WHEN A DESIRED HOME DEATH DOES NOT OCCUR:

FAMILY CAREGIVER EXPERIENCES

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE IN NURSING

in

The College of Graduate Studies

THE UNIVERSITY OF BRITISH COLUMBIA

(Okanagan)

November 2011

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ABSTRACT

Despite a preference among Canadians to die at home, the majority of expected deaths in British Columbia occur away from home. This qualitative research based on interpretive description (Thorne, 2008) examined the experiences of bereaved family caregivers (FCGs) when a desired home death did not occur and happened in either the hospital or in a hospice. The purpose of the study was to enhance the understanding of FCGs experiences in managing end-of-life care at home to guide the development of more effective approaches to hospice palliative care. Eighteen bereaved family members of persons who died of cancer were recruited. Data collection involved semi-structured, audio-recorded interviews that were transcribed. Analysis occurred concurrently with data collection. Field notes and reflective journaling guided and documented the interpretive process and aided in the analytical process.

Unwavering commitment to the promise FCGs made to care for their family member at home until death underpinned FCG experiences. These promises, however, were challenged by a lack of preparedness for caregiving, difficulty with accessing professional support and information, and frustration with the inadequate help they received. The physical, emotional and relational toll FCGs experienced and the impact of unexpected events prevented desired home deaths, and resulted in significant distress and guilt. FCGs were still struggling to live with their deep regret several months to 17 years after their promises were broken. Although the death of their family member was described as peaceful; the death could not be described as a good death.

The study findings provide direction for the provision of care as hospice palliative care is increasingly shifted into homes and caregiving responsibilities handed over to family members. Adequate resources and supports must be in place and accessible at the time they are needed by FCGs to enhance quality of life for dying family members and ameliorate negative effects on FCG health.
PREFACE

This research was approved by the UBC Okanagan Behavioural Research Ethics Board on June 4, 2009, Ethics Certificate # H09-01335.

This research was approved by the Interior Health Ethics Board on July 27, 2009, Ethics Certificate # 2009-026.
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ACKNOWLEDGMENTS

I have so many people to thank for their continued support throughout my years of studies and the writing of this thesis. I have received incredible support and encouragement throughout this journey from my family, friends, the faculty at the University of British Columbia Okanagan, my fellow students in the MSN program, and my many colleagues across the many sectors of health care such as home and community care, hospice, hospital, and the cancer center.

I wish to particularly acknowledge my colleague and friend, Maureen, and my former nursing practice leader, Maxine, who even after I left the cancer agency continued to support me as I struggled through the long process of completing my studies and writing my thesis. I want to acknowledge my colleague Larry who introduced me to the patient’s wife that sent me off on this incredible thesis journey. I want to thank Sharon for her continued support even as the health authority restructured and I no longer reported to her.

I am truly amazed at all of the financial support I received throughout my studies and without this support I could not have completed my studies. I would like to thank each and every one of my funding sources: British Columbia Nurses Union (BCNU), Bryce Carnine Memorial Prize, Canadian Association of Nurses in Oncology (CANO), Canadian Nurse Foundation (CNF), Order of the Eastern Star Shane Fellowship, Psychosocial Oncology Research Training (PORT), and the UBC Okanagan Graduate Fellowship. Knowing that there are people out there who care about and support academics and research is very reassuring. In addition, I am grateful to Interior Health for the leave granted while I was off on fellowship (PORT) and for the subsequent leave granted, as required, in order for me to finish my studies.

I would like to express my heartfelt appreciation to my thesis committee: Dr. Carole Robinson, Dr. Joan Bottorff, Dr. Penny Cash and Cathy Robinson. Not only have they mentored and guided me; they have listened, dried my tears, and encouraged me when I didn’t think I
would make it to the finish. I appreciated their expertise, professionalism, and thoughtful critique throughout this thesis process. Their patience and kindness will be with me always.
DEDICATION

To my husband, Craig, for his love
and enduring support.
He has listened to me and lived this study with me.

&
To my Mom, Ann Balogh, for her words of wisdom
and encouragement
throughout my years of education

&
To the family caregivers
who shared their stories with raw honesty and grace
1. INTRODUCTION

1.1. The Story

It was a cold grey autumn day and I was asked to see a patient, who had just been admitted to the hospital, and his wife; the patient was dying. The wife was in tears and asked how she could have managed caring for her husband in their own home instead of bringing him into hospital. An interview revealed that community nurses had been involved with this family for several months and the patient was registered to the hospice palliative home and community care program, yet the wife was asking about home and nursing support. She requested help to manage her husband’s symptoms, equipment to help with mobilization, assistance to manage finances and to plan his funeral, and support to cope with the intense emotions that she was experiencing. She wanted to know if that kind of help was available. The patient lay quietly, obviously nearing his final breaths, and his wife appeared profoundly sad. We immediately discussed the issue of resuscitation and I gently informed her that the death of her husband was imminent; likely within hours. The wife appeared distressed and expressed regret that she was unable to keep her promise to have her husband die at home. He had wanted to die in their bed. She stated she had not realized he was so ill and now there was no time left to keep her promise. This story has become more and more common in my practice and generated concern as well as stimulated my interest in understanding this experience to better inform care.

1.2. The Issue

The story above is similar to others found in the literature where family members were the primary palliative caregivers advocating for their loved ones (Fisker & Strandmark, 2007). Central to the story was the experience of a couple struggling to manage a desired home death only to find themselves facing a death away from their home. The wife was unaware of the various interdisciplinary supports that may have supported a home death. To support a home death requires understanding not only of the experiences of dying within the home but the
complexities involved in hospice palliative care and the culture of dying in Canada (Brännström, Brulin, Norberg, Boman, & Strandberg, 2005). The situation described above happened in a province where the hospice palliative care mandate includes supporting expected deaths in the home, hospice, or residential care (British Columbia, Ministry of Health, 2006). When dying occurs in the acute care hospital environment, the ability to provide hospice palliative care may be lacking. Although the policies in hospice palliative care in Canada are oriented to the majority of Canadians who wish to die at home (The GlaxoSmithKline Foundation and the Hospice Palliative Care Association, 2004), the current health service delivery model drives the provision of hospice palliative care and consequently does not adequately take into account those who wish to die at home. This serves to create the paradoxical situation described above – a family that desired a home death, a policy context that supports home death, but the inability to realize home death because of inadequate support.

This study focused on gaining an understanding of the experience of family caregivers (FCGs) when circumstances prevented a desired home death for a family member with advanced cancer. For the purpose of this study, when referring to a ‘home death’ or ‘death away from home,’ home was defined as an individual’s house or apartment. Little is known about the experience of FCGs when a desired home death does not occur. It is critical to gain a better understanding of the experiences of FCGs to provide insights and possible directions for providing more effective support to FCGs in the dying experience in a manner that is meaningful to them.

In this chapter, in order to provide context for the study, discussion will focus on a brief overview of hospice palliative care in Canada. The discussion will begin with the definition and philosophy of hospice palliative care in Canada which guided this study, followed by acknowledgment of the grassroots approach to hospice palliative care including volunteer involvement. In addition, the Canadian perspective on hospice palliative care will be addressed.
along with a discussion regarding national standards, and the implementation of those standards at a provincial and regional level.

1.3. Hospice Palliative Care in Canada

1.3.1. Definition and Philosophy

Hospice palliative care is not connected with a specific place or building (Appelin, Brobäck, & Berterö, 2005). It is active care and provides care for the whole dying person and their family. The Canadian Hospice Palliative Care Association (2002) defines hospice palliative care in the following way and this is the definition that informed this study:

Hospice palliative care aims to relieve suffering and improve the quality of living and dying. Hospice palliative care strives to help patients and families: address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears; prepare for and manage self-determined life closure and the dying process; cope with loss and grief during the illness and bereavement (p.17).

