with the health care system was seen as beneficial; since nurses had prior ‘insider’ knowledge they were able to navigate through the system and communicate with HCPs to meet the needs of their dying family member. Secondly, having nursing knowledge itself was seen as beneficial. Participants reported that knowing how to provide care and having experience with death and dying in their professional role were assets. As well, nursing knowledge was seen as beneficial as participants were often able to intuit the prognosis of their dying loved one and other family members and believed they were able to prepare themselves and others for what lay ahead in the dying phase.

Knowing of and Having Connections with the Health Care System

Nurses reported that having knowledge about the health care system prior to their family caregiving experience was beneficial, as they were able to skillfully navigate the

system in order to access necessary care and resources. As well, having connections to the health care system gave nurses ‘insider’ knowledge of HCPs and how to access resources in a timely manner. Furthermore, nurses perceived that their relationships with other HCPs were different from non-nurse caregivers because of their professional stature.

Skillfully Navigating.

In their professional roles, nurses are intimately familiar with the infrastructure, operations, and culture of the health care system. As such, being a part of the system was advantageous to their personal family caregiving experience. Several participants commented they believed they had an advantage over FCGs who were not HCPs because they knew how to navigate through the health care system to access services, supplies, and information.

During their family caregiving experience, nurses often drew on their knowledge of the health care system and accessed networks established through their professional work. This took away the burden of familiarizing themselves with the system and thus they were able to access services in a timely manner. This also applied to nurses who were not in their usual work environment. General knowledge of what personnel and resources are available was also perceived as an asset as articulated by one nurse who traveled to another town to care for her dying father:

I [wasn’t] even sure if [being in a different hospital environment] was an issue because I know who’s on a team and the team’s pretty much anywhere you go so there’s somebody I know who to ask for even if I don’t know that person.

Participants also disclosed they were able to obtain the services of health care personnel that they believed were the best choice for their family member. Some nurses

knew who to talk to about their loved one's situation and knew whom to ask for, as they often knew who was available. For example, when the father of one nurse was being referred to a specialist he didn't approve of, he asked a health care colleague whom he trusted and respected to accept his father as a patient:

[The Emergency Room physician] referred him to a, a respirologist that I was not very keen on. He was the respirologist on-call. So I phoned a friend of mine who's a respirologist and asked him if I could bring my Dad to come see him. And he said "Absolutely". So we arranged a time to bring my father to the intensive care unit at where he was working and review his films and take him on as a patient.

Nurses also accessed colleagues to obtain information about diagnosis, medical opinions, and prognosis. One nurse risked breaking confidentiality regulations to get a second opinion from her colleague. This nurse, who did not agree with an Emergency Room Physician's diagnosis of pneumonia, showed her brother's chest x-rays to a physician colleague who confirmed her suspicions of the likelihood of recurrent cancer:

When nobody was looking I grabbed the x-ray and I ran it down to my doctor friends ...and I said, "Could you look at this?" [The doctor] looked at it and he goes "There's some hilar areas up in his mediastinum that looked enlarged that didn't look normal." And he's found about 3 or 4 things. Then I said, "Well, he has a history of melanoma." And he goes, "It's looking like that's what's going on there." So I run [the x-ray] back and (laughs) put in [back] on the box.

Similarly, some nurses used their work connections and called on colleagues for favours to obtain supplies in a timely fashion. For example, a nurse received a call while she was at work regarding her mother who was having a "panic attack" as she was unable to have a bowel movement. The nurse was able to arrange to have necessary medical supplies picked up from a colleague and avoided a visit to the emergency department. She recounts the scenario:

Mom's in agony, she's on the toilet and she's just having just a bit of a panic attack. 'Cause she has to have a poop and she just can't. We don't have any

enemas at this point in the house 'cause it's fairly early in the game. So of course it's after the hours that the pharmacies are all closed. So having some friends and being a nurse and being in the system, I phoned down to Emerg and said to a friend, "If my brother came (laughs) and picked up an enema for my mom, could you just give it to him rather than have us bring her in?"

Some nurses also used their connections with the system to get medications and medical equipment that they were unable to obtain through usual sources. One nurse, frustrated by both the length of time to obtain oxygen in the home, called upon friends in the ambulance service who responded to her call for help:

Trying to get oxygen from [the General Practitioner] and from the system, you know, it took days. So again, I just called the...ambulance friends and said, "Get me a tank" – and *poof!* The tanks would arrive and the guys would deliver them and they kept us going. So we had resources that other people might not that I was able to pull in to get these things done.

Several nurses shared the view that their connections within the system permitted them access to areas generally 'off-limits' to FCGs who were not nurses. Having admittance to privileged areas allowed nurses to be with their dying family member during stressful situations such as medical procedures and exams. For example, one nurse was permitted to remain during a bronchoscopy procedure and thus was able to provide emotional support to his father by holding his hand and talking to him to keep him calm.

Nurses also seemed to have had privileged access solely because of their professional status. Regardless of whether the nurse was previously known to HCPs, being a nurse opened many doors. For example, an experienced nurse who temporarily moved to another town to provide care to his dying brother was concerned about being accepted into an unfamiliar medical community. He shared his concern: "I'm a stranger going into a strange medical community. They don't know who I am, I don't know who

they are. For me to get into the medical community was my tough spot.” However, he was readily accepted into the community and in fact, was given “carte blanche” access to his brother’s medical chart, blood work and test results and easily acquired needed narcotics: “nobody questioned me. If I went to the pharmacy and said I needed anything, they just gave it to me - no question.”

Another gift of having connections was being known within the medical community. A nurse who had worked in the same organization for over 30 years found being known by other HCPs as extremely beneficial. She believed that the “networking when you’re a nurse helps to a big degree...whenever our paths crossed with people that I knew or knew of me, made it easier to go along...that extra personal touch in a medical system.” She was relieved she didn’t have to explain her situation time and again because other HCPs already knew her. As well, she was able to readily access services for her husband:

I phoned [to arrange a respite stay] and I actually ended up knowing the coordinator. I used to work with her. I found it very comforting to know that there was always a familiar voice or a person that I knew. It just made me feel better and so she was able to organize because it was [a] long weekend and she said, “No I think I can work things around.”

Likewise, another nurse whose mother was deteriorating in a facility that was not appropriate for her needs benefited from her professional connections. A former home care director who was known to her offered to find a facility with a dementia unit that would be more suitable for her mother. The nurse recalls,

We were hoping for [that facility] but it was the same system where it’s an emergency placement. But because my Mom had been an emergency placed, she was still on a waitlist for [another facility]. Within months after [this director] did her little investigating, my Mom got placed very quickly.

Relationships with HCPs.

Having connections with the health care system was also beneficial to participants because they believed many HCPs treated them as colleagues. Many nurses were given information from HCPs that is generally considered privileged. A few nurses were present when their family member received their terminal diagnosis, while some nurses were told of the diagnosis and shown test results before the patient. In some instances, HCPs automatically deferred decision making to the nurse as in this case with a participant who had a collegial and social relationship with his father's specialist:

I got a phone call from my friend and he said that the path[ology] has come back and he had Stage 4 adenocarcinoma of his lungs. I said, "If it was you and you had this diagnosis, what would you do?" And he said, "I would take all my money and go to Mexico." And I said, "Okay". So he said, "Do you want me to refer you to the cancer clinic?" and I said "Not yet".

Also evident from this interaction is that the nurse understood the subtle meanings behind spoken words that non-medical personnel may not pick up on. It was clear to this nurse that his father had a poor prognosis. In a similar episode, another nurse recalls her ability to decipher the physician's allusions. The nurse, who was present when a specialist assessed her husband, understood what the physician was communicating somewhat cryptically:

I was facing my husband but [the doctor] was in between us doing his assessment and just as he started he saw - it was just this ripple down his arm. It was almost like you thought a light flickering but it was just for a split second and then he just stepped back and he didn't say anything but then he just turned to me and said, "Did you see that?" And I said, "Yes." But he never once said what it was. And [he] just turned to me. And just with the look - when I look back normally you would have thought he would have said, "This is what I think it is." But he never did say what it was. I don't know [that specialist] well. I don't work with him. But he knew that I knew and that was fine.

Regardless of whether nurses were in their usual work environment, many

reported they were comfortable communicating with HCPs because they understood medical jargon. As such, when they advocated for their dying family member, many nurses employed the same communication strategies used in their professional role as explained by this nurse:

I've been working as a nurse for years, so you know as a patient advocate stuck in the middle of it all the time, you only get what you need or get what the patient needs if you can advocate for that person in a very positive fashion. If you rant and rave and snap your fingers, you'll never definitely get what you want and you're always in pitch battles trying to communicate.

Many nurses quickly developed close collegial relationships with HCPs caring for their family member. They believed they were able to speak frankly with HCPs about their loved one's terminal prognosis. Another participant who was a home care nurse supports this notion. She observed in her professional practice that FCGs who were nurses seemed more receptive to discussions about their family member's prognosis:

We [home care nurses] deal with this all the time where daughters are nurses. And it's often easier if the daughter's a nurse cause you can just kind of, have that discussion, you know, about where you're going and what this looks like and where you might not with somebody else.

Many nurses were appreciative when HCPs acknowledged their professional status. Several nurses who cared for their family member at home wanted to have the lead role in coordinating and providing care. In most situations, home care professionals kept in touch by telephone, offered support, and intervened when the nurse requested. As such, nurses could remain in control and maintain as much normalcy as possible during the dying phase.

Having Nursing Knowledge

All participants reported having nursing knowledge was extremely beneficial to them as they cared for their dying family member. Data reflects several aspects of having

nursing knowledge. First, knowing how to provide care gave nurses confidence and eased the strain of caregiving. Second, knowing how to provide palliative care helped nurses offer comfort to their dying loved one. Third, having knowledge of death and dying appeared to ease the emotional strain for nurses as they witnessed the deterioration and eventual death of their family member. Experience with death and dying helped nurses to provide emotional support to their dying loved one and other family members. Fourth, knowing how to advocate for care helped nurses ensure that appropriate measures were taken to facilitate comfort and quality of life for their dying family member. Finally, knowing ahead is another dimension of having knowledge. Nurses were attentive to the changes they observed in their dying family members and often had foreknowledge of diagnosis and prognosis before other family members, which allowed them to prepare themselves and others.

Knowing How to Provide Care.

Most participants reported that their professional experiences gave them the strength and confidence to care for their dying family member. They knew they could handle any care needs and this made the task of caregiving significantly less stressful for them. Nursing practice stems from a foundation of care – physical, emotional, psychosocial, and spiritual care (Berman, Snyder, Kozier & Erb, 2008; Canadian Nurses Association, 2007; Thorne, 2003). As nurses were already grounded in the philosophical tenets of care and nurturing, they knew how to provide comfort care. This was most strongly asserted by a male nurse who attributed his ability to nurture and care to his nursing background:

I wouldn't have made his death as nearly as comfortable as I did because I was a nurse. I wouldn't have been able to do it with as much caring and knowledge if I

wasn't a nurse. I would have still probably tried to help him out but...I wouldn't have made his death nearly as comfortable as I did because I was a nurse and that comes from nursing. That's not something that you just get from intuition. It's not a natural ability for a male, I don't think.

A few nurses found that knowing even the "most basic things" were important contributions to their family member's comfort. For example, a nurse who traveled to another city on the weekends to provide care for her father recounts how her family struggled with moving him in bed without causing discomfort. She however, knew that placing a drawsheet underneath him would help them reposition their father more easily. This seemed like "common sense" to her but was new knowledge for her family. As well, another nurse anticipated the potential need for incontinence pads and ensured they were available in the home. She questioned if non-nurse caregivers would have the same knowledge:

Would you have had those things you needed? Would you have had the incontinent pad? Knowing that somebody's going to get to the point where - so having an incontinent pad was an important thing 'cause you could actually convince her, "Mom, you're just too short of breath to get up." If you were just a layperson, would you have known those things? So that was the gift of being a medical person.

Several nurses said they were grateful to be able to provide care that is not usually performed by FCGs. For example, a nurse living with her dying father in a rural community with less formal service inserted a catheter to manage urinary retention. Another nurse caring for his father performed manual disimpaction to alleviate discomfort. Being able to perform all aspects of care allowed them to provide comfort to their family member without delay and without having to rely on the availability of formal caregivers.

Knowing How to Provide Palliative Care.

Although only a few participants' professional work had a significant focus on palliative care, all nurses had experiences of caring for a dying patient. These experiences, combined with knowledge of nursing care and medicine, were perceived by participants as a valuable asset to their family caregiving experience. For example, regardless of their area of work, all participants reported they had knowledge and experience managing symptoms such as pain and dyspnea. As one nurse commented, "in ICU [Intensive Care Unit] we do things like make people comfortable. So the dosing and the drugs is [sic] very familiar." As such, most nurses were confident in assessing symptoms and knew what drugs were commonly used to manage symptoms in their work area.

Having this knowledge was seen as extremely beneficial. Participants believed they were able to provide symptom relief and a better quality of life for their dying family member, compared to the abilities of their non-nurse counterparts. For example, a participant who was familiar with the use of diuretics to manage dyspnea suggested to home care professionals that she would like to try this approach to alleviate her mother's symptom. When she learned that this approach was not generally used in palliative symptom management, she persevered and was successful at getting diuretics ordered. This nurse reflected on how her knowledge and experience made a difference in her mother's quality of life:

I think that was another one of the other gifts that being a nurse gave us - I don't think somebody else would have necessarily gotten any Lasix. And it didn't change anything, it just improved some quality. I'm not sure if she would have lived longer. She just had more symptom free [periods] that she was up and about doing things. But it was a gift to be able to give her that quality. And that's one of the advantages to being a nurse that I don't think lay people would have had.

As well, some nurses reported they were comfortable with giving medications such as narcotics when other family members were hesitant or fearful, as was the case for a pediatric nurse who recalled:

She [Mother] was grunting. And I said to my sister, the [psychiatric] nurse, “I think I’d like to give her a PRN [extra dose]. I don’t like the sound of that. To me I wonder if she’s in pain.” She said, “Don’t, don’t, don’t, don’t. I’m afraid of that, please don’t.” I thought - I’m going to give it to her. It’s not going to be the end of the world whether she dies now or whether she dies 2 hours from now, it’s the comfort that matters. So I gave her the PRN of Morphine.

Another participant, an emergency room nurse caring for his elderly mother who was in hospital dying of heart failure, also drew on his nursing knowledge and advocated for medications to manage severe dyspnea. After failed attempts to advocate for symptom control from the physician, the nurse administered one of his sister’s medications that he knew would alleviate his mother’s dyspnea. In doing so he was able to provide comfort to his mother and relieve the anxiety of other family members. He recounts the situation:

I gave some Ativan to my mother to calm her down, to slow her respirations down. So for the last two three days of her life she was more relaxed. She lay down in the bed. And that calmed the whole works down, the whole family, calmed them right down. So I had stepped outside of my role as a family member and as a nurse and did something that was probably quite illegal. However, I used my medical knowledge in trying to calm down the whole scene, as opposed to just the one individual. And I think I helped my mother out a great deal.

Several nurses believed their nursing background enabled them to facilitate the best possible quality of life for their dying family member. Many participants expressed gratitude that they had the capacity to maintain as much normalcy as possible for their family during the illness phase. As well, some nurses were thankful they could help fulfill the goals and wishes of their loved one because they were able to provide a high level of care. For example, one nurse was grateful for the ability to fulfill her husband’s last

wishes for an overseas family vacation because she was able to care for his central intravenous line. For this nurse, her nursing background was pivotal in facilitating desired experiences and quality of life.

Several participants also shared that their knowledge and experience of providing care in their professional capacity gave them confidence and eased the emotional strain of caring for a dying family member. One nurse caring for her husband stated, “I think being a nurse - the fact that I had a confidence, a strength that I knew that I would be able to look after him...made it easier to deal with all the emotional part...I would understand it for the most part or could find out...from the networking that was available for me.”

Knowledge of Death and Dying

All participants had cared for seriously ill and palliative patients and as a result they developed a comfort in being with a person who is dying. Having knowledge and experience in death and dying appeared to ease the emotional strain for nurses as they witnessed the deterioration and eventual death of their family member.

Some nurses believed they were better prepared during the last days and hours of their loved one’s life than other members of their family because they understood and accepted the inevitability of death. For some nurses, having experienced death in their professional work made them less fearful as they watched their family member die. A nurse sharing the experience of her father’s decline and episode of delirium remarked, “I knew that it was a natural process. It was very sad. It was very sad but it wasn’t particularly scary for me. I didn’t have a hard time with it.” Likewise, a home care nurse reflecting about the last days of her elderly father shared, “I wasn’t scared of him dying, of going through the breathing, the paleness. I could see everyday he was getting closer

and closer.” As well, a nurse who understood there is a spiritual component of dying highlights how understanding the dying process helped her emotionally as she watched her father in a delirious state:

I remember at one point in time, he started talking to some of his friends in the corner of the room - his friends who'd died. And that gave him a lot of comfort, I think too. And we talked a little bit about that and it was okay. But it freaked the heck out of my family. I sort of knew this was okay and normal to do that when you're getting ready to cross over.

Comfort and experience caring for palliative patients in their professional role was also seen as beneficial to nurses as they provided emotional support to their dying family member. Several participants reported they were at ease with their dying family member and comfortable talking to them about death and dying. They explained that while other family members shied away from discussions about death and dying, they usually would initiate open and candid discussions with their terminally ill loved one about their goals and wishes for health care intervention, and about their impending death. As a result, these participants believed that their nursing presence made a significant difference in the quality of life for their dying family member. For example, a nurse who shared caregiving responsibilities with her sisters highlighted the differences in comfort levels between her and her sisters and how this impacted their father:

I knew when I came over to see him, he'd look up, he'd brighten up, he'd relax, you know, “Oh my God, she's here!” And I felt so bad that I couldn't spend more time with him because to me it was pretty evident that he could relax around me that he couldn't - cause my sisters were all pretty tense and didn't really know what to do around him or with him. You know there was a different level of tension for sure cause they never really experienced death earlier and didn't want to expect whereas I did. And so I guess I was more relaxed around him, he could relax more.

Some nurses provided emotional support to other family members by modeling and teaching ways to be with a dying person. Other nurses recounted how they alleviated

fears of their family members by teaching them how to be with a dying person. For example, the sibling of one nurse was uncomfortable being with their dying brother who was near death. The nurse was able to allay his fears by teaching him ways to provide comfort and facilitate the shift from feeling helplessness to demonstrating helpfulness:

He says, "I can't, I can't do this." and I said, "You don't have to do it. If it's not comfortable for you, don't do it. Nobody's asked you to. You be in the house, you just don't have to be in there, that's okay." And once he was told that's okay, he actually did start to come in the room, "Oh, what can I do?" I said, "Well you could rub his feet. You're allowed to touch him." So I think that's part of the fear: what am I supposed to do, right?

As well, this same nurse drew on her work experiences to assuage the fears of her family members as they watched their loved one die. As death approached, the nurse explained to her family what to expect and how to know when death was near:

As he was dying, I'd show them all the signs, "See the purple knees, this is mottling. This is what happens - this is this and that is that and this is why."...If you sort of bring the whole piece of it to reality and understanding I think it takes the fear out of it a bit more. Which I feel fortunate as a nurse you can do that right? It's the unknown..."What is death going to look like? I've never seen it before." It's not that bad, it's not that bad.

Data also reveals many nurses learned the importance of having closure from their professional experiences and encourage their own family members to make amends with loved ones and say their "good-byes". For example, one nurse was instrumental in initiating an opportunity for her cousin to make amends with his estranged father who had just died. She recognized the impact that it may have on him if he did not address the fractured relationship with his father. She reflects, "I said, "So spend some time and tell him how you feel."...I brought him in there and set him up a chair and got him comfortable." Afterwards, her cousin remarked, "That was the best advice you could have offered me.""

Knowing How to Advocate for Care

Several nurses expressed they were thankful for their nursing knowledge and experience as they believed they were better able to advocate for appropriate care for their family member. For example, several critical care nurses shared that in their professional practice, they had witnessed dire consequences of futile treatments. This was evident in the experiences of an Intensive Care Unit (ICU) nurse, who was dismayed at “seeing people flogged to death when we give them too much care” and strongly advocated for only palliative measures for her husband. She recalls recognizing a sign of a potential complication of brain surgery and advocated for adequate symptom management: “I spent some time trying to get adequate pain control for him...my concern was that he was having increased intracranial pressure and swelling. He shouldn’t have been having that much pain ...[if] I hadn’t been there, his pain would have been so much worse”. Similarly, another ICU nurse who was caring for his father at home recognized signs of decline he had seen in his patients and shifted to comfort care. He shared:

I was looking for signs that he was declining so that I could give him more medication so that he wasn’t struggling. And we do that in intensive care all the time so it wasn’t something that I wasn’t familiar with. You just know what you need to do to not make this a 17-hour procedure so you can, you can move to comfort care a little quickly. So that was my goal - once he declined and wasn’t coming back, then I needed to move to comfort care quickly. So I was comfortable with the decisions.

Participants whose family member was in facility care had similar experiences advocating for care. While some participants felt relieved to hand over care to facility staff, most continued to provide care in the form of advocacy and consultation. For example, a home care nurse experienced in palliative care recognized signs of pain her

mother with dementia was exhibiting and successfully advocated for analgesics and sedation to relieve symptoms.

Knowing Ahead

Several nurses shared they had an intuitive sense that their family member was gravely ill and were not surprised by news of a terminal diagnosis. Nurses recognized the significance of reports from other family members and their own observations of profound weight loss, which they identified as a hallmark sign of a cancer. For example, a nurse who noticed cachectic wasting in her mother's leg at a family gathering remarked, "I knew then, a good ten days before the bronchoscopy, that she had terminal cancer! Right? Like there was just no doubt in my mind that she had lung cancer."

Nurses highlighted advantages to having foreknowledge of diagnosis. Several nurses, while shocked at the news of a terminal diagnosis, took time to grieve, then took action to advocate for medical care and began to prepare themselves and others. Nurses prepared themselves by seeking more information through talking to colleagues with expertise in the area and connecting with local cancer clinic staff to gain knowledge about diagnosis and current treatments. For example, one participant recalled how upon hearing about his father's significant weight loss, she began to advocate for timely diagnostic exams and medical follow up. In the same situation, the nurse was told of the terminal diagnosis prior to the patient. Knowing the diagnosis before other family members gave this nurse opportunity to gain insight into the situation by researching information about the diagnosis, current treatments, and prognosis. He believed that knowing ahead of time gave him insight and benefit. His research confirmed his suspicion that the long-term outcomes for the type of cancer his father had were not

positive. Armed with this information, the nurse felt better able to prepare and support his father and other family members for a terminal diagnosis subsequent shift of focus toward palliative care:

Knowing ahead of time helped me to build my supports - put my supports in place...I wanted [my mother] *prepared* to deal with what we were going to deal with because she's always been the one that's needed everything, she's always been the mom that we've scrambled for. And now he needed us to change gears *rapidly* and come onboard and support him.

A few nurses believed that knowing ahead helped to prepare them for the death of their family member. This was the perspective of a nurse who believed she was more prepared for her husband's death than his family as she understood and accepted the prognosis long before they did:

I knew longer than they did that he wasn't going to make it. People who aren't nurses - not all nurses think the same way I do either, I know that, but, you know, you got cancer and it spread to two major organs and then you get a brain tumour you know – *hello!* But people want to have hope. I don't see how you can in that situation but...it was just so much more sudden for them than it was for me. So that was an advantage.

In summary, participants provided many examples of the benefits of having knowledge and personal connections that accompanied their professional role as a nurse. Familiarity with the infrastructure of the health care system and established connections through their professional work made their family caregiving easier and less stressful. As well, nurses believed they could focus on providing care, as they did not have to spend needless time familiarizing themselves with the health care system.

Nurses also shared that because they had the knowledge and experience of caring for patients, they were confident in the care they provided to their family members and believed they were better able to ensure a satisfactory quality of life for their dying loved one. They also shared how they were able to facilitate a positive death experience for

other family members by providing comfort, reassurance, and support through the death process.

Caught in the Middle

While having connections to the health care system, and knowledge and experience of palliative care were cited as assets by many nurses, these factors also underpinned the tensions nurses experienced during caregiving. As reflected by one nurse, “It is an interesting journey and you’re caught in the middle sometimes being the family nurse but you’re part of the [health care] team - you’re caught in the middle.”

Being ‘caught in the middle’ centred on having nursing knowledge and the expectations generated about the care they and others provided to their family member. In turn, these factors caused conflict with HCPs and family members. Having knowledge also appeared to contribute to the high expectations nurses placed on themselves to provide the best care possible. In addition, several participants also described how they suspended their emotions in order to stay in control so they could provide a high level of nursing care for their dying family member. Another dimension of feeling ‘caught in the middle’ is reflected in the tensions nurses experienced as they juggled work and family caregiving responsibilities.

In this section, I will highlight the three sub-themes of ‘caught in the middle’: *conflicts with HCPs, having knowledge, and juggling paid work and family caregiving responsibilities*. First, I describe the conflicts and tensions nurses experienced when communicating with HCPs. Second, I describe the sub-theme of having knowledge, which highlights how having knowledge, although beneficial, was also a source of tension for nurses. I describe the expectations nurses placed on themselves and how they

suspended their emotions to keep in control. Finally, the third sub-theme, *juggling work and family caregiving responsibilities*, will be described.

Conflict with HCPs

Many participants shared they had conflicts with HCPs because they had knowledge of what care could and should be provided. A major source of frustration for them occurred when it was difficult to obtain the care they expected their dying family member to receive from HCPs. This included expectations of appropriate care for their family member and appropriate response and support to them as FCGs. As one nurse commented, “if you go into something not knowing anything and you’re not a nurse - an ordinary person - they don’t have expectations and they don’t know whether someone doesn’t do something, it’s not the way [or] that it wasn’t supposed to be.” As well, whilst advocating for such care, several participants reported they were cautious about how they communicated with HCPs to obtain the desired results.

Expectations of HCPs.

Conflicts with HCPs arose when nurses had great difficulty when advocating for appropriate care for their family member. Nurses experienced conflict with HCPs when care and treatments provided were not congruent with their family member’s wishes or what they believed to be appropriate given the palliative focus of care. In addition, many of the conflicts arose when nurses believed that HCPs were not appropriately responding to pain and other symptoms experienced by their family member. Some nurses experienced conflict when they believed HCPs were taking over control of their family member’s care.

Several nurses experienced anger and frustration when HCPs were providing

medical treatment, which they believed would prolong life rather and lessen the quality of life for their family member in their remaining days. For example, one participant recalled speaking to the physician about giving a medication that she believed would only prolong death and decrease the quality of her mother's life:

I [knew] the kind of person she was and how I feel too, is that we didn't want to prolong her death. And it did get prolonged by the system, with continuing with Decadron type...I felt that when she was in the hospital that it would have been better for her to have stayed in hospital and [be] treated like a hospice palliative patient which she sort of was at home but by continuing to give her the Decadron, they just really made her well enough to send her home, so that she could die at home. And it took four months and in that time she was at home, she got out of the house once...for a car ride and she didn't last very long. So, I felt the system really lets people down. It's not so much as being a nurse - except that I know. I know how it can be and I know what's available.

Nurses also had conflict with HCPs when they believed that their family member's symptoms were not well managed. It appears that from their nursing experience, participants had considerable knowledge about medications and treatments used to provide symptom relief. Several nurses experienced increased stress, frustration and anguish when their family member was not receiving adequate symptom relief, as they knew from their professional role that it was not acceptable. For example, knowing it was not acceptable palliative symptom management, a hospice nurse was distressed by the sight of her best friend in severe pain. She recalls, "I just saw...a woman in a fetal position, in screaming pain, and I knew that was not okay, that that was unethical."

Some participants had conflicts with physicians who did not respond to the hospital nurses' calls for orders or who were unwilling to order medications the participant knew would provide symptom relief; this caused distress not only for the nurse but also for other family members. For example, a nurse recognized that his mother's laboured breathing was causing extreme distress for his family as they stood by

and watched. He asked the physician for an anxiolytic medication to relieve his mother's dyspnea and voiced frustration when the physician would only order a narcotic for pain relief. Similarly, a nurse who wanted to have Narcan, a drug used to treat respiratory depression, available in the home was met with resistance from her husband's physician. Through her connections within the health care system, she was able to obtain the drug to have on hand and was thankful that she had it available:

We found a lot of the time we had to bash our heads against the wall to get kind of [get] the GP [to order medications] saying, "This is what we need" or I'd say, "I'd really like some Narcan, I'd like an order for some Narcan." And "No, no, no, you don't need it."...And as it turned out we needed it. [My husband] overdosed himself one day, his morphine was 50 [milligrams] to 1 [millilitre] and he thought he was getting Gravol, so he gave 50 [milligrams] IV push but he ended up tolerating it okay but I had the Narcan. So sometimes we'd have to - we were frustrated by trying to get things, usually from the GP to get drugs.