The domains of hospice palliative care are all-encompassing and require a holistic approach with an interdisciplinary team (Ferrell, 2005). Issues that are addressed encompass the cultural, ethical, existential, legal, psychiatric, psychological, physical, religious, social, and spiritual care of the dying person (Ferrell). Ferrell states important elements of hospice palliative care include: a) acceptance of hospice palliative care by the individual who is dying and their FCGs, b) appropriate timing of initiating hospice palliative care, c) attention to the relief of suffering, d) continuity of care across all health care delivery settings, e) effective and sensitive communication, f) equitable access to hospice palliative care for all ages, and g) skilled care with the dying. Hospice palliative care occurs throughout all parts of the health care system and crosses into the home, hospital, and hospice in a variety of ways.
1.3.2. Grassroots Approach

Cicely Saunders was instrumental in the modern day movement for hospice palliative care. In the 1960s she founded the hospice palliative care movement in England, which introduced an all encompassing approach to the care of the dying that included the medical aspects of care and an holistic approach to care (Saunders, 1996). One of the impetuses for her involvement in this movement was the invisibility of patients who were dying and the negative attitudes they faced from doctors, neighbours and even their own family (Saunders). Many individuals were alone in their suffering, receiving inappropriate treatments, and living with unsupportive families. Saunders was a pioneer in the care of the dying as she tried to instil public acceptance of narcotics for pain relief, include the spiritual aspects of caring for the dying, and further develop hospice palliative care through changing attitudes and skills of health care professionals in the care of the dying. She began to identify the principles of hospice palliative care as including “openness, mind together with heart, and a deep concern for the freedom of each individual to make his or her journey towards their ultimate goals” (Saunders, p. 319). Saunders also reinforced the need for health care professionals to work with and care for the families of dying individuals.

In 1975 hospice palliative care came to Canada (Syme & Bruce, 2009). In the early years of hospice palliative care, it was considered a type of care outside of the mainstream standard medical care. Hospice palliative care was initiated by hospice societies that were grass roots organizations in origin, community-based, funded by charities, and led by individuals and groups who had a passion in the field (Syme & Bruce). The grassroots approach was volunteer driven and volunteers remain an essential component of hospice palliative care to this day. In British Columbia, the Hospice Palliative Care Association (BCHPCA) is a member-driven association that is run by volunteers (British Columbia Hospice Palliative Care Association, 2010). Members are diverse and include physicians, nurses, families, and caregivers, among others. The
BCHPCA embraces a vision for all British Columbiains to have access to quality hospice palliative care through building capacity in communities. Some of the initiatives they are involved in regarding hospice palliative care include raising public awareness, supporting new and developing programs, promotion of recognized standards, provision of a network of communication, and provision of educational resources. Another example of the continued work of volunteers is in individual hospice societies and free-standing hospices where they are involved in activities such as fund-raising, clerical support, night-time vigils, home visits, and grief and bereavement support.

Grassroots work and volunteer involvement in hospice palliative care is the foundation on which program development for hospice palliative care has been built. The volunteer work involved in hospice palliative care is ongoing; however, hospice palliative care is dependant on the wide-scale involvement of government on a federal, provincial and regional level to ensure hospice palliative care is available to all Canadians.

1.3.3. What Canadians Know and Want

Hospice palliative care is complex and for the care to meet the needs of Canadians, the development and initiation of services depends on understanding what Canadians know, want and currently receive in terms of health care service delivery. Current literature indicates that the vast majority of Canadians wish to die in their homes and there are efforts to orient health care service delivery to support this (Brannstrom et al., 2005; The GlaxoSmithKline Foundation and the Hospice Palliative Care Association, 2004). However, 75% of expected Canadian deaths occur in hospital or residential care (Canadian Hospice Palliative Care Association, 2006). Given that over 90% of Canadians would like to die in their own home (The GlaxoSmithKline Foundation and the Hospice Palliative Care Association, 2004), the reality is that most deaths do not occur in the home. There is an expectation by government that hospice palliative care can be supported in the home through adequate preparation and resources, and that care provided in a
hospice or residential care can be a reasonable alternative when expected deaths cannot be supported in the home (British Columbia Ministry of Health, 2006).

Canadians reported they required improved support in dealing with death including both physical and psychosocial care (Carstairs, 2005). The support they requested extended well beyond improved pain and symptom management, and included being fully informed about their prognosis. They did not want to wait passively for death when faced with a life-limiting illness, but indicated they wanted the opportunity to live their life in a positive and fulfilling way. They wanted to find meaning in their own value as a human being and to find opportunities for healing and forgiveness (Tiedemann & Valiquet, 2008). In order to act on these preferences, they needed to know they had a life-limiting illness.

Legar Marketing (Canadian Health Reference Guide, 2008) conducted two national on-line surveys to gain an understanding of the knowledge of hospice palliative care and unmet needs among Canadians. This national survey, released in September 2008, reported that 81% of Canadians believed more should be done to improve the lives of palliative patients. Eighty-nine percent of Canadians believed that hospice palliative care was important yet 81% of Canadians had not discussed hospice palliative care with a health care professional (Canadian Health Reference Guide, 2008). This suggests that many Canadians may not be fully aware of what is involved in hospice palliative care. The number of Canadians preferring to die at home may be different if there was a better understanding of what is involved with caring for those who are dying in their own homes.

There is an urgent need to expand and improve hospice palliative care for patients with advanced cancer and their family members. Twenty-eight percent of Canadian deaths are now due to advanced cancer (Canadian Hospice Palliative Care Association, 2010). It is estimated that the number of new cases of cancer and subsequent deaths will continue to increase. For example, compared to 2008, an increase of 4600 new diagnosis of cancer (2.69%) and 1500
deaths (1.99%) were reported in 2009 (Canadian Cancer Society, 2009). Each year more than 259,000 Canadians die and over 70,000 of these deaths are currently due to advanced cancer. This is a particularly salient situation, given that by 2020 there is an anticipated 33% increase in deaths in Canada over what occurred in 2003 (Health Canada, 2008).

1.3.4. National Leadership in Hospice Palliative Care

There have been many successes and challenges in Canada regarding the provision of hospice palliative care for Canadians. Care delivery is multifaceted and is affected by all levels of government at a national, provincial, and regional health care level. Although the Federal government may make recommendations concerning hospice palliative care, it is the responsibility of the provinces to act on the recommendations and enact the necessary legislative changes (British Columbia Ministry of Health, 2006). The provinces provide the overall funding for hospice palliative care services to regional health authorities and the health authority has a responsibility to deliver the hospice palliative care services (British Columbia Ministry of Health, 2006).

Senator Sharon Carstairs has played an integral role at a federal level in drawing attention to the need to improve the quality of care in hospice palliative care in Canada at a federal level. Even before 2001 when she was given special responsibility for hospice palliative care in the federal government, she was working towards ensuring hospice palliative care was meeting the needs of all Canadians. In 1995, Carstairs supported recommendations for universal access to competent and effective hospice palliative care, the provision of national guidelines and standards, recognition of hospice palliative care as an essential service and a top priority in the restructuring of the health care system, increased training for all health care professionals in hospice palliative care, and an integrated approach to hospice palliative care whether in the home, hospice or in health care institutions (Carstairs, 2005). Carstairs stated that by 2000 little was accomplished regarding these 1995 recommendations for improving hospice palliative care.
for Canadians and further recommendations were made for developing a national strategy. This strategy included ensuring compassionate leave benefits for FCGs, improving education and education opportunities for health care professionals and informal caregivers, and creating a public information program (Carstairs).

In 2001 hospice palliative care was recognized in Cabinet and a department in Health Canada, the Secretariat on Palliative and End-of-Life Care, was created to provide leadership for a national initiative for hospice palliative care. In 2002 the Canadian Strategy on Palliative End-of-Life Care was developed and provided an action plan for hospice palliative care to address best practices and quality of care, education, public information and awareness, research, and surveillance. Advance care planning was noted as imperative for understanding the wishes of those individuals who are dying and may no longer be able to communicate or make decisions for themselves. Also in 2002, the Canadian Hospice Palliative Care Association published a national model to guide hospice palliative care practice in Canada that included frameworks, principles and norms of practice and standards (Canadian Hospice Palliative Care Association, 2002). This model was made possible by hundreds and thousands of individuals and organizations that contributed and shared their vision of hospice palliative care in a national consensus-building process (Canadian Hospice Palliative Care Association, 2002).