Some nurses believed that HCPs were reluctant to give pain medications and attributed their reluctance to a lack of knowledge about pain assessment and management. For example, a home care nurse who was knowledgeable in palliative pain management wanted to have morphine for her mother with end-stage dementia who appeared restless during her last days. However, she believed that the long-term care facility nurses did not recognize non-verbal cues of pain and as a result only administered analgesic when she requested it. Another nurse had conflicts with the hospital nurses caring for her cousin, who was near death, as she believed they did not understand the need to continue with administration of medications to provide comfort:

Because he was unconscious they seemed reluctant to give him pain medication. And I said, "Even though he's unconscious, he's still uncomfortable. You have to give him his pain medication." So I was not looked upon favourably because I bugged them and made sure.

Conflicts also arose with HCPs because nurses expected timely responses to their family member's symptoms. For example, a mental health nurse caring for her father felt

“horrified” by the lack of response from hospital nurses to her father’s congested respirations:

It just broke my heart that I had to listen to my Dad during that and it took so long. And if I had been his nurse I would have been on the phone with [the physician] in less [time] than [that]...so that disappointed me that it wasn’t important to the nurse.

In addition, several nurses believed that they were different from non-nurse caregivers because they functioned at a higher level and would only call on professionals for help when they believed that they needed more information to safely provide care. As such, some nurses had expectations that HCPs would respond to their calls quickly, as one participant asserted: “There’s a difference, I’m a nurse. I’m not going to complain about everything or call about everything. When I do call, it’s important.”

The lack of appropriate symptom management in some situations led to nurses’ loss of trust and confidence in the care given by HCPs. Nurses believed they needed to keep vigilant watch over the care their family members received. One nurse believed that she could not leave her dying husband alone in the hospital because she could not “trust the system to look after him” and feared that if she “hadn’t been there, his pain would have been so much worse. I couldn’t leave until then cause I was afraid to not be there! I didn’t trust anybody.”

Some nurses had conflicts with HCPs when they believed control of their family member’s care was taken out of their hands without consultation. This was particularly evident for nurses who provided care in the home setting. Most nurses caring for their family member at home wanted to be the main decision maker and caregiver as they believed home health care professionals could not fully understand their family member’s needs as they only visited sporadically and usually for a short time. Many participants

believed they were the best persons to provide care, as they knew their family member more intimately. Conflicts arose when HCPs took over without consulting the nurse and implemented care that they thought was appropriate. This is vividly illustrated in the case of a nurse who was powerless to challenge the palliative care nurse who offered to make a home visit to help her make decisions about further care and treatments:

A few minutes later the [palliative care] nurses has arrived. Everything just went out of our hands. I'm usually able to speak up for what I want for [my husband]. I think we just lost our voices. Even [my husband's] brother who's a big support, who was here as well, did sense that these nurses came in [and took over]...That was [my husband's] couch and he was here and he wanted to be in this room cause it's the hub of the kids and teenagers and the food and the meals and this is where he wanted to be. So this is where he was going to be. And that's when I said so. And it was the minute they came in, well let's get him into his bed, he needs to be into a bed...But we did say, "No, no, no, he needs to be here, this is where he wants to be, he really wants to be here." "Let's get him out of those clothes, let's get him into a pajama." And he wanted his warm favourite sweater on. It was a comfort sweater but *poof* that came off and it didn't go back on.

Communicating with HCPs

Although many nurses easily developed collegial relationships with HCPs, at the same time, they reported tensions in communicating with them. The tensions appeared to be centred on participants' awareness of the workload pressures of HCPs from their own work experience. As well, nurses knew firsthand from their professional role what it is like communicating with patients and family members who were dissatisfied with care received.

Participants were cognizant of the workload pressures faced by HCPs and as such, some participants reported they hesitated to communicate their needs because they did not want to bother them. As one nurse commented, "I'm dealing with other nurses and they're always busy and...because we're nurses we don't want to cause problems for people."

Several nurses reported in their professional role, they experienced the brunt of the anger of family members who were dissatisfied with the care the patient received. As such, some nurses believed they needed to be cautious in how they communicated to HCPs because they did not want to appear being pushy and demanding. As one nurse described: “it was kind of a balancing act to say what I wanted and thought should be [said] and yet not come across as the overpowering dominant nurse-daughter.” Another nurse believed that she had to “bite [her] tongue” lest she jeopardize her cousin’s care. Likewise, a hospice nurse described her fragile communication with HCPs as she experienced the push and pull of wanting to strongly advocate for her dying friend and at the same time wanting to maintain effective relationships with HCPs:

I was walking on tender hooks. I didn’t want to invade their territory but by the same token, I knew that what was happening was not okay...There was a whole piece of me that felt on very shaky ground because I know on my unit when we have a family member blow in from Toronto who’s a doctor, arrives on the scene and says, “I want you to do this, this, this, and this.” And I was very cognizant of that. I was so aware. I did not want to be like that.

Some nurses believed that conflicts could have been avoided if there were continuity in HCPs. Participants found it comforting to have the same nurse who knew them and their family member. Their stress was lessened when they did not have to repeatedly explain the situation and when they could develop a relationship with the nurse and receive emotional support.

Having Knowledge

A second sub-theme of *caught in the middle* is having knowledge. While all participants reported that having nursing and medical knowledge was beneficial, at the same time, it could be burdensome. First, there was the burden of knowing ahead. As nurses have knowledge of disease and likely prognosis, oftentimes they recognized the

signs and symptoms of illness before other family members. Although knowing ahead was seen as beneficial as described previously, nurses also experienced tension when they knew about diagnoses and prognosis before other family members. Second, having knowledge was also a burden as it placed nurses' expectations on themselves to use their knowledge to provide the best possible care to their family member. Third, data revealed that some nurses suspended their emotions in order to maintain clarity to focus on the task of caregiving. For some nurses, suspending emotions during their caregiving experience led to personal health problems after their family member's death. For example, nurses reported ill health, exhaustion, and emotional breakdowns, which they attributed to the high intensity of care they provided.

Burden of Knowing Ahead

Many participants knew that their family member's illness indicated a poor prognosis and there was little hope for a cure based on their nursing knowledge and experience. In some situations, nurses believed they were more fearful because they knew what was to come and felt the burden of responsibility to prepare other family members. Others struggled with whether or not to share the information with other family members. Sometimes sharing knowledge caused conflict between nurses and their family members. Participants reported they found it difficult to remain hopeful and optimistic in view of their knowledge about their dying family member's prognosis.

Some nurses wished that they did not have the foreknowledge because it was difficult enough for them to accept the information, let alone be the "bearer of bad news" and tell their own family members. For example, one nurse recalled standing back and observing her family together during her father's last days:

It's hard. You almost wished you didn't know... You're preparing your family but you're also trying to prepare yourself at the same time... I remember... standing there looking at [my dad] going, "Oh my God, this is the last hurrah"... The nursing part of me knew that and the daughter part of me went, "Oh God, no, no, no, no it's not, no it's not." It was just so bizarre... That was hard, that was really hard. I mean, how do you say that to the rest of your family?

Some nurses reported that they were hesitant to share what they were witnessing for fear that their ill loved one might lose hope and give up. As well, they did not want to dash the hopes of other family members. This placed some nurses in a difficult position of deciding whether or not to share their knowledge and in some situations, determining the right time to disclose what they knew to other family members. For example, one nurse whose family was gathering together during the last days of her father's life disclosed that although she knew that death was imminent, she did not want to share this knowledge with her siblings until they could "acclimatize themselves to it", sensing that her siblings needed time to accept what was happening. Similarly another nurse questioned the fairness of sharing their knowledge with others who they felt were not ready to accept the information. One nurse questioned her motives for sharing what she knew:

"Who do you share it with? Is it fair to share it?... Are you actually telling people things they need to know? Or are you just trying to share your load because you know and you don't want to carry it alone? Truly, it's all gonna come out in the wash, do they really need to know ahead of time this is going to be bad news?"

Nurses who disclosed information before other family members were prepared to accept the information reported they were sometimes met with anger and antagonism. One nurse experienced the brunt of her father's difficulty accepting his wife's prognosis. Although the nurse wanted to be honest and share information she had obtained from her mother's physician, she believed her father directed his anger toward her because she was

a nurse and expected her to be optimistic and bring only “good news”.

As well, tensions arose when family members were not in agreement with the nurse to accept a palliative focus of care and wanted more aggressive treatments aimed at cure. For example, one nurse knew that the type of cancer her father had usually indicated a poor prognosis. She believed her sister did not accept the prognosis and aggressively advocated for more treatments, which caused conflict between the two of them:

[I’m] trying to sort of gently say to her, “You need to back off and let him have some quality of life here cause quantity is not an option now. Let’s have quality.” She just couldn’t go there. She really couldn’t go there. And so that added difficulties cause it barred me from being more involved with my Dad. She wouldn’t let me go in when we were in the cancer clinic at the very beginning. She wouldn’t let me go in and listen to what the doctor had to say to Dad so that I could interpret the information. I could see that it was really important to her to do that and so I just let it go without making a lot of waves because it wasn’t...It didn’t matter cause I knew he was going to die. There’s nothing you can do to change that, but let’s try and make what time he has left good quality. Let’s not go nuts here. And she wanted to go nuts and so that was hard to try and balance that.

Knowing ahead also was challenging for nurses themselves. Often nurses experienced internal conflict while trying to remain optimistic when they knew that there was little hope. Others struggled with feeling of guilt because they were not being more hopeful of curative treatments as was the case of one nurse whose father was using alternative therapies to cure his cancer who recounts, “I was more conflicted with respect to my...doubting. I doubted the efficacy of what he was doing. And that laid a bit of a burden on me.” For some, there was guilt associated with giving up hope and as a result, some of these nurses felt isolated from their dying loved one and other family members as articulated by one nurse:

I wasn’t in the same state that they were because I knew what was coming. I’d known what was coming all along...I knew that he had metastases and he was not

going to get better. They still had hope and there wasn't any hope.

Others believed they were more prepared for death than other family members. Some believed that their family member's death came sooner for them because they knew it was inevitable. A strategy that several nurses used to avoid being pessimistic was to purposely put aside their knowledge of what was to come and focus on the present. By doing this nurses believed that they could allay their fears of what they knew the future would bring. One participant's advice to other nurses who are caring for a dying family member was: "Don't be the doom and gloom. You do know what's going to happen but try to put that aside as much as you can."

Expectations of Self.

While having knowledge was seen as extremely beneficial, the data indicates that nurses had expectations of themselves to use their professional knowledge and skills while providing care to their family member. Some participants reported it was difficult not to take on a nurse role, as it was a place of comfort and control. The narratives of several participants show that they provided care for their family member similar to how they cared for their patients. Nurses had expectations of themselves to provide the best possible care to meet the needs and wishes of their ill family member. As a result, some reported feelings of stress, fear, anxiety, self-doubt and inadequacy. Additionally, participants reported they did not attend to their own emotional needs and in a few situations, the needs of other family members such as dependent children. In this section, I will describe the tensions nurses experienced between their professional and family caregiving roles related to the expectations to use their knowledge and skills. I will also highlight the tension nurses experienced while providing care and discuss the outcomes

associated with the expectations they placed on themselves.

Several nurses had expectations of themselves to use their nursing knowledge and skills. Oftentimes, this created tensions for nurses as it placed expectations on themselves to apply their knowledge in their family caregiving role. Moreover, in their family caregiving experience, many nurses found it difficult to move out of their professional nurse role. One nurse believed she couldn't let herself be an "ordinary person" as it was easier for her to be a nurse than a relative, as this was a place of comfort for her.

This sentiment was expressed by other participants who reported that being a nurse gave them a sense of control because they knew what to do and how to provide care. Others believed that because there was so much to do and so many tasks to perform they assumed a nurse role over a family member role. This was the case for one nurse who shared: "somehow [I] couldn't move out of that rule of being the nurse and being his daughter more." One participant described having knowledge as a "double-edged sword". Although she believed knowledge was a huge benefit, at the same time she viewed it as negative because it engendered "massive expectations" to facilitate the wishes of her dying husband:

He was so thin, couldn't talk, he could hardly swallow...and I guess that's because I am a nurse that wasn't hard for me to deal with. I can look after sick people. I always knew that I could look after him. So that wasn't the hard part. The hard part was making sure his journey was what he wanted it to be.

In their professional roles, nurses use their knowledge to assess potential problems that may arise and to implement interventions to mitigate problems. Although some participants recognized that attempts to predict what might happen were ambiguous at best, they still had expectations of themselves as nurses and did not allow any room for error. This was a source of stress for some participants as evidenced by a nurse who

expressed: “I think the negative part would be the knowledge and knowing how to control, the fear and the unknown...and that feeling of trying to always be ahead of the game.”

In the course of their family caregiving, many nurses performed tasks that were not generally carried out by FCGs, such as inserting a urinary catheter and stool disimpaction. Some nurses had mixed feelings about providing this type of intimate care to their family member but did so as they felt a sense of responsibility to use their nursing knowledge. For example, a nurse who inserted a urinary catheter when her father was unable to void reflected on the tension that she experienced performing this task:

I actually put in a catheter, a Foley...it was getting on toward within a two or three weeks of him actually passing away...that was strange, catheterizing your father, that was strange but because he was so ill it wasn't a hard thing to do. I guess it was hard in a sense but I knew it had to happen and I was wanting to problem solve for him... I still did the nurse role, like I still did the catheter.

Although some nurses were prepared to provide intimate care, they reported a sense of relief when HCPs arrived at the home and took over. They were relieved they could hand over care to someone else and be the family member rather than the nurse.

This was the case for a nurse whose mother was declining:

We tried to get her up to the commode and she was just too short of breath. I had taken a catheter home (laughs) and all the things that you needed cause I thought we might get to this. So I'm about to catheterize her (laughs) because she just has to pee so badly and she can't get up and she didn't want to pee in the bed and I had a big incontinent pad on the bed and I'm just about to catheterize her and you know, it's not a thing you want to do to your mother. I don't know why but you just don't...[I] hadn't quite put the catheter in when the hospice people arrived. Thank goodness!

Having knowledge also placed expectations on nurses to be vigilant over the care their family members were receiving from HCPs and provide high quality care themselves. Some nurses caring for family members in the home did not want to leave

because they believed other family members would not be able to cope with the intense care needs. A few nurses who were the sole caregiver reported their caregiving experience was at times intense. For example, a nurse caring for his father at home devoted “110% of [his] love and caring and attention to him”. This nurse’s overwhelming devotion was evident by the care he provided during his father’s last hours, putting his own needs aside and providing constant care throughout the night administering medications to control symptoms:

He couldn’t get out of bed any more cause he had enough Morphine and Valium that he was kind of sitting back but he wasn’t resting so he was just sort of surging forward and with a bit of anxiety so I just laid behind him with pillows, just let him rest against me. And just kept giving him his Morphine and Ativan on either side to keep him in bed and not jumping up and panic all the time cause I couldn’t safely get him from the window anymore. So I just stayed there with him laying against me all night long and just talked to him. And then throughout the morning, I just stayed there with him and he was calm now and his body was a bit more relaxed and a little bit calmer...I stayed just bit behind, supporting him with pillows and holding him up...When you’re emotionally exhausted and you don’t know it, cause you don’t. You’re caring for somebody and you’re going, pulling up all the stops. You’re going without sleep, you’re going without food, you’re going without everything. My Dad laid against me for about 14 hours before he passed away, so there wasn’t an opportunity for me to get to do a lot of other things. I had no one to jump in and take my place.

Providing intensive care was not without cost. The expectations nurses had of themselves to provide high quality and intensity of care to meet the needs and wishes of their dying family member had several negative outcomes. Some nurses expected themselves to be experts in providing care, which engendered feelings of guilt and inadequacy when they did not have the knowledge to make decisions about care. Several participants expected themselves to always know what to do even if they had limited palliative care experience. For example, some nurses felt inadequate when they did not know about all of the medications used for symptom management and this placed a

tremendous burden on them. As well, some nurses believed they were not thinking clearly because they were outside of their usual work routine and in emotionally charged situations with their own family members. As such, they didn't think of management strategies that they were familiar with using in their professional role. Consequently, some nurses felt guilty that they didn't do enough. A medical surgical nurse with little experience in palliative symptom management, experienced considerable guilt after her caregiving experience because she did not know how to manage her father's nausea:

I had no idea that you needed to take three [antiemetics] at once. And I didn't know anything at all about the Haldol thing. So it made me feel really bad that I as a nurse didn't know that. So that's probably the biggest thing that I felt over that time was this terrible burden that somehow I wasn't a good enough nurse...I felt - trigger guilt that I couldn't help him. As a nurse I couldn't help him...This is one of the things to this day I feel guilty about is I should have gone back to the cancer clinic sooner.

Fear and anxiety was also triggered when nurses felt unsure if they were making appropriate clinical decision. Some nurses feared making decisions that would negatively impact their family member, as was the experience of an ICU nurse who was the main caregiver for his father. This nurse put extreme pressure on himself to ensure that his father's dying phase went "perfect" and as a consequence experienced stress, anxiety, and self-doubt:

You know what the prognosis is that's he's not going to survive but to try to forecast what kind of time frame am I looking at? What do I need to do? What should I set up? What kind of care needs to be built in? What are we looking at here? And I think that was the hard part because I sort of had an idea, but you never really know. And so you're always walking around that anxious fine line. That is, if you pick wrong that's going to impact him in a negative way...it's kind of like, "Okay, am I picking wrong here?" Am I going in the wrong direction? Am I picking the wrong drug at the wrong time? Is that what I'm doing?"...In ICU we have the ability to make things perfect in our opinion, right? We raise medication by a fraction of a micro-metre and we can titrate things to make perfect blood pressures and perfect heart rates and perfect everything. And I think I had this belief that I wanted this to be perfect. I was trying to do everything I

could to make it perfect. And when it didn't go perfect, I was always trying to think how to make it more perfect or how to optimize it and I think that was the part that I was - I didn't realize I had put that much stress on myself.

Several nurses questioned whether they should have accessed more assistance from HCPs. Some felt hesitant to involve HCPs because they wanted to maintain normalcy and privacy. Other participants reported they did not have confidence in some HCPs because they believed HCPs could not contribute additional knowledge. Most nurses who asked for help from health care system, wanted HCPs to be available for consultation only to augment the knowledge they already had. On the other hand, a few nurses wanted to be treated like non-nurse caregivers that did not have medical knowledge so they would not fail to identify symptoms and provide appropriate management.

Some participants wondered if they should have asked for more help HCPs but thought they were able to handle the situation. One nurse who felt remorse that she did not think of using a medication that would have helped relieve her brother's respiratory congestion was hesitant to admit that she needed help:

I think it was interesting how part of me wanted to say, "I know how to do that." But there was a big part of me that needed to be taught again...the Atropine - if someone had kinda clued me in into those things - but I probably took on more than I - at the time maybe - I don't know. Maybe I didn't think I needed this much help as I [did] always, right?

One nurse who did share her feelings of inadequacy with a HCP felt extremely supported when the home care professional acknowledged her role as a daughter. This helped to alleviate the burden she placed on herself to be the "expert" nurse:

What was really nice about that was that it relieved me of that whole burden of feeling like I had to be the expert. That I had to know what I was doing and that I needed to be the one to solve the problems. I could just be more the caregiver nurse, rather than the expert nurse. And I mean I've never done palliative care in

my career so I mean, it wasn't, it wasn't something that I had expertise in.

Another consequence of nurses having high self-expectations was neglecting their own needs and placing their dying family members' needs and wishes ahead of their own. For example, a nurse who was the sole caregiver for his younger brother put his life on hold to provide care. He asserted: "his wishes were the only ones that I was there for. And my life at that point was to me completely irrelevant, that I'm only there for him and whatever he wants. Whatever is going to make him more comfortable was the only reason I was there."

Expectations to provide care and providing a high intensity of care also impacted other family responsibilities. This was particularly evident for nurses who had dependent children. One nurse felt "constantly in a tug-pull situation, push me-pull me situation" as she struggled with balancing caregiving responsibilities to her infant son whom she was still nursing and her dying father who lived in another city. Similarly, two nurses juggled household responsibilities, caregiving needs of their young children, and being the main caregiver for a dying parent. One of these nurses gave priority to caring for his dying parent, as he felt believed attending to his father's needs were most critical, especially nearing death:

I wasn't making myself the center of the care... And even to the point where I didn't spend a lot of time with my family. I would go kiss and hug and then I'd take off and go and care for grandpa. And that was the relationship we had and I just separated myself.

The other nurse felt guilty that she had "robbed" her children of quality time with their mother during her caregiving experience. It was also upsetting for this nurse that she was not available for her children to support them through their grief and loss. Her children came to visit briefly when her mother died but shortly afterwards she sent them home so

she could take care of other family members:

I just could not be their mother and help them through grief and be the nurse. And somewhere in there was the daughter. That was a very tough role...It was awkward to play all those roles at once and I thought about having the kids stay and I thought: I can't cope!

Suspended Emotions.

Expectations to use the knowledge they possessed coupled with their expectations to provide a high level of care to their dying loved one and other family members added to the stress of caregiving. In order to cope with the demands of caregiving, several nurses disclosed they suspended their own emotions during the course of providing care and support to their family. Nurses described they suspended their emotions by ignoring their emotions during the provision of care and emotionally detaching themselves when in stressful situations as they did in their professional role. Participants shared that they suspended their emotions in order to maintain mental clarity and objectivity so they could make appropriate clinical decisions and keep focused on the task of caregiving. However, this may have had negative outcomes for some participants. Some nurses reported they experienced acute physical and emotional turmoil following the death of their loved one. Two respondents reported that several months after the death, they suffered a significant emotional breakdown. In this section, I describe when and how nurses suspended their emotions during the course of caring for a dying family member. As well, I will highlight consequences nurses experienced as a result of suspending their emotions.

Participants revealed that in their professional role, they would detach themselves by suspending their emotions and be emotionally distant in order to maintain clarity for appropriate clinical decision making. An ICU nurse explains:

Very few, I think, nurses getting patients into the ICU start crying just seeing

them come in. You've got a job to do. You've got assessments to do, charting to do, [medications orders] to write, orders to prepare and you've got work to do. So you don't attach yourself emotionally to that person because in order to help them, you've got to move through that. So we separate ourselves emotionally first ... to do a job.

In their personal caregiving role, many compartmentalized their emotions so they could think clearly and make important clinical decisions, as articulated by this nurse who cared for his father in the home:

I think if my emotions lead me around all the time, I don't think I would have been able to provide care for him. I need to separate *my* love for him away from my, the care I need to provide for him. I couldn't do both cause then I would just fall apart all the time and wouldn't be able to pull it together. I'm falling apart now and it has been years right?

Many participants also believed that they would be unable to provide care if they allowed their emotions to run free, particularly when they were carrying out stressful activities such as sharing bad news, providing emotional support, and providing intimate care. As reported earlier, breaking bad news to their family members was difficult for some nurses. A few nurses reported they took on a professional persona when sharing bad news. This helped them to maintain their composure to relay the information, as they believed that if they were emotionally distraught they could not provide emotional support to their family member. For example, a nurse caring for her younger brother shared the experience of telling her brother of the reoccurrence of melanoma. She initially shared the news in a casual manner but then reverted to explaining the circumstances to him as she would to a patient as this was a more comfortable role for her:

I was able to feel like I was the professional doing what a professional would say and do but I was still the sister of the brother I'm caring for...I went to that place that was comfortable, right? You know how you can go to that place of knowledge? And that was easy. It was easy for me to come away and tell him

what was wrong with him if I went to the place of knowledge as opposed to the place of emotion...Got the x-ray and said "See [Brother], here it is, here." That felt easier to do than being able to go "Oh my god, you're full of cancer, what are we going to do?"...But I think you have to, you have dissociate yourself...I think it was a place that I needed to go in order to be able to say it. And believe it myself, support him at the same time by not breaking down...funny about anything to do with medicine and illness and family, you tend to want to go to that place of knowledge cause that's your control. You control that information and how you deliver it...But you don't have control over your own inner emotions on how it's going to affect you sometimes. So it's much easier talking in a professional manner to someone about their problem than go to that emotional place. So I think for me anyways. And that might be a little bit of a protection.

Some nurses felt compelled to put their own emotional needs aside because they believed they had to maintain their composure as their dying relative and other family members looked to them for emotional support. For some nurses, caregiving was intense and tiresome because of the emotional support their family members required. Quite often nurses found themselves answering a plethora of questions from their dying loved one and other family members. Some participants adopted their professional persona to keep their own emotions in control so they could respond to the demands of caring for their family. A critical care nurse attending to the needs of her family members believed she had to take on a professional persona in order to cope with the barrage of questions:

I think because I was a nurse, I...didn't let myself be an ordinary person. I think I stayed a nurse. It was tiring that I had to always be, this is the other side of the control coin, that I had to always be explaining things to them. I didn't really have a lot of time to think myself about, I guess, maybe that's why I wasn't so emotional. It's just a very different role...I think as a nurse I didn't let myself be as emotional as I would have been if I hadn't been a nurse.

Nurses also suspended their emotions to manage the awkwardness of providing intimate care to their family member. For example, a nurse whose mother-in-law passed away in hospital was asked by a family member to prepare her body. While assisting a

student nurse to wrap the body in a shroud, she made light of the situation, making jokes and this helped to alleviate her discomfort with the procedure. Another nurse caring for her father at home approached the provision of personal care by adopting a professional persona to cope with the task. She shared “when you do the actual care, when I was washing him and stuff, you do - you switch off the [daughter]-part and become the nurse-part to be able to do the tasks, to do the thing.”

Notably, only one nurse voiced disappointment that she was unable to address her own emotional needs and the emotional needs of her loved one as she desired. This hospice nurse believed an important part of support was to have candid discussions with her best friend about death and dying; however, her friend was not open to her attempts to talk about this. As a result, the hospice nurse left feeling like she had not had closure:

I left her in a ball, lying on a stretcher in the hall, at the hospital, knowing that I wouldn't see her again and unable to say goodbye. Like, no closure whatsoever... And yet we had another friend, very good mutual friend, the three of us were really close. And the other friend got her on either side of my time. Got her before she was in such acute pain so they had a lovely time together and she got her at the end when she ended up in hospice. So both times were softer and they did some amazing stuff together. And I really miss that opportunity.

Suspending their emotions during caregiving caused a few nurses to feel guilt and remorse. For example, a nurse who neglected his own emotional needs and focused on making everything “perfect” for his dying father, recognized in hindsight that “the only thing that would have, would have made it more perfect is if I had realized the emotional impact it would have had on me and worked a little bit more actively to manage that.” Another nurse who was focused on the “business” of caring and keeping everything running smoothly regretted she missed out on spending social time with her dying mother:

[My sister] actually did a lot of playing with Mom...They did more shopping trips. I know they went out and bought, both bought new dresses for Dad's party. So, she played more, right? And I don't think I played enough cause I was too serious. I wish I would have. If I was to change one thing I would have played more, been less serious, been less focused. Let the guard down a little bit more and played more. Advocated for her but didn't (tearful) didn't play as much. The parties and stuff that Mom was so excited about, I just couldn't get into. I was almost angry about. Just like, oh do we have to do this? Do we have to do this?...I just didn't - I was more into the business of it. The business of keeping everything organized, the medications...To her that may have been fun now that I think about it...So I didn't always get into the playful part of it.

This nurse also believed that she arrested her grieving process as a result. As her focus was on providing care for her mother and keeping things running as efficiently as possible, she neglected to address her own issues of grief and loss. When her mother died, she felt the impact of not attending to her emotional needs: "when she died, it was sort of like – *Wham!* Now what? And, realizing you hadn't even started the process even though you always knew it was comin'." In bereavement, she felt extreme exhaustion and had difficulty dealing with her mother's death.

Having delayed reactions to grief and loss was common in other participants as well. Two nurses reported they had difficulty in the bereavement period because they focused intensely on caring for their dying family member and avoided addressing their emotions during caregiving. This appeared to be associated with nurses who shouldered most of the clinical decision-making with little or no support from family members or HCPs. For example, although she had several siblings, a nurse who lived with her parents provided most of the care for her father. It was not until several months after his death that she experienced an outpouring of grief and emotions. Subsequently, she sought help from a counsellor and took an extended leave from her job to work through her grief.