Carstairs (2005) noted that although much had been accomplished in Canada regarding hospice palliative care between 2000 and 2005 there was still much more to be done. Although FCGs were able to access compassionate leave benefits to care for their family members, eligibility requirements were too restrictive and the time limit for benefits was too narrow. Improvements in advance care planning were still needed. For example, Carstairs cautioned that more attention must be paid to the burden versus the benefit of treatment, and that non-initiation or cessation of futile treatment may be effective strategies for improving quality of life, relieving suffering and allowing natural death to occur. Finally, she pointed to the need for continued
research regarding how well Canadians are dying in the current health care system and the socio-economic impact of dying on family and informal caregivers.

Although many areas in Canada have hospice palliative care societies that provide volunteer and bereavement services, these services, depending on the location and a whole host of factors, vary in the way they are funded. The majority of hospice palliative care programs are at least 50% funded by charitable donations (Canadian Hospice Palliative Care Association, 2010). Free-standing hospices and designated hospice beds in either hospitals or residential care facilities have been specifically organized to support dying individuals and their families. Home and community care services are available to support hospice palliative care in the home; however, location compromises equitable access to the services (Canadian Hospice Palliative Care Association, 2010). For example, larger urban areas in home and community care may have specialized consultation teams whereas rural and remote areas may have a generalist approach to care and far fewer resources.

The Canadian government has leadership responsibility to continue to improve hospice palliative care services. Although there have been significant advances in hospice palliative care, it is estimated that only 16% to 30% of Canadians have access to hospice palliative care services and this is influenced by where they live (Canadian Hospice Palliative Care Association, 2010). Canadians have the right to know what is available in terms of hospice palliative care in their communities in order to develop a clear plan of care (British Columbia Ministry of Health, 2006; Cherlin et al., 2005). However, assumptions that all Canadians have a home and have access to healthcare services that are well resourced and capable of meeting the needs of those who are living while preparing to die at home are not well founded. This creates a situation where many people have inadequate hospice palliative care and the expectation of a home death cannot be supported.
1.3.5. Hospice Palliative Care Service Provision

In British Columbia, the Ministry of Health (2006) acknowledges the government’s roles and responsibilities in hospice palliative care in providing leadership and direction. The government acknowledges the need for support systems to relieve suffering and improve quality of life for the dying through improved access to physicians and health care professionals (British Columbia Ministry of Health, 2006; Interior Health, 2008). Over the last 10 years in British Columbia there have been important developments in hospice palliative care. For example, there has been the development of a provincial framework with specific indicators identified to guide hospice palliative care within health authorities and the establishment of a Palliative Care Benefits Program which helps to offset the costs associated with equipment, supplies and medications (Syme & Bruce, 2009). The British Columbia Ministry of Health (2008) advocates for home death or, alternatively, death in specialized hospices or residential care facilities, rather than the acute care setting. However, there are challenges in meeting this mandate due to health care restructuring and budget cuts in health care that have resulted in reductions in institutional-based palliative care beds and disproportionate funding to community-based hospice palliative care programs (Canadian Hospice Palliative Care Association, 2004).

The health authorities in British Columbia organize and deliver hospice palliative care services at a regional and local level and this includes home care services, numerous free standing hospices, and residential care. The health authorities are expected to provide quality hospice palliative care services with the funding they receive. The Interior Health Authority initiated regional standards for eligibility, assessment, referral and service delivery for hospice palliative care (Interior Health, 2008). In addition, in conjunction with the Ministry of Health, this health authority developed reporting systems to demonstrate progress in hospice palliative care service delivery by collecting statistics based on a variety of politically and economically derived measures of specific outcomes such as: home support hours, home care nursing visits,
social work visits, and location of death (Interior Health). The aim is to improve care by standardizing all aspects of hospice palliative care including data collection, clinical pathways, and education. What appears to be missing in the accountability structure is the individual and family who are facing a life-limiting illness. Attention needs to be paid to satisfaction with care, and quality of life indicators for both the ill family member and the family caregivers.

In British Columbia there is recognition that the majority of British Columbians prefer to die at home and improved hospice palliative care services are necessary if this goal is to be met. It has been acknowledged that some groups of individuals will require more support and care than others and not everyone requires highly specialized hospice palliative care services (British Columbia Ministry of Health, 2006). The role of the home and community health professionals and family physicians is recognized and supported as essential in the delivery of quality hospice palliative care. Currently in British Columbia, there is a physician practice support program focusing on hospice palliative care that is being initiated province wide (British Columbia Ministry of Health, 2010). The training program includes physicians and their medical office assistants, specialists, and nurses from home and community care. The aim of this program is to support family physicians to develop registries of patients with a palliative diagnosis and to develop care plans that would aid in ensuring “the best quality of life for dying patients and their families” (British Columbia Ministry of Health, 2010, p.9).

This brief overview of hospice palliative care in Canada highlights some of the successes and challenges through the years and acknowledges the need to continue to improve health care services in this area. Recently, Carstairs (2010) made recommendations to ‘raise the bar’ for quality hospice palliative care for all Canadians through ensuring a “culture of care, caregiver support, integration of services and leadership” (p. 4). She stated “It is the responsibility of every Canadian to work together at all levels-federal, provincial/territorial and community – to ensure quality hospice palliative care for the 90% of Canadians who will need it” (Carstairs, pg.4).
Carstairs emphasized that hospice palliative care views the individual who is dying and their family as a unit and all members are recipients of care throughout the disease trajectory including bereavement services. She acknowledged the need for continued support for those who care for the dying including the FCGs. FCGs need to be provided with adequate supports to keep the family unit functioning and hospice palliative care service delivery must facilitate caregiver support through financial, education and training, respite care and bereavement services.

This study builds directly on Senator Carstairs’ mandate for improved hospice palliative care by focusing on a problem I have observed in practice. There appear to be gaps in supporting FCGs in desired home deaths for their relatives. Some FCGs are experiencing difficulties supporting a desired home death. In Chapter 2, the background literature underpinning this study will be summarized. This will be followed by a description of the study methods in Chapter 3. The findings of this study will be presented in Chapter 4, and this will be followed by a discussion of the findings and implications for hospice palliative care in Chapter 5.
2. REVIEW OF THE LITERATURE

2.1. Overview

The purpose of this literature review was to situate this study in the context of what is currently known about the experiences of FCGs who care for a terminally ill family member and, in particular, offer care with the aim of supporting a home death. Relevant literature was identified through an electronic search of peer-reviewed articles, government and agency reports, and hospice palliative care websites. Data bases included Academic Search Complete, CINAHL, Cochrane Data Base of Systematic Reviews, Eric, Google Scholar, Medline, Psych Info, PubMed, and Women’s Studies. All literature reviewed was published in English. Inclusion criteria included studies within the palliative adult population, with a focus on home care, published from 1998 – 2010, as well as seminal or additional works stemming from the publications reviewed. Excluded publications were studies related to pediatrics, residential and long-term care because the focus of this research was on terminally ill adults living at home. Search terms included multiple variations of: caregiver, carer, communication, death, decision-making, decision or choice, difficult death, discussion, dying at home, end-of-life care, family, family caregiver, good death and bad death, home environment, living with dying, nurse-family caregiver relations, nursing role, palliative care, relationships, supporting dying, terminal care, and terminally ill patients.

It is generally accepted that FCGs can be defined broadly as whoever the terminally ill individual says they are and can include immediate family, friends and neighbours (Canadian Hospice Palliative Care Association, 2002). For the purpose of this study, the FCG was defined as the person “providing the majority of the emotional and/or physical care to the patient” (Mangan, Taylor, Yabroff, Fleming & Ingram, 2003, p. 248) while at home. The literature review is organized as follows: good vs. difficult death, palliative family caregiving, preference
and changing preference for supporting a home death, and factors influencing caregiving at home.

2.2. Death and Dying: Good vs. Difficult

Descriptions of good, dignified and desirable deaths were well represented in the literature (Callahan, 2005; Thomas, 2005; Wilson, 1989). Death and dying is described as sacred and memorable and as often accompanied by dramatic emotional events that affected the person who was dying, their family, and family caregivers (Byock, 2002; Charme, 2002; Valentine, 2007). Underpinning these emotional events, a variety of perspectives related to what makes for a good versus a difficult death are reported.