Similarly, another nurse who was the sole caregiver for his father did not realize

that he placed considerable stress on himself until the day after his father's death - he experienced heart palpitations while on a morning run:

The weight of the emotions of the weeks that just really weighed heavy on me and I just felt really not running very strongly. And just emotionally I felt like I had nothing left. When I finished my run, I went home and I started having all this ectopy, all this irregular heartbeat. And it just was non-stop. And it was really irritating to have all this irregular heartbeat. And it went on for two weeks.

During the months following his father's death, this nurse also experienced overwhelming emotions. Oftentimes, his emotions were triggered while he was at work, bearing witness to his patients who were making decisions about continuing life saving measures. During these times, he did not have strength to control his emotions as he usually did at work:

I'm watching [family members] and I'm looking in their eyes and seeing the strength that they have to make that decision [to discontinue life saving measures]. And just, I just fell hard emotionally. I just couldn't take it. I would just - I'd already, I think, I burnt myself out. I didn't have any emotional reserve left to kind of pull back and be a clinical decision-maker. And so my emotions were at the front and that's what I had been preventing for all the 3 and 4 months that I looked after my Dad is that my clinical decision-making came first and my emotions came second. And I found that after losing Pop, my emotions were raw and they're right at the tip there and *anything* - I would bring up Pop and cry. I would talk to somebody and cry...if somebody lost a pet, I would cry. It was just, there was this non-stop crying festival that I just - it took weeks for it to actually calm down.

A few nurses commented on the lack of available counselling and bereavement services that met their unique needs. These nurses believed that because of their knowledge as a health care professional, their emotional needs differed from other non-nurse caregivers. One nurse suggested that having another nurse who had similar experiences of caring for a dying family member to talk to would have been more useful than a counsellor. He believed that a nurse could identify with the unique struggles because of his position as a nurse. Another nurse, who was faced with not only her own

bereavement but also the bereavement of her two teenaged children, believed that the local bereavement support group did not meet her needs. She believed that a nurse peer who had gone through a similar experience would have helped her through this difficult time.

Juggling Work and Caregiving Responsibilities

Being 'caught in the middle' also centres on the tensions nurses' experienced while juggling work and their family caregiving responsibilities. Two main sources of work related conflicts were identified: being interrupted at work to respond to family caregiving responsibilities and juggling work schedules to provide care.

Many participants reported being interrupted at work by their distressed family members who sought advice about symptom management or needed emotional support. As described earlier, oftentimes nurses found themselves giving direction to family members over the telephone, such as how to perform a care task.

Several nurses reported it was challenging to balance their work schedule to meet family caregiving demands. For some nurses it was tiresome having to constantly review their work schedule to accommodate caregiving responsibilities such as accompanying their family member to medical appointments or being available to meet with specialists in the hospital. One nurse found it challenging to juggle her work schedule to be available to relieve her mother's live-in home support workers for their break.

Most participants reported they took sick or holiday time to provide care especially during the last weeks and days near death when caregiving was required around the clock. Some nurses were hesitant to take time off work as their absence may leave co-workers short handed. They were concerned about the impact it would have on

their co-workers if they took time off especially during Christmas and summertime, as they knew covering their absences would be difficult.

Support from managers and supervisors during the caregiving varied among participants. Some nurses reported little or no support from their managers. For example, one nurse who went to another town in the province to care for his dying brother recognized that he was terminally ill with a poor prognosis. He emailed his Manager to inform her that he would be away longer than the week he had booked off work as he was the sole caregiver for his dying brother. Her response was disappointing to him: “she wrote back and said you’d better be back to work for your next shift which was 10 days away.” Similarly, a home care nurse who needed to take time off from work to be with her mother who was near death was distressed by her supervisor’s lack of support when she asked for time off:

I kind of [had] rough experiences with [my supervisor]. She had made it quite clear that – I told her that I was going to go up [to another city] to be with my Mom who was not doing well. And she made a comment that I wouldn’t get paid unless she died. I remembered that so vividly in my mind and I remembered the night my Mom died just phoning [my supervisor] and just saying, “She’s died and I will be taking the next week off.”

Conversely, several nurses reported their managers and co-workers were extremely supportive and sensitive to their needs. They felt supported when managers were flexible in allowing them to take time off work and adjust their work schedule to meet caregiving responsibilities. One nurse explained how her Manager supported her throughout her husband’s illness and after death. This manager came to the hospital to see her after husband died, stayed with her until other family members arrived, and helped provide emotional support to her young adult children. Similarly, many nurses were supported by their work peers and appreciated accommodations that were made for

them when they had to leave work to attend to family matters.

While several nurses reported work and family caregiving conflicts, only one nurse reported that the stress of family caregiving directly impacted her work performance. This nurse believed the emotional and physical strain of caring for her dying mother especially during the last weeks impacted her ability to concentrate at work.

In summary, the second theme arising from the analysis of the data highlights the tension participants experienced of being caught in the middle as a result of being both a nurse and a FCG to a dying loved one. Three dimensions of ‘caught in the middle’ were identified: conflicts with HCPs, having knowledge, and juggling paid work and family caregiving responsibilities. To provide the quality and level of care they expected of themselves, many nurses compartmentalized their emotions to maintain clarity and focus. Tensions of being ‘caught in the middle’ were also experienced as nurses’ juggled paid work and their responsibilities of caring for a dying family member. Conflicts with work included interruptions whilst at paid work to attend to family caregiving issues and juggling work schedules to meet caregiving demands. Support from work supervisors was mixed with most nurses reporting very supportive managers while a few nurses received little or no support or recognition of the demands of caring for a dying family member.

Gaining Insight

The third main theme that arose is *gaining insight*. Most participants reported that first hand experience of caring for a dying loved one provided them with many insights. This in turn honed their professional practice and made them into a “much better nurse”. Several participants found that having “walked the walk” of caring for their own dying family member gave them insight of what it is like on the “other side”. As a result, their

nursing practice changed in several ways. Nurses reported they had more patience, compassion and deeper understanding for patients and their families. As well, nurses believed that they had more legitimacy with patients and their families because of they had lived experiences of caring for a terminally ill family member. Furthermore, participants shared insights on how HCPs might provide better support for FCGs who are nurses and provided advice for nurses who are caring for dying family members.

Increased Awareness, Understanding, and Empathy

Several nurses reported they changed the way they approached patients. Some nurses believed that they provided better care to patients and their families because they were more attuned to emotional needs. One nurse believed she could be more honest and direct with her patients' families because she understood what they were going through. She learned that family members may not be at the same place in their grief and used this insight when she sensed families were having difficulty sharing their emotions.

Other nurses became more aware of the powerlessness of their patients to be heard in the midst of the busyness; they recognized the influence of their attitudes on the patient experience. For example, an Emergency Room nurse reported that prior to his caregiving experience he sometimes was insensitive and aloof as a professional and impatient with those he cared for. He believed he viewed patients as "just a number going through my department" and not as human beings. As well, he believed he was rigid and inflexible to his patients' needs as he went about with his usual ward routine for the day. After caring for his brother, he noticed he was more tolerant and took more time with patients, listening and responding to their needs, particularly their emotional needs:

The little old ladies [who were] a hassle on night shift 5 years ago were no longer a hassle on night shift...[I] catch myself at work in the emergency department with

little old ladies especially- taking more time to hear them, taking more time to understand them, taking more time to help alleviate their fears, whereas I didn't do that 5 years ago.

Other nurses believed they were more aware of how care was being provided to patients. For example, a home care nurse recalled an incident seeing her mother naked sitting on a cold bath seat as a home support worker was bathing her. Although she recognized that there was no alternatives at that time, the experience made her reflect on “the things that we [HCPs] do to people”.

Increased Legitimacy.

Several nurses also reported that their experience engendered a deeper understanding of the dire circumstances dying patients and their family members were undergoing. Several nurses reported that it was different to “live” the experience of caring for a dying family member than watching others go through similar experiences. Some nurses believed that they always sympathized with the plights of patients and families but now they could truly empathize with them. For example, one nurse believed that before her experience, she knew about the grief process but didn't understand it. Now she understood on a deeper level of the depths of anguish family members of her patients felt losing a loved one. Similarly, a hospice nurse believed her practice changed after caring for her best friend. She was more comfortable with being silence, bearing witness to a family member in grief:

My practice has changed in terms of when someone – when I see their grief, I *know* what grief is like, I *know*. So I don't have to say anything. Sometimes we try to make it all right. There's nothing, there's nothing that anyone can say. The most important thing is just be present. Don't even have to say a word. Just shut up, sit there and go – just be there with them. If that means holding hands and crying, great, then so be it.

Several nurses reported that caregiving experiences gave them insights that could

not have otherwise been gained in their training or professional practice. For example, a pediatric ICU nurse whose care extended beyond her young patients to their parents believed she became more compassionate and understanding after this experience - she learned something that she never “would have ever read it from a book”.

Some nurses believed that having cared for and experienced the death of a close family member gave them more legitimacy with patients. Prior to her experience, a home care nurse felt “bogus” when she was working with palliative patients because she “hadn’t a clue of ...what people were going through”. After the death of her mother and father, she felt more sensitive to her patients’ needs and had a better sense of what would help her patients. Likewise, another home care nurse believed that having cared for her dying father she now has a different relationship with her patients’ families. Since her father’s death, she disclosed her personal experience with a few of her patients’ family members when they were overwhelmed by what they were dealing with. As such, she believed this gave her more legitimacy with her patients’ families:

[Family members] look at you like, ‘You don’t understand do you? You don’t get it, you’re just a nurse.’ If you just stop and say, you share that moment and say, “You know, I had to go through this with my Dad.” And their whole face just relaxes and their whole body relaxes and they go, “Oh, thank God, you do understand.”...They feel like they can tell you their story, they can unload, they can debrief with you and you can debrief with them. Like you can help them get through that together because you do really get it. You’re not just sitting there giving them advice and telling them what to do, you’re actually a feeling, caring human being, who’s got that connection with them because you’ve had that experience yourself.

Supporting FCGs Who Are Nurses: Advice for HCPs

Participants also shared insights they learned from their experience that would be helpful for HCPs who are supporting a family caregiver who is a nurse. The advice to HCPs from several participants was to not assume that all nurses who care for their own

dying family members desire the same level of involvement in care. Some participants reported they wanted to be involved only as a liaison between their family and HCPs. Others shared they wanted to be the main caregiver and do all the care and expressed appreciation when HCPs were astute and sensitive to their desire to be the main decision-maker and caregiver. They found it helpful when health care professionals were available for consultation and validated that the nurse was providing appropriate care.

Some nurses did not want to provide intimate care and wanted HCPs to offer to take on those tasks. Others wanted to be more available to provide emotional support for their dying loved one and other family members. As such, several nurses advised HCPs to recognize that a nurse may be “caught in the middle” and want to be involved as a family member and not a nurse. The main advice that these nurses offered to HCPs was to take time to discuss the desired level of involvement with the nurse caregiver, assess their skill and comfort level, and provide appropriate support.

Several nurses also advised that HCPs should recognize that nurses work in a variety of clinical areas and to not assume a nurse should have the knowledge to provide palliative care. For example, a home care nurse felt challenged to care for her dying mother who was in a facility even though she was experienced in palliative care. Another nurse shared how relieved she felt when a home care professional reminded her that she was a daughter as well as a nurse: “All of a sudden I realized that I didn’t have to be the nurse! So it let me ‘off the hook’ so to speak, of guilt.” This simple acknowledgement seemed to relieve this nurse of the burden of feeling like she had to be the expert and expectation to provide care to her father.

Finally, participants also advised that nurses take time to care for themselves, as

caregiving is extremely exhausting. These participants urged nurses in similar situations to not “take it all on your own” and encouraged nurses to share caregiving responsibilities with other family members. This may mean letting go of feeling like they should be the expert and be open to ask for help from the formal system as one nurse articulated:

If you have to shut everybody else out and say, “I’m going to do this all by myself. I have to, it’s my duty”, you do your loved one a great disservice because in the event of something happening to your...you don’t have anything in place to help and people are scrambling.

In summary, participants reported their professional practice was enhanced by their family caregiving experience. Many nurses shared their experiences engendered deeper compassion and understanding and empathy for patients and their family members. In particular, nurses believed they understand more fully the nature of grief and how this has increased awareness and sensitivity in the professional practice. As well, several nurses believed their personal caregiving experience gave them more legitimacy with family members of their palliative patients.

Participants also shared learning gained from their experience that they believed would benefit HCPs who are supporting FCGs who are nurses. They encouraged HCPs to determine nurses’ desired level of involvement in care and advised nurses who are caring for dying family members to be kind to themselves, not to “do it all alone”, and ask for help from other relatives and HCPs.

Summary of Findings

This study explored the experiences of nurses caring for a dying family member. Three main themes were identified: knowing the ropes, caught in the middle, and gaining insight. All participants reported their nursing role, knowledge, and affiliations were beneficial to their palliative family caregiving role. Knowledge of and having

connections with the health care system allowed participants obtain access to privileged medical information and services. Participants believed they were better able to provide palliative care to their family member because they had nursing knowledge and experience. However, having medical and nursing knowledge was at times problematic for some participants. Knowing the diagnosis and prognosis ahead of their dying loved one and other family members placed nurses in dilemmas of whether or when they should disclose the information to others. This was an awkward and isolating position for some nurses because they believed other family members perceived them as being negative.

Having extensive knowledge of health and medical care, participants reported they had expectations of the care they and others provided. Nurses believed they needed to be vigilant in ensuring their family member received appropriate care. Some nurses also expected themselves to be the “expert” and reported feelings of guilt and inadequacy when they lacked the knowledge to provide aspects of care. In order to make sound clinical decisions and provide intimate care, several nurses reported suspending their emotions. Consequences of compartmentalizing emotions included guilt and remorse, ill health, and delayed grief reactions.

Nurses also reported caregiving conflicted with other family and work responsibilities. Conflicts with work included interruptions whilst at paid work to attend to family caregiving issues and juggling work schedules to meet caregiving demands. In addition, nurses reported their professional practice was honed by their experience of caring for a dying family member. Nurses believed they had more patience and had deeper compassion and understanding of the palliative experience. Participants also advised palliative care professionals who are in positions of supporting FCGs who are

nurses to not assume all nurse desire the same level of involvement in care. As well, participants encouraged nurses who are caring for or may be caring for a dying family member to take care of themselves and to not “do it all alone” but to involve other family members and ask for help from HCPs.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

Introduction

Research in palliative family caregiving has expanded significantly over the past decade. However, there is a dearth of studies focused on the experiences of FCGs who also provide care in their professional role. The primary purpose of this study was to explore registered nurses' experience of caring for a dying family member. Three major themes arose from the data analysis: knowing the ropes; being caught in the middle; and gaining insight.

Findings from this study suggest that nurses face similar challenges caring for a dying family member as other palliative FCGs and similar yet differing experiences from nurses who care for dependent children and chronically ill or elderly relatives. However, there are unique tensions associated with being a health care professional caring for a dying family member. The experience of registered nurses differed from other FCGs because the nurses had baseline nursing knowledge and connections with the health care system. Whilst nurses benefited from their knowledge of the health care system, medicine, and nursing care, these factors were also burdens and challenges for nurses.

In this chapter, I will focus on two significant aspects of the findings from this study. First, I will discuss the nature of having health care knowledge and how it influenced the nurses' experiences as they cared for dying family members. Second, I discuss the tensions nurses experienced as they mediated the boundaries between their professional and personal experiences. In addition, I outline the limitations of this study and the implications arising from the findings. Finally, I will provide a summary of the

study including conclusions drawn from the findings.

Significance of the Study

Influence of Knowledge

In this study, the findings suggest that having prior knowledge of palliative nursing care connection with the health care system influenced nurses' experiences of caring for a dying family member. Knowledge was aptly described by one participant as a "double-edged sword": while having knowledge was seen as beneficial to the care they provided to their family member, at the same time it was also a major burden and a source of tension for most participants.

In terms of the benefits of having knowledge, nurses were grateful they had the knowledge and skills to provide care. They were able to facilitate the needs and wishes of their family member, better advocate for appropriate care from HCPs, and provide timely response to pain and other distressing symptoms. Nurses also used their knowledge and skills to assess their family member's health status and make clinical decisions. Similar to a British study of nurses providing care for family members with a life threatening illness by Mills and Aubeeluck (2006), nurses in this study voiced confidence in providing emotional care to their family members and a sense of control knowing they had the skills and ability to provide care.

These same benefits however were also burdensome for nurses in several ways. First, knowing the prognosis of illness and signs of impending death before other family members while beneficial, was burdensome as nurses experienced tensions about whether or not to disclose this information. Second, while having nursing knowledge was extremely beneficial, nurses placed high demands on themselves to provide all aspects of

care and to do it perfectly. Third, because of the baseline knowledge they possessed, nurses had expectations of the care that health care professionals provided to their dying family members. I will discuss each of these three elements in the following section.

Knowing Ahead.

Having knowledge about poor prognosis before their dying loved one and other family members impacted nurses' experiences both positively and negatively. While knowing what was to come before other family members allowed nurses to prepare themselves, their dying loved one, and other family members for the inevitability of eventual deterioration and death, nurses faced the burden of deciding whether or not to disclose this information to other family members. When nurses did choose to disclose, this created conflict in some situations as nurses felt other family members viewed them as being negative for giving up hope. Some nurses were met with anger and antagonism from other family members when they did share "bad news".

Having knowledge of what was to come also created internal conflict for nurses as they themselves struggled with maintaining optimism for the future. This finding confirms results in the above mentioned study by Mills and Aubeeluck (2006) in which nurses caring for family members with a life threatening illness struggled with whether or not to share this information with other family members. In my study, nurses also hesitated disclosing their knowledge of prognosis to their dying family member, fearing the member would lose hope if they knew. The findings reveal that nurses felt isolated not having another family member to share their own fears and burden. Some nurses did not disclose information to other family members, recognizing they needed time to come to terms with prognosis and as such were not able to relieve their own emotional burden.

There is considerable evidence in palliative care literature that having social and emotional support is a significant factor in how well FCGs cope with their role and also in their health and well being (Cantwell et al., 2000; Maida, 2002; Proot et al., 2003; Perreault et al., 2004; Stajduhar et al., 2008; Strang & Koop, 2003; Visser et al., 2004; Zapart et al., 2007). It is possible that the lack of emotional support provided to some nurses in this study may have negatively influenced their health and bereavement.

Expectations of Self.

This dichotomous nature of knowledge was also reflected in the expectations nurses had of themselves. Nurses in this study felt that they had advantages over non-nurses because they had knowledge and experience from their professional practice. However, having this knowledge produced expectations of the quality of care provided by themselves and other HCPs. This finding is supported by other studies of nurses caring for elderly relatives (Ward-Griffin, 2004), and other ill family members (Mills & Aubeeluck, 2006). Nurses in Ward Griffin's study found it difficult to be the "nurse" for their frail elderly family members, feeling they had no choice but to provide care because they were the "nurse in the family" and they felt HCPs expected them to participate in care. In contrast, similar to findings from Mills and Aubeeluck's research, in my study most participants found it difficult *not* to be the "nurse". In my study, participants reported they preferred being in a nurse role as it was a comfortable place and they felt a sense of control; in Mills and Aubeeluck's study, nurses were frustrated by their inability to separate the two identities of family member and nurse.

This study confirms previous research on nurses caring for dependent children and ill elderly family members (Mills & Aubeeluck, 2006; Ross et al., 1994; Ward

Griffin, 2004) that nurses caring for their own family members have high expectations of themselves, which may serve to the nurses' disadvantage. Findings from this study revealed that nurses had a high ethic of care and expectations to be the 'expert' while at the same time experienced guilt and anxiety when they did not have the knowledge they needed. As in their professional practice, nurses wanted to be prepared for any care needs and this put considerable pressure on them to "stay ahead of the game." When they didn't have the necessary knowledge, they had feelings of inadequacy and stress because they felt that they should know. This finding is supported by nurses in Ward Griffin's (2004) study of nurses caring for elderly relatives who reported tremendous guilt when they lacked knowledge and skills required for care, particularly if they perceived this contributed to the deterioration of their family member's health. In addition, the self-expectations of nurses that they have the knowledge and skills to provide all aspects of care is reflected in other studies (Mills & Aubeeluck, 2006; Ross et al., 1994). Nurses in these studies also voiced feelings of guilt, distress, and inadequacy when they did not have the necessary knowledge and skills to provide required care and when they felt they made poor clinical decisions.

Also, in regards to information needs, findings from this study show that nurses caring for a dying family member also have knowledge gaps regarding care and may have difficulty expressing their information needs. This is similar in other studies of palliative FCGs (Dunbrack, 2005, Stajduhar et al., 2008; Zapart et al., 2007), however, the level of information needed is different for nurses. For example, FCGs in other studies reported they depended on health care professionals to teach them how to provide basic care and symptom management (Dunbrack; Lowey, 2008; Stajduhar et al; Visser,

2004; Waldrop et al., 2005; Zapart et al.). In my study, nurses did not need information on how to provide basic care but they sometimes required information about complex symptom management, especially if they had little or no professional experience in the palliative care field.

Expectations of HCPs.

The findings reveal nurses drew on their professional knowledge to determine the appropriateness of medical intervention and nursing care. Many participants had witnessed the detrimental effects of providing futile treatments. Having this knowledge and experience, nurses felt better able to advocate for appropriate care for their dying family member. However, because nurses knew what could and should be done, they had certain expectations of HCPs to provide appropriate care and this sometimes created conflicts with HCPs. Other studies show that FCGs also have conflict with HCPs centred on the provision of care (Hudson, 2004; Stajduhar et al., 2008; Strang & Koop, 2003). However, the source of conflict with HCPs in this study of nurses providing palliative care to their own family member was unique. Some nurses believed they had more points of conflict with HCPs about the care provided than FCGs who did not have the same level of knowledge because they knew what could and should be done. In particular, nurses had conflicts with HCPs when they had difficulty advocating for appropriate symptom management or for discontinuing futile treatments. Lack of success in advocating for appropriate and timely care was extremely stressful and frustrating for nurses.

Mediating Professional and Personal Boundaries

Much of the literature on the experience of nurses as FCGs highlights the issue of negotiating the boundaries between personal and professional roles (Mills & Aubeeluck,

2006; Ross et al., 1994; Ward Griffin, 2004). These studies reveal that nurses experience tension when there were conflicts between the responsibilities of their paid work and family caregiving demands (Ross et al., 1994), when they felt obligations to provide competent nursing care (Ward Griffin, 2004), and when they wrestled with using their professional status to obtain information about their family member (Mills & Aubeeluck, 2006).

The data from this study supports the notion of mediating tensions between professional and personal caregiving roles found in other studies of nurses as FCGs. Because nurses played a significant part in the care of their dying family member, the complexity of mediating professional and personal boundaries appeared more pronounced. Nurses experienced role conflicts in two ways: negotiating between their role as a nurse and family member, and between their role as a member of the health care team and family member. Both positive and negative outcomes of dual caregiving roles were identified in this study.

Being a Nurse.

The findings from this study suggest that professional and personal boundaries of nurses caring for a dying family member are extremely blurred. Moreover, it appears that the roles of professional nurse and FCG are not viewed as separate entities but on the contrary as inexplicably interwoven. Many nurses in this study found it difficult to step out of their nurse role and be the family member; they tended to provide care as they would in their professional role. Some nurses felt that they needed to compartmentalize their feelings in order to distance themselves from the emotional aspects of bearing witness to a dying family member and to carry out stressful activities such as sharing bad

news, providing emotional support, and providing intimate care. Participants also put their emotions aside in order to maintain objectivity and clarity to make clinical decisions, and to avoid being overwhelmed. Several participants feared that if they allowed their emotions to surface, they may not be able to provide the quality and level of care they believe that their dying family member needed.

Putting emotional needs aside in order to provide care is also found in studies of palliative FCGs (Osse et al., 2006; Zapart et al., 2007) and in studies of nurses in their professional role (Georges, Grypdonck & De Casterle, 2002; Ward Griffin, 2004). Zapart et al.'s study revealed that FCGs neglected their own emotional well being because of the time demands of caregiving. Nurses in Ward Griffin's (2004) study reported difficulty in providing care because of their emotional attachment to their family member. Nurses in that same study also believed that they could not adequately provide care if they became too emotionally attached to their patients. Similarly, Georges and associates' study of nurses working in an acute care setting in Belgium demonstrates that nurses preferred a detached attitude in order to focus on problems and tasks they had to perform.

The findings of my study confirms previous research in terms of how nurses emotionally detached themselves while providing care to their dying family member. This study also demonstrates that suspending emotions may lead to negative outcomes such as regret and remorse, ill health, and significant emotional disturbances after the death of their family member. Nurses reported delayed reactions to grief and loss as well as emotional difficulties in the bereavement period. Some nurses associated this to their intense focus on caring for their dying family member and to their emotional detachment during caregiving. This appeared to be associated with nurses who were the main

caregiver shouldering the brunt of clinical decision-making with little or no support from family members or HCPs.

Being Part of the Health Care Team.

The findings from this study demonstrate the benefits for nurses with knowing about and being part of the health care system. As such, they were able to navigate the health care system and use their professional contacts to access better care for their family member. Nurses used their professional contacts to access information. Since they were familiar with the language and culture of health care and with their professional connections, they were in a better position to advocate and care for their dying family member. However, the findings also suggest that nurses experienced the tension of being “caught in the middle” since they were both part of the health care team and a FCG. Several participants felt they easily established rapport and collegial relationships with HCPs caring for the family member because of their association with the health care system because they understood workload and organizational pressures faced by nurses and other HCPs. The tensions experienced by nurses related to their association with the health care system is corroborated in other studies which reveal the distress nurses experience when HCPs discuss their family member’s care with them as if they were in their professional role (Mills & Aubeeluck, 2006; Ward-Griffin, 2004).

My study builds onto this work by demonstrating the “push and pull” nurses experienced with wanting to advocate for their family member especially knowing from their professional position the difficulties of being faced with an angry family member. As well, this study highlights the ethical tension experienced by some nurses who in their efforts to advocate for health care services for their family member and provide symptom

relief, chose to break rules and overstep professional boundaries. A few nurses believed they were entitled to having privileged access to health services because of their association and connection with the health care system. Others were aware of the professional and ethical implications of their actions but rationalized the need to overstep boundaries to provide symptom relief and comfort and ease the emotional turmoil for other family members watching their loved one. This conflict may have contributed to the burden experienced by nurses in their family caregiving role.

Outcomes.

Research reveals that the emotional strain experienced by family members who are bearing witness to the physical and emotional suffering of their dying loved one is further compounded by the stressors of caregiving (Hudson, 2004; Ward Griffin, 2004). FCGs in Hudson's (2004) study found it difficult to observe the deterioration of the family member. Similarly, nurses caring for frail elderly family members in Ward Griffin's (2004) study experienced feelings of distress watching the deterioration of their loved one. In my study, nurses also reported they did not attend to their own emotional needs because they were intensely focused on caring for the dying family member. As such, after their loved one died, they report having extreme physical and emotional reactions. A few nurses reported they experienced an emotional breakdown several months following the death of their family member.

Several studies identify negative outcomes associated with nurses caring for and bearing witness to the suffering of seriously ill and dying patients (Dickerson et al., 2007; Vachon, 2007). As well, nurses constantly deal with life and death issues and grief associated with exposure to multiple deaths in their professional work (Georges et al.,

2002; Sherman, 2004). Findings from my study corroborate studies of nurses caring for an ill and elderly family member and those with a life threatening illness. These studies demonstrate negative outcomes such as ill health (Gottlieb et al., 1996) and emotional stress (Ross et al., 1994; Scott et al., 2006; Walters et al., 1996) as a result of providing care in dual roles: professionally and personally. Nurses in my study also reported ill health and emotional disturbances particularly after the death of their family member. This study also highlights how providing dual care has the potential for nurses' ill health, stress and burnout in the bereavement period.

In summary, this study highlights the uniqueness of the experience of nurses caring for a dying family member. The experience for nurses is unique because of their baseline knowledge and connections with the health care system. This study also highlights the uniqueness of the experience caring for a dying family member as opposed to caring for dependent children and chronically ill loved ones. As a result, the supportive needs for nurses may be different from non-nurse palliative FCGs and nurses in other family caregiving roles.

Limitations of the Study

The limitations of this study must be taken into account when interpreting the conclusions drawn from this study. While the relatively small sample size allowed for rich descriptions and insights into the phenomenon under investigation, the legitimacy of generalizing the findings is limited.

Implications of the Study

The findings from this study highlight the needs and challenges of nurses who care for a dying family member. Moreover, the findings suggest that lack of support from

the formal health care system may compound the stress of caregiving for nurses and may lead to health problems. In this section I highlight implications in five areas: practice, health care organizations, policy and program development, education, and research.