Experts suggest a good death requires an environment of support, resources, and an experienced team of professionals (Appelin, Brobäck, & Berterö, 2004; Brazil, Bedard, & Willison, 2002a; Thomas, 2005). Others have identified the following attributes of a good death: all persons involved in the death and dying process are able to accept the individual’s dying, the individual and significant others have resolved all and any psychosocial issues, the individual’s pain and symptoms are controlled, and death is neither prolonged nor too sudden (Duggleby & Berry, 2005; Wilson, 1989). Hope has been viewed as integral to the experience of a good death because it maintains and strengthens relationships between the FCG and the individual who is dying (Borneman, Stahl, Ferrell, & Smith, 2002; Callahan, 2005; Coulehan, 2005; Herth, 1995; Thomas, 2005). Hope was described by Herth (1995) as involving self-awareness and openness to new possibilities while taking into account a sense of one’s past, present and future. Hope has been reported to contribute to quality of life and give life meaning and direction to dying particularly for FCGs (Borneman et al., 2002). Researchers reported that FCGs found ways to maintain hope through doing what had to be done, living in the moment, staying positive, and supporting and connecting with others (Borneman et al., 2002; Holtslander, Duggleby, Williams, & Wright, 2005). Understanding and supporting FCGs in finding hope is argued to be an
essential component of providing compassionate and effective hospice palliative care to achieve a good death (Holtslander, 2006).

Difficult death was most often defined through comparison with a good death. For example, death with dignity was equated with a good death; therefore, a loss of dignity was viewed as one of the many factors that contributed to a bad or difficult death (Coulehan, 2005). For instance, loss of dignity occurred in situations where FCGs witnessed ill family members’ wishes being disregarded by health care professionals, and when unmanageable pain, unrelieved symptoms, and psychological distress were not addressed (Coulehan, 2005; Kristjanson & Aoun, 2004). Another factor associated with a difficult death was unexpected change in the family member’s personality; for example, they no longer acted like themselves and became aggressive or agitated (Dumont, Dumont, & Mongeau, 2008). A change or loss of relationship between FCGs and the individual who was dying, and the experience of severe social and emotional distress, also contributed to the experience of a difficult death (McPherson, Wilson, & Murray, 2007; Proot, Abu-Saad, Crebolder, Goldsteen, Luker, & Widdershoven, 2003).

One might assume that place of dying and death would be a factor in judgements about good and difficult death. Current policy suggests good hospice palliative care includes dying in the place of one’s choosing such as home, hospice, or hospital. However, there is little known about the specifics of what makes for a good vs. difficult or bad death at home. What is imminently clear is that dying and death at home requires a dedicated family caregiver (FCG).

2.3. Palliative Family Caregiving

According to an Ipsos-Reid 2004 survey, most Canadians wish to die in their homes (The GlaxoSmithKline Foundation and the Hospice Palliative Care Association, 2004). However, in order for this to happen, a primary FCG is required (Dumont et al, 2008; Dunbrack, 2005; Fisker & Strandmark, 2007). On average, 54 hours of care per week are required of FCGs to care for a dying loved one at home (Canadian Hospice Palliative Care Association, 2008; The
GlaxoSmithKline Foundation and the Hospice Palliative Care Association, 2004). Indeed, FCGs are reported to be responsible for 75 to 90 percent of hospice palliative care provided in the home (Dunbrack, 2005). This included shopping, housekeeping, coordinating and accompanying their ill family member to medical appointments in addition to attending to their family member’s physical, psychosocial, and spiritual care needs. A recent Canadian study (Stajduhar, Funk, Toye, Grande, Aoun, & Todd, 2010) suggests that caregiving responsibilities may be increasing. In this study, FCGs were observed to be involved in care that was formerly provided by nurses such as managing medications, administering oral, rectal and sub-cutaneous medications, and administering bowel care. It is not surprising, therefore, that experts conclude that the impact of caring for a dying spouse or family member or friend should not be underestimated (Riley & Fenton, 2007).

2.3.1. Home Death: Preference and Changing Preference

Although most Canadians prefer to die in their own homes, death happens most often away from home (Canadian Hospice Palliative Care Association, 2010; The GlaxoSmithKline Foundation and the Hospice Palliative Care Association, 2004). In 2010, 75 percent of Canadian expected deaths took place in hospitals and residential care (Canadian Hospice Palliative Care Association, 2010). In an Ontario study, Brazil and colleagues (2005) reported that of the 68% of terminally ill individuals who expressed a preferred location for death, 77% desired a home death. However, only 47% actually died at home.

Stajduhar and colleagues (2008) found that death was more likely to occur in the hospital when the FCGs and the individual who was dying were not in agreement regarding preferences for place of death. Higginson and Sen-Gupta (2000) found that the dying individual preference for a home death decreased in the last eight weeks of his/her life. Researchers found a home death was more likely to occur if pain and distressing symptoms were under control, equipment and medications were available in the home, and both the FCG and the individual who was dying
were aware and accepting of death (Stajduhar & Davies, 2005; Thomas, 2005). In a study by Stajduhar and Davies (2005), it was reported that FCGs who negotiated decisions to support a death at home with their dying family member and with the involved health care professionals were better prepared to provide care at home. Major considerations when preparing for a home death included the expressed preference by the dying person for a home death, the availability of the family physician, the knowledge and skills of available health care professionals, and the caregivers’ capacity to manage the complexities involved in caregiving (Brazil et al., 2005).

There is also evidence to indicate that FCGs’ preferences to support a death in the home may change over time for a variety of reasons. For example, one factor influencing changes in FCG preference relates to challenges in communication between the FCG and the family member who was dying especially when one or the other was in denial of the illness and the approach of end-of-life (Dumont, Dumont, & Mongeau, 2008). Dumont and colleagues (2008) provided an account of a dying individual who was “not letting himself see that he was ill … [and] denied the whole disease” (p.1053), and they suggested this created a hostile environment for the FCG. Research evidence also indicates that FCGs experienced difficulty managing a home death when their own health is compromised or when they lack support from other family members or friends (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005; Brink & Smith, 2008; Dudgeon & Kristjanson, 1995). Factors that appear to influence death occurring away from home include: insufficient at-home nursing support, the lack of availability of a physician to do a home visit, and the lack of access to out-of-hours professional supports (Brazil et al., 2002b; Brink & Smith, 2008). It has been recognized that despite their best intentions, FCGs may find themselves unable to cope with a home death. However, there is a limited understanding of the effect of this experience on FCGs themselves and further research is needed (Funk et al., 2010; Hudson, Trauer, Graham, Ewing, Payne, Stajduhar, & Thomas, 2010). Given that the majority of hospice palliative care delivered in the home is provided by FCGs, it is
important to have a better understanding of FCGs’ experiences as they take on supporting and providing care for a terminally ill family member, and the challenges they encounter (Dunbrack, 2005).

Many factors have been identified that enhance and inhibit family caregiving within hospice palliative care. The following section will focus on the promise to care at home, communication and information sharing, the consequences of caregiving in the home, the question of whether home death is necessarily the best death, and grief and bereavement.

2.3.2. Promises Made

Promises made to dying family members are often a basis for FCGs motivations to provide hospice palliative home care. Stajduhar and Davies (2005) describe FCGs’ decision-making processes and the promises FCGs made to care for the dying patient in the home. They discussed how the FCGs’ promise to care was influenced most often out of a sense of duty or obligation and for one participant was tied to her marriage vows. For others the promise they made was related to negative encounters with the health care system (Stajduhar & Davies, 2005). Their findings highlighted FCGs determination to keep their promise regardless of the burden and stress they experienced. Some FCGs reported feeling coerced and did not feel they had a choice to refuse to support the death of their family member in their home, whether due in part to the influence of the dying family member or of the health care providers themselves (Stajduhar & Davies, 2005). Further exploration of the experience of promises made by FCGs and their influence on hospice palliative caregiving is needed.

2.3.3. Communication and Information Sharing

There is agreement among experts in the field that good communication and information sharing is critical to FCGs’ ability to provide care (Cherlin et al., 2005; Higginson & Sen-Gupta, 2000). These two important factors were identified as key to family caregiving in the context of hospice palliative care. Each is described below in more detail.
The unique challenges of communication in hospice palliative care have been recognized. For example, communication may be hampered due to the difficulty family members have hearing or accepting the news that their family member is dying (Cherlin et al., 2005). Even so, communication is important between all who are involved: the ill family member, the FCG, and the health care professionals. Experts purport that FCGs want to discuss fears of death related to their own death as well as the death of their loved one with health care professionals (Goelitz, 2003). They want to feel comfortable when talking about the issues surrounding the incurable disease and begin the work of accepting that their terminally ill family member is indeed dying (Cherlin et al., 2005; Egan & Hovarth, 2006). Unfortunately, effective communication about the emotional, spiritual and relationship issues FCGs may face is often compromised by the failure of health care professionals to discuss prognosis and to clearly indicate that their family member’s life is nearing its end (Cherlin et al., 2005).

There is evidence about what constitutes good communication from the family perspective. In one study, family members were reported to prefer a responsive approach rather than a directive approach from health care professionals (Hudson, Aranda, & McMurray, 2002). In other research, FCGs who experienced good communication with health care professionals described the experience as empowering because they felt listened to and their competency was supported (Ceci, 2006; Holmberg, 2006). However, developing and maintaining effective communication with health care providers has been reported to be difficult for FCGs when health care providers make assumptions or are directive in the delivery of services (Evans, Cutson, Steinhauser, & Tulsky, 2006). Breakdowns in communication may result in the needs of FCGs not being addressed.

Information about hospice palliative care is essential for families to provide hospice palliative home care. For example, a skilled and sensitive introduction to hospice palliative care is necessary for FCGs to be well informed regarding the complexities involved when caring for
their terminally ill family member at home (Duggleby & Berry, 2005). This is critical to informed decision making. There is some evidence to suggest that knowing how to access supports and understanding the health care system, along with knowledge regarding the management of physical symptoms and psychosocial needs, is related to death occurring in the home (Brazil et al, 2005; Egan & Horvath, 2006; Stajduhar & Davies, 2005). FCGs have indicated they would like to know more about caring and supporting their family member, how to navigate the health care system, and how to prepare for and recognize impending death (Ceci, 2006; Hudson et al., 2002). When they do not have adequate information, FCGs are left to make decisions about caring for their terminally ill family member based on best guesses (Ceci, 2006; Cherlin et al., 2005; Egan & Hovarth, 2006).

Effective communication and information sharing requires listening to and understanding what the dying person and their FCG need and want (Ceci, 2006; Higginson & Sen-Gupta, 2000). Proot and colleagues (2003) state that health care professionals who are unaware of the actual needs of FCGs may provide care in the home that is less than adequate and that fails to address informational needs, as well as emotional and psychological concerns. They suggest further research is needed to explore the needs and experiences of FCGs of terminally ill persons who find themselves in a hospital or hospice environment to enhance communication and information sharing in the context of hospice palliative care.

2.3.4. Consequences of Caregiving in the Home

As previously noted, there is some evidence that FCGs are able to effectively provide hospice palliative care in the home, particularly when they receive strong support from other family members and health care providers (Brazil et al, 2005; Ceci, 2006; Holmberg, 2006). Nevertheless, the demands of caregiving in this context can be difficult. FCGs’ quality of life can be severely affected by fatigue and constant adjustments to their role of caregiver (Hudson, Aranda, & McMurray, 2002; Poot et al., 2003). In addition, research indicates that FCGs often
find themselves in a continuous balancing act between “care burden” and the “capacity to cope” and this can have a profound effect on the FCGs’ health and emotional well-being (Proot et al., 2003). Although many FCGs have found the experience of caregiving to be rewarding, some FCGs have found themselves unprepared for the level of responsibility required and have become physically and emotionally exhausted; even with health care provider support (Hudson et al., 2002; Kristjanson & Aoun, 2004). Egan and Hovarth (2006) suggest that understanding the unique experience of FCGs is important to supporting a meaningful and positive caregiving experience at the end-of-life.

There are many studies reporting FCGs’ struggles in providing care to the dying person in the home. FCGs’ experiences of care burden and feelings of being overwhelmed, guilty, out of control and helpless are well documented (Proot et al., 2003; Riley & Fenton, 2007; Stajduhar, 2003). In addition, FCGs have shared their experiences of feeling trapped, alone, isolated and fearing death (Stajduhar, 2005; Stajduhar & Davies, 2003; Goelitz, 2003). It has been reported that FCGs have difficulty in acknowledging their own needs while caring for the terminally ill and often feel uncertain, unprepared and experience great discomfort in addressing the many challenging aspects of care for the dying with health care professionals (Graham, Andrewes, & Clark, 2005; Hudson et al., 2002; Riley & Fenton, 2007). In spite of all the difficulties and challenges FCGs face, what appears to matter most to FCGs is ensuring a comfortable, dignified closure of their relationships with those who are dying (Egan & Hovarth, 2006). The consequences for FCGs when they are not able to achieve this goal are not well understood. However, one Canadian study reports that FCGs felt guilty and experienced a sense of failure when they were unable to keep their promise to care for their family member in the home regardless of the reasons why death in the home did not happen (Stajduhar, 2003).
2.3.5. Is a Home Death Really the Best Death?

Despite preferences for a home death and idealized notions of dying at home, there is some evidence to indicate that there are a number of factors that need to be taken into account when FCGs take on supporting a death in the home. Government policy acknowledges the importance of providing high quality patient and family centered care and the necessity of services that would enable people to choose to die at home (Interior Health, 2008). These services would be equitable and care would be provided by a coordinated interdisciplinary team (Interior Health, 2008). However, in spite of the best of intentions, death at home may not always be possible or appropriate. Stajduhar (2003), for example, found that FCGs often assumed home was the best place for their family member to die, but their experience indicated that this was not always the case. Researchers have reported that FCGs can find themselves unable to cope with a home death in the face of uncontrollable pain and symptoms, or when they are overwhelmed by the enormity of the physical and emotional support required for a death to occur in the home (Brink & Smith, 2008; Dudgeon & Kristjanson, 1995). A FCG who is ill or frail themselves with little or no family support has also been reported to find managing a home death impossible (Brazil et al, 2005; Brink & Smith, 2008; Dudgeon & Kristjanson, 1995). When supporting a home death becomes too difficult, a hospital or hospice admission may be required (Brink & Smith, 2008; Dudgeon & Kristjanson, 1995). Health care delivery system pressures, promises between the individual who is dying and their FCG, the demands of caregiving at end of life, availability of resources and communication difficulties at all levels have all been identified as factors influencing where death occurs (Brink & Smith, 2008; Dudgeon & Kristjanson, 1995; Stajduhar, 2003).

2.3.6. Grief and Bereavement

FCGs’ experiences of grief and bereavement have been a focus of attention in the literature. Kristjanson and Auon (2004) found that for some FCGs memories of the palliative
care experience resulted in complicated grief and feelings of regret. Anecdotal evidence suggests that some FCGs who did not achieve their goal of a desired home death for their family member experienced psychological difficulties and prolonged bereavement; however, this type of caregiving experience has not been systematically studied. We know little about what places particular FCGs at risk of complicated bereavement or prolonged health deficits following palliative caregiving.

2.3.7. Summary

Family caregivers have been the focus of some attention in the literature because of their increasingly important role in providing hospice palliative care to family members. There is a beginning understanding of the complex range of factors that influence their caregiving experiences and their ability to support a home death. However, it is not clear how to provide the most appropriate hospice palliative care services to FCGs when, in spite of preference and the best of intentions, death occurs away from the home. A thorough understanding of FCG experiences is needed to support family caregivers with accomplishing what they truly want and need. In a policy and practice context where home death is being promoted as the best death, better understanding is urgently required in order to provide direction for health care providers and health services. This study was designed to address this critical gap in knowledge.
3. RESEARCH METHODS

3.1. Study Purpose and Objectives

The purpose of this study was to develop an interpretive description of the experiences of bereaved FCGs whose terminally ill family members died away from home when the intent was a home death. The aims of this study were to:

1) Understand FCGs’ experiences of providing hospice palliative care at home with the intent of supporting death at home.