Implications for Practice

From the findings of this study, it is evident that nurses who provide care for a dying family member have unique needs. As such, the HCPs who are involved with FCGs can provide support in a number of ways that will address the specific needs of nurses. It is imperative that HCPs not assume that every nurse desires the same level of involvement in the care of their family member. Nurses may want to provide all aspects of care with incidental support and consultation with HCPs, provide only the care they are familiar and comfortable providing, or have little or no involvement in care. HCPs are advised to initiate discussions with nurse FCGs regarding their desired level of involvement at the beginning of their encounter. As well, HCPs should recognize that the desired level of involvement may be dependent on factors such as the care needs of the patient, other family responsibilities, and emotional and physical health of the nurse FCG, and may change over time. In addition, HCPs should respect the nurse's choice regarding involvement in care and provide support according to the nurse's wishes. For example, nurses wanting a high level of involvement should be supported to maintain as much control over clinical decision making as they desire. Moreover, HCPs should not usurp control by taking over care without consultation with the nurse. As well, it is imperative that HCPs provide timely response to calls for help from FCGs who are nurses, be available for consultation, and not abandon nurse caregivers because they have the knowledge and skills to provide care.

It would be beneficial for HCPs to recognize that nurses who are palliative FCGs may have high expectations of themselves to provide care to their families. Furthermore, many nurses unknowingly expect themselves to be the expert in providing care. Strategies might include helping the nurse recognize his/her own expectations and limitations and acknowledging the nurse's role as a family member. As well, regular assessments of the nurse's emotional needs and ability to cope is important to address potential problems before they arise. HCPs can assess and identify the emotional needs of nurses and facilitate access to appropriate peer and formal counseling supports.

The findings also revealed that several nurses were very cautious in how they communicated to HCPs. Some nurses hesitated to strongly advocate for their family member because of they could identify with HCPs, knowing what it was like being faced with angry FCGs. As such, HCPs can facilitate open and honest communication with nurses who are FCGs. As well, incorporating collaborative provider/caregiver models of care would be supportive for all FCGs including nurse FCGs.

Implications for Health Care Organizations

Implications for health care organizations also arise from findings in this study, in both policy and human resource areas. This study and others (Aranda & Hayman-White, 2001; Axelsson & Sjöden, 1998; Perreault et al., 2004; Stetz & Brown, 2004; Zapart et al., 2007) demonstrate that FCGs of the dying can suffer from physical and emotion strain. Findings from this study suggest that nurses' emotional health may be complicated when they for a dying family member. Health care organizations can ensure appropriate resources are available to meet the unique needs of nurses. For example, increasing the availability of social workers and counsellors skilled in addressing the emotional needs of

FCGs who are nurses would be a supportive resource. In particular, there is a need for these resources to be available around the clock in acute care settings where care is provided 24 hours a day, seven days a week. As well, counselling and bereavement programs could be expanded to include peer counseling resources that would better support nurses who are caring for a terminally ill family member.

In this study, nurses reported a range of support from their supervisors. Some nurses received overwhelming support from their supervisors while others reported little or no support. Supportive measures identified included: supervisors who took time to make a supportive phone call or visit to the nurse, especially around the time of death, being flexible in authorizing time off, and allowing nurses to adjust their schedules to meet caregiving demands. Health care organizations can better support nurses by incorporating policies that reflect flexibility for staff who are providing informal care so that employees can adjust their work schedules to meet family caregiving demands.

Implications for Policy and Program Development

Findings from this study demonstrate the growing complexity of care provided in the home by FCGs. In view of financial cutbacks, more nursing care is being off loaded to FCGs. As well, the care home FCGs are asked to do is increasing in complexity which in turn increases the stress of palliative caregiving (CHPCA, 2004; Hauser & Kramer, 2004).

Policy and program development at local, provincial and national levels could be considered to better support FCGs, in particular FCGs who are nurses. On a local and provincial level, policies related to the allotment of home support hours could be reviewed to ensure that FCGs are not obligated to provide care because of a lack of

formal supports. Often these policies limit the number of home support hours based on a gerontological population but do not address the needs of palliative patients may who require around-the-clock care, especially during the weeks and days leading up to death.

Nationally, in Canada, there is an employment insurance program (Service Canada Employment Insurance (EI) Compassionate Care Benefits) that provides funding for employed FCGs who care for critically ill family members. Although it enhances support for employed caregivers, the funding has restrictive eligibility criteria and a wait time before resources can be accessed. Often, it is difficult to predict when these resources would be most needed and therefore may not be available in a timely manner. National policy makers could broaden the criteria for eligibility, decrease wait times, and make the application process less bureaucratic.

Implications for Health Education

There needs to be stronger emphasis in nursing and other HCPs curricula, orientation of new staff, and continuing education focused on the challenges experienced by palliative FCGs. Curricula could include information and care needs of palliative FCGs, the development of effective and sensitive communication skills, and strategies to support FCGs through the dying phase such as empowering the family. As well, curricula could include examination and recognition of power imbalances between FCGs with emphasis on the importance of developing collegial relationships with FCGs. Furthermore, students and staff should be encouraged to reflect on their own beliefs and values about death and dying and to recognize its influence on therapeutic relationships with FCGs. For example, HCPs may have preconceived ideas about what constitutes a “good” death versus a “bad” death and this may influence their care and interactions with

patients and their FCGs.

Implications for Further Research

This study is unique in its exploration of the experiences of nurses providing care to a dying family member. As such, there are many ways for this phenomenon to be more fully understood in relation to family caregiving and to HCPs as FCGs. For example, understanding the experience of nurses caring for a dying family member from the perspectives of HCPs who are supporting nurse FCGs would provide a comprehensive picture of this phenomenon.

In relation to FCGs and the role of nurses as FCGs, further research is needed in areas such as examining nurses' self expectations of providing a high quality and intensity of care. Potential questions could include: what are factors influencing self expectations? Is this a learned response from nurses' professional practice? Examining the ramifications of self-expectations will help to better understand caregiver burden and mitigate its impact.

In this study, nurse FCGs voiced that although they benefited from having prior knowledge of and connections with the health care system, being part of the system created tension for them. Challenges included conflicts with HCPs particularly when nurses felt HCPs did not listen to them or took over control of care. Further research is needed to explore the communication between HCPs and family members who are nurses from the perspective of HCPs. Questions concerning HCPs relationships with family members who are nurses could include: did having a peer-like relationship with a FCG change the dynamics of the relationship for HCPs? How do HCPs view FCGs who are peers who may have more knowledge and experience than they do? Did they have

different expectations of nurse FCGs than non-nurse FCGs? Did this change their practice in terms of providing more or less information and care to FCGs who are nurses? Exploring these questions further with HCPs would augment current literature on client-nurse relationships (Oudshoorn, Ward-Griffin & McWilliam, 2007; Ward Griffin & McKeever, 2000) and nurse-FCG relationships (Ward Griffin, 2004).

This study highlighted several negative outcomes for nurses as a result of providing care to a dying family member. Findings support other studies (Gottlieb et al., 1996; Mills & Aubeeluck, 2006; Ross et al., 1994; Scott et al., 2006; Walters et al., 1996), which show negative outcomes of dual caregiving roles. However, there is a lack of literature focused on nurses who are exposed to death on a frequent basis, such as those working in critical care and palliative care areas and who simultaneously are providing care to dying family members. Understanding the phenomenon of palliative care nurses providing care to a dying family member would help to identify potential outcomes such as compassion fatigue.

The findings from this study also highlight how nurses distanced themselves from emotional aspects of bearing witness to a dying family member in order to maintain objectivity that was necessary to make clinical decisions and to avoid being overwhelmed. Further research is needed to explore the phenomenon of suspending emotions in both professional and personal caregiving roles: how this protective measure is learned? In addition, how does suspending emotions impact caring? Does enhance or impede care and compassion?

It is known that the greatest impact of family caregiving is on the female gender as women comprise the majority of caregivers (Morris, 2004; Scott et al., 2006). As well,

research shows that employed female caregivers provide more family caregiving and report higher levels of stress than their employed male counterparts (Scott, Hwang & Rogers, 2006; Walters et al., 1996). As such, further research examining the experiences of female nurses and other female HCPs caring for a dying family member from a critical social or feminist lens could be conducted to fully understand FCGs from a gender perspective. As well, focusing on the experiences of male nurses in both professional and personal caregiving situations would further our understanding of the gendered nature of caring and nurturing.

Finally, further research exploring the influence of personal experiences on professional practice is warranted. In this study, all participants reported gaining insight into their professional caregiving roles from their personal experiences of caring for a dying family member. Further research is needed to explore how poignant personal experiences, such as caring for a dying loved one, influences and impacts the caring and compassion in professional roles. This knowledge would augment HCPs' understanding of how personal experiences may influence professional caring relationships.

Summary

This study was designed to explore the experiences of nurses who cared for a dying family member. The study design chosen was an exploratory, descriptive, qualitative methodology informed by ethnographic principles. Fourteen nurses were recruited and data collection was achieved through individual face-to-face interviews. Analysis of the data provided rich descriptions of their experiences of caring for a dying family member. Three main themes were identified: knowing the ropes, caught in the middle, and gaining insights.

The first theme, *knowing the ropes*, revealed the assets nurses brought to their family caregiving experience from their professional background. *Knowing the ropes* referred to knowing about and having connections with the health care system and having nursing knowledge. The second theme, *caught in the middle* highlights the tensions nurses faced as they negotiated their professional and personal boundaries. Findings revealed the dichotomous nature of having nursing knowledge. While seen as extremely beneficial, having knowledge placed a burden on nurses to provide a high quality of care to meet the needs and wishes of their dying loved one and other family members. As a result, several participants reported health issues and emotional difficulties following the death of their family members. Finally, the third theme, *gaining insight*, describes the insights gleaned from caring for a dying family member. Through their experiences, nurses gained perspectives from a FCG point of view, which in turn changed their professional practice. Nurses reported increased awareness, understanding, and empathy for patients and their families. As well, nurses believed that they had more legitimacy with patients and their families because they had “walked the walk”.

Conclusion

The findings from this study contribute to the current state of knowledge about palliative FCGs and to the growing body of knowledge of nurses who are in dual roles of being both professional and personal caregivers. As well, the study findings add to the gap in knowledge related to the experience of nurses caring for a dying family member. Although some of the experiences of nurses are also found in literature on palliative caregiving, this study uncovered some needs that are unique to nurses. In particular, the uniqueness of the experience for nurses was associated with having baseline nursing

knowledge and connections with health care system. Based on the findings, the following conclusions are made:

1. Nurses' experiences of caring for a dying family member is influenced by their prior knowledge of palliative nursing care and the health care system and their connection with the health care system.
2. Nurses caring for a dying family member have unique needs and require support in their family caregiving role although they may be reluctant to disclose their needs.
3. Nurses may not identify their own gaps in knowledge and/or HCPs may assume nurses have knowledge, therefore nurses may miss receiving information they need.
4. Nurses may feel obligated to provide care because of their professional background.
5. Not all nurses desire the same level of involvement in caring for their family member
6. Nurses may compartmentalize their emotions in order to keep focused on the task of providing care and may suffer physical and emotional consequences in bereavement.
7. Nurses' experiences with caring for a dying family member provides them with insight into patients and their families' experiences, which in turn can benefit their professional practice.

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APPENDIX A

INVITATION POSTER / ADVERTISEMENT OF STUDY

RNs

I am a registered nurse with a background in palliative care and a student in a Master's program in the School of Nursing at the University of Victoria. I am initiating my thesis research project to learn about the experiences of nurses who have cared for their own dying family member.

I am looking for RNs who have lost a loved one at least 1 but not more than 5 years ago, to volunteer to be interviewed about their experiences. Face-to-face interviews will be scheduled at a mutually convenient time.

If interested, please contact me:
Brenda S. Lee, RN, MN (Cand.)
(Phone)
(Email)

APPENDIX B

Registered Nurses' Experience of Caring for a Dying Family Member

LETTER OF INVITATION TO PARTICIPATE

Dear Colleague,

I am a registered nurse with a background in palliative care and a Master's student in the School of Nursing at the University of Victoria. I am initiating my thesis research project to learn about registered nurses (RNs) and their personal caregiving experiences. Specifically, I am interested in examining the personal caregiving experiences of RNs who have cared for a dying family member. I anticipate that the results of my study will enhance our understanding of family caregiving experiences.

I am seeking RNs to volunteer to be interviewed about their caregiving experiences. Nurses who have lost a loved one at least 1 but not more than 5 years ago will be considered for participation.

Not all nurses who volunteer will be chosen for the study. I would also like to include a diverse sample of RNs. For example, I would like to interview both male and female nurses, experienced and novice nurses, and nurses who are administrators and those who provide direct care. I am hoping that this diverse sampling will allow for a great in-depth understanding of the caregiving experience for nurses.

The face-to-face interview will last about 1 to 1.5 hours and will be scheduled at a mutually convenient time. The interview will be audiotaped and transcribed by a paid transcriptionist or myself. At the time of the interview, I will also be asking other information such as age, relationship to the family member, area of professional practice, and length of nursing experience. This information will be used to describe the sample of nurses I interview and used to highlight variations in perception and experiences among the diverse group of participants. Following the interview, with permission, I may contact participants by phone to clarify information shared during the interview.

With permission from the participant, I may also want to conduct a second interview to ensure that I am capturing all participants' experiences correctly and make modifications based on their thoughts and suggestions. I anticipate that the 2nd interview will be less than ½ hour in length and will be conducted either face-to-face or by phone.

Participation in this study is entirely voluntary. Participants are free to refuse to answer any questions and may request at anytime that recorded information be erased or notes destroyed. As well, they are free to withdraw from the study at any time. I will ask permission to use any data collected to date. The participant may ask for any information shared or notes taken to be destroyed.

A signed consent form for each participant will be obtained. Confidentiality will be attended to by assigning a code number or letter to each participant, which will be used

on any interview notes, data collection tools, and transcribed data. Participants' names will not appear in any transcription. Nor will any interview material (e.g. tapes, observational notes, and transcriptions) be made available to anyone other than my Thesis Committee and myself. Interview materials will be kept secured and only accessed by my Thesis Committee or myself. In addition, anonymity of all participants will be attended to by ensuring any biographical details are altered as necessary in published and unpublished work to mask identifying characteristics. All of the information that shared will be used for purposes of this thesis research, future publications and presentations, and for future research I might do. Information will be destroyed once the work is complete. Follow-up summaries of the study results will be offered to all participants once it is complete.