2) Understand the FCGs’ thoughts and feelings when caring for a terminally ill family member when they found they could no longer sustain a desired home death.

3) Understand the influencing factors and decision-making processes that led to death in either the hospital of hospice.

4) Describe the impact on FCGs’ quality of life when expected home deaths were not realized.

5) Describe implications for practice, health care services policy, and research.

3.2. Study Design

A qualitative research approach based on interpretive description was used in this study (Thorne, 2008). In keeping with qualitative research, interpretive description is an inductive approach and focuses on describing the experiences from the perspective of participants themselves. Through the researcher’s interpretation of the experience of the bereaved FCGs, concepts and themes related to their situation can be discovered and explored in depth (Thorne). Data is transformed into a meaningful and logical structure that provides direction for optimizing the quality of care that is given and received (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). Interpretive description research contributes to evidence-based practice in nursing.
because it is a method that captures or represents human health reality (McPherson & Thorne, 2006).

Nursing science addresses human health and illness issues as a set of truths or ideas that are “comprised of the complex interactions between psychological and biological phenomena” (Thorne et al., 1997, p.172). Within these complex interactions, common patterns of the human health and illness experience are generated. These common patterns represent the core of nursing practice knowledge and are where the principles within nursing practice are derived. These common patterns are then individualized to the context of the particular nursing interaction (Thorne et al.). This approach is an interpretive orientation that encourages nursing researchers to take into account an individual’s experiences of health and illness while allowing for shared realities (Thorne et al.).

3.2.1. Sampling

Interpretive description research requires selection of research participants whose accounts reveal the constructed and contextual nature of the human experience under investigation (Thorne et al., 1997; Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004). It is important to recognize that no single research participant can represent the essence of human experience (Thorne et al., 1997). However, sampling in interpretive description is directed toward including people who have lived with the experience because they are the authority on the given situation.

Bereaved FCGs were recruited who had the experience of caring for a family member with advanced cancer in the home, who died away from the home in either the hospital or hospice, in spite of the intent to support a home death. In the North Okanagan, 90% of patients who are on the hospice palliative care program have a cancer diagnosis. Recruitment of participants was through notices in local newspapers, churches, websites, and FCG support groups (Appendix A).
Inclusion criteria for the participants in this study included: an adult 19 years and older who provided care to a family member with advanced cancer care in their home; the death of the family member occurred in an acute care hospital or hospice setting when a home death was desired; was English speaking; and the provision of informed consent (Appendix B). To ensure that FCGs were not interviewed at a time when they were particularly vulnerable, it was originally determined that those whose family member had died in the previous six months would not be eligible to participate (Constantini & Beccacaro, 2005; Ferrario et al., 2005). However, potential participants who were bereaved for less than six months responded to the newspaper advertisements and requested to participate in the study. They were disappointed when they were told they did not meet the inclusion criteria. After further deliberation it was decided that this exclusion criterion affected the participants’ right to autonomy and their ability to make decisions with regard to their own health and future. A further review of recent literature regarding the participation of bereaved FCGs in research indicated that FCGs would let the researchers know if becoming involved in the research was right for them or not, and that it did not cause them undue distress to discuss the option of participating in research (Funk & Stajduhar, 2009; Gysels, Shipman, & Higginson, 2008; Takesaka, Crowley, & Casarett, 2004). The inclusion criterion was amended to include FCGs who requested to participate even though the time since death was shorter than 6 months. Exclusion criteria included FCGs who cared for their terminally ill family member in assisted living, residential care, care homes, and nursing homes. For this study 18 bereaved FCGs were recruited (including both woman and men) and provided informed consented.

3.2.2. Data Collection

The goal of data collection was to get as close to the subjective experience as possible in order to address the phenomena of concern (Thorne, 2008). Following informed consent, data was collected through a single individual semi-structured, audio-recorded interview with the
option of a second interview to insure in-depth understanding and to confirm interpretation. However, the need for the second interviews was not necessary due to the rich data collected in the initial interviews. Interviews were conducted at a time and place that was convenient to the participant and the total commitment of a participant’s time was 2-4 hours. Open-ended interview questions were constructed in such a way to explore the varying experiences of the participants while being cognizant of the sensitive nature of the phenomena being studied (Appendix C). All interviews were conducted with a high level of sensitivity and compassion. The interview approach took into account the potential for participants to re-experience the difficulties of caregiving. Adequate time was factored into the interview process to address the psychological or emotional concerns that could arise. The researcher provided a list of potential psychological and emotional professional supports to the participant prior to beginning the interview. The interview questions were pilot tested and resulted in some refinements to the interview guide. Demographic information was collected at the time of the interview (Appendix D).

The interviews were not easy for the participants. The recalling of their experiences brought back a flood of emotions. Despite this, participants were adamant that they wanted and needed to tell their stories because their experiences and those of their family member could be instructive and help improve care for other families. When participants became emotionally upset, offers by the interviewer to stop the interview were dismissed. Participants focused on intimate details of their experiences to help the interviewer comprehend the significant consequences of the experience both for themselves and their family members.

3.2.3. Field Notes

Field notes (Appendix E) were kept to ensure the interpretation of the FCGs’ experience was comprehensive and contextualized (Thorne et al., 2004). Field notes are a useful descriptive account which supplements the tape recorded data and can aid in remembering the many details
identifying “ideas about relationships within the data” (Morse & Field, 1995, p. 112) and record details about the context of the interview. In this research study, field notes were informed by Morse and Field’s approach for capturing the salient points of the interview and recording the researcher’s impressions of the experiences shared by the participant, as well as researcher and environmental influences during the interview. The field notes were completed within hours after the interview was completed.

3.2.4. Reflective Journaling

Reflective journaling was maintained in order to guide and document the interpretive description process (Thorne et al., 1997). Reflective journaling is a means to “acknowledge and document the nature and substance of the ideas the researcher holds about the phenomena” (Thorne, 2008, p. 109) being studied before and during the research process. The purpose of the journal was to aid the researcher subjectively and conceptually in the analytical process. The reflective journal provided a place to record thoughts, questions, and ideas as the research unfolded.

3.2.5. Data Analysis

Audio-recorded interviews were transcribed verbatim. To address the dialectic between individual cases and common patterns early in the analytic process, data collection and analysis were completed concurrently (Thorne et al., 2004; Thorne et al., 1997). Interpretive description requires researchers to “know the individual cases intimately, abstract relevant common themes from within these individual cases, and produce a species of knowledge that will itself be applied back to individual cases” (Thorne et al., 1997, p.175).

Initial interviews and field notes were reviewed to identify first-level codes. These codes were compared across interviews to develop categories for a coding framework. Once the coding framework was developed, all transcripts and field notes were coded using NVivo 8, a computer software program to facilitate coding and retrieval of narrative data. The focus of this
analysis was to understand through description and interpretation, the patterns, variations, and dimensions of the experience under study (Thorne, 2008). There was a commitment to remaining open to new meanings and ways of understanding the complex interactions between the psychosocial experiences and other aspects of caring for the dying during the data analysis process (Thorne et al., 2004). Although caring for the dying is an individual experience, the focus was on identification of patterns and shared realities (Jacobson, Gewurtz, & Haydon, 2007).

The intent in this study was to collect data until theoretical saturation had been achieved to ensure that the variations inherent in the phenomena had been addressed. This involved seeking out cases that might be contrary to emerging patterns and themes (Thorne, 2008). It is important that the researcher looks beyond superficial features and similarities (McPherson & Thorne, 2006). According to Thorne (2008), interpretive description studies do not have to rigidly adhere to the full scale depth of theoretical saturation found in grounded theory methodology because the intent is not to theorize but rather to uncover knowledge that may be relevant to clinical practice. Exemplars from the data were used to illustrate FCGs’ experiences. Using this approach, a rich description was developed that reflected identified patterns in the FCGs’ experiences.

3.2.6. Credibility

The credibility of this study was supported through the use of multiple strategies including the use of both field notes and reflective journaling (Thorne, 2008; Thorne et al., 1997). In this study, these records included specific analytic decisions and provide an audit trail about how decisions were made, presented, and contextualized. The reflective journaling also provides a detailed record of how knowledge was constructed and how ideas and relations were shaped (Thorne et al., 2004).
In the coding process the researcher consciously set aside pre-conceived notions or assumptions to prevent premature conceptualization of the data (Thorne et al., 2004). During the coding process, data were sorted and organized, and reflective questions were used to deepen the analysis. Data segments that appeared at odds with other data were not discarded; rather these data prompted further inquiry to understand their relationship to emerging themes (McPherson & Thorne, 2006).

Data were verified using a number of strategies. During interviews, probes were used to explore experiences in more depth, clarify issues and fill gaps, and questions were introduced to validate interpretations that arose from the data analysis. During interviews conducted in the later stages of this research, questions were included to verify preliminary interpretations of the data. Experiences of participants were also compared and contrasted to verify emerging themes. Related concepts identified in the literature were used to raise questions about the data and were compared with emerging findings. In addition, verification of the findings was addressed through review and critical appraisal of the process and findings by the researcher and the thesis committee who had expert knowledge of the phenomena and confirmed the findings as conceivable (Thorne et al., 2004). For this study, my own knowledge as a practitioner in hospice palliative care and the expert knowledge of my thesis committee enabled ongoing critical appraisal that enhanced credibility.

As qualitative research acknowledges multiple realities, consistent efforts were made to reflect the perspectives of the participants clearly to add to the credibility of the study (Morse & Field, 1995). This included using the words of the participants in the form of direct quotations to support key findings. Common patterns in experiences as well as differences observed in FCG experiences were described.

Researchers are understood to be translators of the participants’ words and actions. It is imperative for the researcher to be aware of the power that is innate in the social relationship
between the researcher and the participant and to acknowledge that access to the participants’ experiences depends on reciprocity (Corbin & Strauss, 2008; Jacobson et al., 2007). As a nurse whose practice involves working with patients and families in a palliative context, reflective journaling was a way to examine my own biases, assumptions and perceptions and to acknowledge their influence on data collection and interpretation (Thorne, 2008).

### 3.3. Summary

In this chapter the methods used in this qualitative study were described. In the following chapter, a description of the sample and the findings of the study will be presented.
4. FINDINGS

4.1. Overview

The aim of this study was to understand the experiences of FCGs of persons at end-of-life, when preferences for a home death were not realized and resulted in the death of their family member taking place in either the acute care hospital or hospice. These findings represent FCGs’ perceptions of their experiences as reflected in their narratives. Their stories were constructed around the promise they made to care for their family member but were unable to keep for a variety of reasons. As their stories unfolded, the impact and consequences of not keeping this promise and how it shaped their lives were revealed. FCGs were deeply committed to supporting changes that would help others in similar circumstances and to leave a legacy for their family member. They believed that sharing their stories was an avenue to make changes in how palliative care is delivered and received in order to make a difference for other FCGs who find themselves in similar circumstances.

To aid in understanding the context of this experience, this chapter will begin with a brief description of the FCGs. This will be followed by an interpretation of the FCGs’ experiences, from their perspectives, when a desired home death did not occur and happened instead in the acute care hospital or hospice. Exemplars from the data will be used to substantiate the interpretations.

4.1.1. Family Caregivers: Who They Were

Eighteen bereaved FCGs who cared for seventeen terminally ill family members in the home with the intent to support a home death shared their experiences. The death of their family member had occurred anywhere from several months prior to the interviews to seventeen years ago. Of the seventeen family members who died away from home, seven died in hospital and ten died in hospice. The FCGs included five men and thirteen women ranging in age from 23-91. Eight FCGs were spouses and the others were sons, daughters, daughters-in-law, aunts, brothers
and sisters. Eleven FCGs lived in the same home as the family member while they were caregiving. The others travelled back and forth from their own homes. At the time they were caregiving some were retired and others were teachers, housewives, resource workers, students, business entrepreneurs and health care professionals. In addition, many of the FCGs managed a variety of other commitments such as maintaining their homes, other family commitments, relationships, their own health problems and other losses such as the death of a friend or another family member.

4.2. Key Findings

4.2.1. The Promise: To Care for their Family Member at Home until Death

For FCGs the realization that their family members were terminally ill marked the beginning of a transition in their lives and prompted their promise to care for their ill members at home until death. It was difficult to hear the words that their family member was going to die within a short time period and to make plans for the time that was left. One FCG shared how she learned that her husband was dying:

And finally it came to about maybe the middle of August and the cancer specialist said to him, and I was sitting there with him, and she said, “Well there isn’t anything else I can do for you.” And then it just stopped. Boy that’s a shocker. You know, that’s a pretty cold way of breaking it. I don’t know how else you could break it, really. But she said there isn’t any other treatment. And so [my husband] sat quietly for a bit, registered it, and then he said to her, “So how long have I got?” And she said, “Oh two to three months at the most.” And while I had admired her and felt she was wonderful and kind and good all the way through it, but when it came out with that, it was close up the file and get out... leaving us two sitting there. I looked at him, and I don’t care what you say, but you never really see the final at that stage, you don’t. You know that there is no improvement and no chance of a return to being what you were, but you still don’t face the, this is it.
He’s going to die. Well, I thought quickly, I’ve got to do something; I could tell by the look on his face he was shocked too. And I said, “Well, [husband] we’ve just got to make use of whatever time we’ve got left. And we’ll just be happy doing that. And that’s it.” And so, we came, got up, put our coats on, came out, and walked to the car and went home. And I just didn’t know what you do now, to make him see that hey, I’m going to die (FCG 9).

For another FCG the realization that his wife was dying came more gradually as he witnessed her illness progression.

The chemo, the initial chemo had taken quite a toll on her. Not serious, serious, I mean we were still able to go out and do some shopping and stuff like that, but so when she made the decision not to go on this experimental drug, nobody at the cancer clinic would say how long she had. You know and so, oh she could go on for two years or she could live five years, you know… and then [wife] started bleeding from her vagina. She was bleeding a lot, and she refused any more blood transfusions, any more operations. The doctor told us that he could continue to remove the tumours as they grew, but it was, you know, going to take too much out of her and ...of course the tumours in the lungs were continuing to grow too, so. That’s when she started getting, you know, pretty sick (FCG 17).

Although the way in which FCGs came to realize that their family member was dying varied, the realization the end was near prompted a promise to care for their loved one at home that marked the beginning of an intense journey. The promise FCGs made to family members to care for them at home until death was a pivotal event in their lives. Juxtaposed with the realization that their family member was dying, the promise was made reflexively out of love, obligation, and the desire to honour their family members’ wishes in their final months, weeks,
and days. Their promise idealized the idea of dying at home and was made unconditionally and with little reflection.

4.2.1.1. The Promise: Explicit and Implicit

The promise to care for their family member at home and to support a home death was very powerful. Most often the promise was explicitly made, but for some it was implicit. For example, one FCG spoke about how her husband became very ill and wanted to come home from the hospital. She was clear in her decision to support a home death and to do anything to ensure this happened. She said:

So after the second hospitalization, the doctor suggested going to the hospice and he said “No, I want to go home.”… He said, “I want to go home.” And I said, “I will do everything to bring you home, keep you at home, nurse you at home, and run around the clock if necessary. You will be at home (FCG 5).”

For others, the promise to care was implicit; just simply understood. There was an unspoken understanding that this was what the ill person wanted; to die in familiar surroundings at home:

Well I can’t remember, you know if we actually verbalized a lot about it, it just went, when you are on the same wavelength with a person, there are some things that are just innate, you understand about each other and you don’t have to discuss. So, there was just no contest, like I mean we both just knew that was what we wanted, that that was where we were going to go with it and there was just going to be no question (FCG 19).

As one FCG said, the decision to support a home death was just assumed. She cared for her son, who had been away for quite awhile, and who was very much the ‘wayward son.’ To have her son back at home was an incredible gift to her. He loved being home, and she just assumed that he wanted to die there and she wanted to make this happen:
It [home death] was just assumed, you know….He would get up in the morning and say, “Oh look at this place.” And he would look down at the meadow and everything. He did want to die there, and we were certainly prepared to do that (FCG 12).

Other couples had talked about preferences for care when they were dying many years prior to the illness. There was no questioning this decision now that one of them was gravely ill.