Participation in this study will be an important contribution in helping to advocate for improved services and support for family caregivers who are nurses. If you are interested in finding out more about the study or would like to discuss your participation, please contact me by phone at (number) or by email (address).

Thank you.

Sincerely,

Brenda S. Lee, RN, MN (Cand.)
Student, University of Victoria, School of Nursing

Thesis Supervisor: Dr. Kelli Stajduhar

APPENDIX C

Registered Nurses' Experience of Caring for a Dying Family Member

SCRIPT FOR INITIAL PHONE CONTACT

Thank you for your interest in my research project. This research is a part of the requirements of my Master's program in the School of Nursing at the University of Victoria. I am interested in learning about the personal experiences of RNs who have cared for a dying family member. I'd like to tell a bit about the study and what it entails so you will have the information you need to decide if you would like to participate. As well, we can determine if you meet the criteria for the study.

Not everyone who is interested in participating will be interviewed. RNs who have lost a loved one at least 1 but not more than 5 years ago will be considered for participation. I am also looking for a diverse sample of RNs. For example, I would like to interview both male and female nurses, experienced and novice nurses, nurses who are administrators and those who provide direct care. I am hoping that this diverse sampling will allow for a great in-depth understanding of the caregiving experience for nurses. I will select participants if they fit the main criteria (RNs, cared for a dying family member, bereaved for more than one year but less than 5 years). As well, I will be selecting participants who are diverse ages, nursing backgrounds/length of experience, and gender etc. (Other criteria include: English speaking and live in the Victoria area.)

I would like to conduct at least one face-to-face interview with each participant. The interview will last about 1 to 1.5 hours and will be scheduled at a mutually convenient time. The interview will be audiotaped. At the time of the interview, I will also be asking for and recording other information such as age, relationship to the family member, area of professional practice, and length of nursing experience. This information will be used to describe the sample of nurses I interview and used to highlight variations in perception and experiences among the diverse group of participants.

During the interview I will be jotting down my observations and notes about the information shared. These notes will be used to cue me to ask for clarification later in the interview or to jog my memory as I review the audiotape. Following the interview, with permission, I may contact participants by phone to clarify information shared during the interview.

If the participant is agreeable, I may also want to conduct a 2nd interview to ensure that I am capturing perceptions and experiences correctly and make modifications based on participants' thoughts and suggestions. I anticipate that the 2nd interview will be less than ½ hour in length and will be conducted either face-to-face or by phone.

A hired transcriptionist or I will transcribe the audiotaped interview. All hired transcriptionists will be asked to sign a confidentiality agreement. At the time of the interview, I will provide participants with a copy of this agreement. A printed and an electronic copy of the interview will be produced and used for analysis.

I must obtain a signed consent form for every nurse I interview. Confidentiality will be attended to by assigning a code number or letter to each participant, which will be used on any interview notes, data collection tools, and transcribed data. Participants' names will not appear in any transcription. Nor will any interview material (e.g. tapes, observational notes, and transcriptions) be made available to anyone other than my Thesis Committee and myself. Interview materials will be kept secured and only accessed by my Thesis Committee or myself. In addition, anonymity of all participants will be attended to by ensuring any biographical details are altered as necessary in published and unpublished work to mask identifying characteristics. All of the information that is shared will be used for purposes of this thesis research, future publications and presentations, and for future research I might do. Information will be destroyed once the work is complete. Follow-up summaries of the study results will be offered to all participants once it is complete.

All of the information that is shared with me will be used only for purposes of this thesis research, future publications and presentations, and will be destroyed once the work is complete. A summary of the study findings will be offered to all participants once it is complete.

Participation in this study is entirely voluntary. You are free to refuse to answer any questions and may request at anytime that recorded information be erased or notes destroyed. As well, you are free to withdraw from the study at any time. I will ask permission to use any data collected to date. You may ask for any information shared or notes taken to be destroyed.

Do you have any questions about the study? About what will happen if you participate in the study?

I would like to go over the criteria for participant selection again.

Are you a RN?

Have you provided care to a dying family member?

When did your caregiving experience take place? (January 2002 to January 2007)

Do you live in Victoria?

How long have you been a RN?

What was your professional nursing role during your caregiving experience?

If selected:

Do you understand what your involvement in the study will be? Do you have any questions about the study?

Arrange interview time & location

APPENDIX D

DEMOGRAPHIC DATA COLLECTION SHEET

Code Number: _____

1. Gender: M F

2. Age: 19-24 ____
 25-30 ____
 31-35 ____
 36-40 ____
 41-45 ____
 46-50 ____
 51-55 ____
 51-55 ____
 55-60 ____
 60+ ____

3. Caregiver relationship to dying person

Friend Partner Spouse

Parent —▶ Mother Father

Sibling —▶ Sister Brother

Adult Child ▶ Daughter Son

In-Law —▶ Daughter Son
 —▶ Mother Father

Other: _____

4. Diagnosis of dying person: _____

5. Status of residence at time of caregiving

Shared the same household as the dying family member

Lived independently —▶ Reside in Victoria
 —▶ Live outside Victoria but moved to provide care

6. Location of death

Home Acute Care LTC Facility Hospice

Other: _____

7. Date/Year family member died: _____
8. Length of informal caregiving experience
9. Number of years bereaved, years of nursing experience, and area of professional practice during caregiving experience.

Professional Demographics

10. Number of years of Registered Nursing experience: ____

11. Level of education

- Nursing Diploma
- Baccalaureate
- Masters
- PhD

12. Employment status at time of caregiving experience

- Unemployed
- Employed full-time
- Employed part-time
- Self Employed

13. Area of professional practice during caregiving experience

- Home Care Acute Care LTC Facility Hospice
- Other: _____

14. Role of Employment during caregiving experience

- Direct Care Manager Administrator
- Other: _____

APPENDIX E

Registered Nurses' Experience of Caring for a Dying Family Member

**Researcher: Brenda S. Lee, RN, MN (Cand.)
Student, University of Victoria, School of Nursing**

Thesis Supervisor: Dr. Kelli Stajduhar

CONSENT TO PARTICIPATE

You are invited to participate in this research study entitled Nurses' Experiences of Caring for Their Own Dying Family Member that is being conducted by Brenda S. Lee.

Brenda S. Lee is a Graduate Student in the department of Nursing at the University of Victoria and you may contact her if you have further questions by phone) or email.

As a Graduate student, I am required to conduct research as part of the requirements for a Masters degree in Nursing. It is being conducted under the supervision of Dr. Kelli Stajduhar. You may contact my supervisor by phone or by email.

Participation in this study is entirely voluntary. You are free to refuse to answer any questions and may request at anytime that recorded information be erased or notes destroyed. As well, you are free to withdraw from the study at any time. I may ask you permission to use any information shared to date. You are free to refuse and ask for any information shared or notes taken to be destroyed. At your request I will erase any audiotaped information and shred transcripts, notes or other documents.

Purpose

The purpose of this study is to enhance our understanding of the experiences of registered nurses who have provided informal care to their own dying family member.

Potential Benefits

You will not receive any direct benefits from participating in this study. However, it is anticipated that the results of the research have the potential to provide knowledge of how nurses' experience informal caregiving. Understanding this experience may inform other nurses who are either contemplating this role or currently in the role. As well, findings from this study has potential to inform health care professionals, administrators, and policy makers in developing services, programs, and supports that best serve unique populations such as nurses who are informal caregivers. At the completion of the study, you will be sent a summary of the findings.

Procedures

You are invited to participate in this study to share your experiences of caring for a dying loved one. If you consent to participate in an interview, a time and place for the interviews will be set at your convenience. The interview will last approximately 1 to 1.5 hours and will be audiotaped. At the time of the interview, I will also be asking for and recording other information such as your age, relationship to the family member, area of professional practice, and length of nursing experience. This information will be used to describe the sample of nurses I interview and used to highlight variations in perception and experiences among the diverse group of participants. During the interview I will also be jotting down my observations and notes about the information shared. These notes will be used to cue me to ask for clarification later in the interview or to jog my memory as I review the audiotape.

Following the interview, with your permission, I may contact you by phone to clarify information shared during the interview.

If you agree, I may also want to conduct a 2nd interview to ensure that I am capturing your perceptions and experiences correctly and make modifications based on your thoughts and suggestions. I anticipate that the 2nd interview will be less than ½ hour in length and will be conducted either face-to-face or by phone.

A hired transcriptionist or I will transcribe the audiotaped interview. All hired transcriptionists will be asked to sign a confidentiality agreement. At the time of the interview, I will provide participants with a copy of this agreement. A printed and an electronic copy of the interview will be produced and used for analysis.

Risks

There may be a potential risk to discussing your experiences in that these discussions may bring up unexpected grief reactions. In this instance, you may request to take a pause from the interview or stop the interview at any time. At anytime during the interview you may ask to have the audio recording stopped. As well, you may discontinue the interview at any time you wish. If you request it, a list of counseling support services will be given to you.

Monetary Compensation

There will be no monetary compensation for participating in this study.

Confidentiality and Anonymity

Confidentiality will be attended to by assigning a code number or letter to each participant, which will be used on any interview notes, data collection tools, and transcribed data. Any interview notes, audiotapes, and transcripts will have all

identifying information removed and participants' names will not be used in the research reports. Interview materials (e.g. tapes, observational notes, and transcriptions) will be kept in a locked cupboard in my residence and will only be available to my Thesis Committee and myself. Electronic documents will be stored on a computer, which is password protected or on a memory stick, which will be kept in a locked drawer. In addition, anonymity of all participants will be attended to by ensuring any biographical details are altered as necessary in published and unpublished work to mask identifying characteristics.

All of the information that shared will be used for purposes of this thesis research, future publications and presentation. At the end of the study, the audiotapes will be erased on completion of my thesis. Electronic or typed transcripts, data collection tools, and notes may also be used after the completion of the study for preparation of manuscripts for peer review publications and preparing presentations for conferences. These documents will be shredded once presentations and publications resulting from this study are completed. Any electronic data will be erased from the researcher's computer hard drive and any memory storage device(s) used. It is anticipated that presentations and journal publications will be completed within the next 2 years.

Findings from this study will be written up in my thesis document. The findings may also be disseminated by publication in peer review journals or by presentations at conferences. As well, a summary of the study findings will be offered to all participants once it is complete.

If you have any questions or concerns during this study, please contact Brenda S. Lee or her thesis supervisor, Dr. Kelli Stajduhar, as above. In addition to being able to contact the researcher and her supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Health Authority Research Ethics Office at (number).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

~~~~~

I have read the above information and I have had an opportunity to ask questions to help me understand what my participation will involve. I freely consent to participate in the study and acknowledge receipt of a copy of the consent form.

Signature of participant: \_\_\_\_\_

Date: \_\_\_\_\_

## APPENDIX F

### Registered Nurses' Experience of Caring for a Dying Family Member

**Researcher: Brenda S. Lee, RN, MN (Cand.)**  
**Student, University of Victoria, School of Nursing**

### INTERVIEW GUIDE

#### Opening Remarks

As you know, I am interested in learning more about the experience of registered nurses who have cared for a dying family member. I think it is important to learn about the experience of nurses who provide care to their own family caregivers so that health care and palliative caregivers know and understand these experiences so they can plan effective interventions to better support nurses – both as clients and colleagues.

This interview will be audiotaped. Are you okay with that?  
 Review the consent letter and obtain signature.

If at any time during the interview, you would like to take a break, please let me know. I may be jotting down a few notes during the course of our conversation to cue me to ask you for more information or to jog my memory as I review the audiotape. I hope this won't be too distracting.

Just to remind you that you may pause at any time and at anytime you may ask to have the audio recording stopped. As well, you may stop the interview at any time you wish.

Are you ready to begin? Maybe you could start by describing your caregiving situation – when was your experience and which family member did you provide care to? Describe what a typical day was like for you when you were caring for your family member.

#### Prompting Questions for Informal Caregivers who are Nurses

What was it like for you as a nurse caring for your family member?

Please tell me a little about how you came to take on caregiving roles.

Did your professional role as a nurse influence your decision to provide care?

Tell me about your sense of responsibility towards your loved one.

What did you expect of yourself in relation to support for your family member?

What do you think other family members would say about your responsibility? Would they expect it? Why do you think that/how do you think this came about?

Did you take on different roles/tasks than your non-nurse family members?

As a nurse, what were the challenges in providing care to your family member? How did you manage these challenges? Can you tell me about an experience you had that was particularly challenging?

What was it like for you to be both a provider and recipient of health care?  
What do you feel responsibility FOR, specifically? What do you expect of yourself?  
What are your thoughts and feelings about your role as a family caregiver?  
What was it like to provide care at work and care at home?  
What were the benefits in providing care to your dying family member? Can you give me examples?  
What were the challenges in providing care to your family member? Can you give me examples?

Is there anything else that you would like to add that we haven't talked about?

### **Examples of Prompts**

Can you tell me more...  
Can you provide an example..  
What I hear you saying is...  
What was that like for you...  
The experience was...  
How did that feel...

**APPENDIX G****Registered Nurses' Experience of Caring for a Dying Family Member****Researcher: Brenda S. Lee, RN, MN (Cand.)****Student, University of Victoria, School of Nursing****Thesis Supervisor: Dr. Kelli Stajduhar****CONFIDENTIALITY AGREEMENT: TRANSCRIPTIONIST**

I have agreed to work on this study by transcribing field notes and interview materials. I will protect confidentiality in this study by assuring that the anonymity of each participant is maintained at all times. This will mean that each participant is assigned a number/letter that will be used on all tapes and written notes that apply to that participant so that her or his name and identity is protected. Thus, all identifying information within the transcriptions of the interviews and field notes that I transcribe will be deleted or alerted to preserve anonymity.

All research materials for this study will be kept secured in a locked filing cabinet while in my possession. After completing any work pertaining to the research project, I will return all tapes, discs, original print outs, and copies to the researcher. I will also erase any materials pertaining to the research project from the hard drive of the computer I am using once the information is given to the researcher.

Finally, I will not, under any circumstances, disclose any information in the field notes or interviews to any persons or agencies, including staff employed by the health region where the study is taking place.

I have had the opportunity to discuss these requirements with the researcher, Brenda S. Lee, and have received a signed copy of this confidentiality agreement

Print Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_