It was always the wanted outcome [home death] for sure; regardless of what type of illness. It’s just something we’ve known for a long, long time. Regardless of what type of illness, we just know we knew we wanted to be in our home, together and either one of us would be caring for the other (FCG 19).

A few FCGs recognized that it was difficult to predict what lay ahead. They were committed to doing everything possible for their family member and to care for them at home for as long as they could. However, they realized that at some point things could change and home death might not be possible, despite their promise. As one FCG shared:

Well I said I would do everything possible but of course you don’t know how things are going to progress, right. I’ve really learned to go with the flow and I don’t resist change and things that happen in my life. I was prepared for whatever (FCG 6).

In another situation, both the FCG and the family member considered that there may come a time when they could no longer cope at home:

He was a realist so he understood that there might come a time when he would have to go, but his preference was how much he would love to be in his own home and he didn’t want to be a bother ... but he always said it very lovingly with a lot of affection how much he loved his home. And we always said to him, “Let us know what we can do to make it happen” (FCG 7).
4.2.1.2. The Promise: Underpinnings

The underpinnings of the promise FCGs made to care for their family member at home until death were characterized in important ways. Their promise was constructed out of love, obligation, and the desire to honour the wishes of their family member. In addition, the promise idealized the notion of dying at home. For most FCGs, their promise to care for their family member was rooted in love. Reflected in their promise to care was a deep desire to be with the dying person and show their love through caring. In fact, for some, caring for their family member was equivalent to loving them. This love was shown through being with their family member in all aspects of care, physically, relationally and emotionally. In addition, implied in the FCGs’ promise was a construction of caregiving as a blessing, an opportunity to serve and protect their loved one, and a gift to give to their family member.

I mean it was sad, but it was very satisfying for me to care for this person, that I had such deep devotion for and loved. So, you know it seems strange maybe to say that but it was very satisfying.... We knew the end was coming, we didn’t know when but to be able to spend every waking moment with her in her last year of life was very, very special to me and very satisfying…. This is how I took care of my emotions, was helping [wife] and being there for her. It wasn’t my time. I didn’t want anyone feeling sorry for me, right (FCG I7).

For others, although the promise was rooted in love, it also encompassed a sense of obligation. FCGs felt it was their unquestioned duty and responsibility to care for their ill family member.

And so, he didn’t himself he didn’t want to go to the hospital, at all. He wanted to pass away in the house. [His wife] had mixed feelings, because again, she wasn’t sure if she was able to care for that whole time, and not knowing how long it would take you
know… but [his wife] was absolutely okay with him to stay at home and pass away at home… and he was adamant about staying home (FCG 20).

Also underlying many of the promises was the desire to honour their ill family member’s request to die in their own home and to help their family member live well in the time that was left.

There was an unquestioned belief that home is the best place to die:

His wishes were what we wanted and my mom again was his best friend. To be able to stay at home, in your home that you love, with the person you love who is your best friend, helping to care for you, and she did everything she could right to the end. I think that makes a big difference [pause]. He was able to sleep in his own bed; he was able to eat his own food. He basically had his own life right up until the last three hours, which physically and emotionally and I think spiritually that was a very, very good thing for him and knowing that he had it, and knowing that he had it (FCG 7).

4.2.1.3. The Promise: Unconditional and Without Hesitation

Many FCGs made the promise to care for their family member in the moment. The promise was unconditional and without hesitation:

So he said, you know, “I just couldn’t imagine saying goodbye to you in a hospital, like that, or having the end, and knowing I was in a strange place and you maybe hadn’t made it or whatever, to get here.”… He just didn’t want to be alone....I was determined I’d keep him home. And he said, “Yes, that’s just what I would hope you would say, except I don’t want it to be unpleasant or work for you.” I said, “No, I was in agreement with that.” And we talked about that. We both knew that it was a short span ‘til the end (FCG 9).

Accordingly, the promise involved little forethought. As one FCG explained, when they were told her husband’s cancer was terminal she immediately assured him:
We will strain every cell, every fibre, to make sure that you get the maximum care and I will put myself totally behind your well being, your care, your comfort, these are my priorities (FCG 5).

The promise was the foundation of the FCGs’ commitment to caring for their family member at home until death. Once the promise was made, FCGs were steadfast in their efforts to keep it.

4.2.2. A Promise to be Kept

FCGs immediately enacted their promise by taking up the job of caregiver, despite having only a vague idea of what the work entailed. It was similar to being thrust into a new position with little or no orientation to what is involved. Unprepared as to what to expect, FCGs set out to do their very best to care for their family member. Over time, their world changed drastically and they came to realize that they would need help if they wished to keep their promise to care for their family member at home until death. Their courageous efforts to keep their promise were affected by three major factors – lack of knowledge or preparedness in taking up the job, difficulty accessing the help required and the resulting frustration, and receiving help that was helpful but not helpful enough to keep their family member at home until death. Each of these factors will be described in the following sections.

4.2.2.1. Enacting the Promise: A Labour of Love

FCGs took up the job to care for their family member at home with little if any understanding of the enormity of work involved in providing care. As a result, FCGs found themselves unprepared for the job at hand. Many factors contributed to the unpreparedness FCGs experienced in caring for their dying relative. This included a lack of knowledge of their family member’s expected illness trajectory, insufficient discussion with health care professionals regarding the depth of care required, and a lack of preparedness for the last dying days and hours.
Not only did FCGs lack of knowledge about the expected progress of their family member’s illness inhibit their ability to understand and plan for care, it also caused them significant distress. One FCG described how when she was seeking information regarding the seriousness of her husband’s condition she felt minimized and dismissed by her husband’s family physician. She shared:

The hardest part was we did not medically know or understand what was going on. Because I think so often I would have just liked to talk to one person who knew the whole picture; to be more informed. It was hard to get information on what’s this infection about, why did he get this, and trying to connect with the doctors and just ask questions. And I remember the doctor joking and saying wow you are really persistent. But I was [with emphasis], I was like tenacious, like tell me what’s going on, I need to know (FCG 19).

Furthermore, discussions between FCGs and health care professionals regarding what FCGs could expect when caring for the dying at home were sporadic at best. One FCG spoke about how she had lots of community care involvement; however, discussions related to what would be involved in supporting a death at home did not happen. She explained:

Well, as far as having a home death … there was advice for safety around the house, what equipment to use. Like we got that walker and fixed up the bathroom so it would be a little bit safer so he could use it. That sort of thing… I thought you could have [a death] at home but as far as talking about having him at home, that never came up really [with the community nurses]….Well if he stayed at home I’d have done all of his care. Keep bathing and feeding him all that sort of thing….There was no discussion how that would occur (FCG 10).

FCGs did not hold health care professionals responsible for initiating discussions regarding caring for the dying at home. According to one FCG, she was not even sure if the community
nurses were aware that a home death was being considered. She said that it was not until her son was at hospice that a discussion occurred regarding what dying may look like. She believed it was up to her to find out that type of information:

   It was not until we got the pink pamphlet [in hospice] [What to Expect in the Last Days of Life] [she laughs]. But that is up to me though. I could have got a book….I don’t think anyone ever actually went into detail about the final moments or anything. I’m not sure that they [community nurses] were aware about [our plan for] the home death. … I don’t think there was any kind of complete talk about it (FCG 12).

Over time, FCGs exhausted their personal resources and came to understand that they needed help in order to fulfill their promise to care until death at home. They could not do it unsupported and alone.

   4.2.2.2. Help Wanted

   Just as in all other aspects of keeping the promise, in taking up the job of caregiving, the FCGs worked diligently to get the assistance they and their loved one needed. They were often unsuccessful. Even when there was clear discussion between the FCG, the dying family member, and the doctor, this did not mean that critical information would be received. One FCG spoke about how she and her husband discussed what they wanted with each other and how her husband was clear he wanted to die at home. This was communicated to the family doctor but then never discussed again. As she shared:

   FCG: And it’s really hard, because we knew [husband] was going to die, he wanted to die at home and I wanted him here….When they stopped [husband’s] chemo, it only took him a week to die.

   Interviewer: So, was there ever a discussion with a health care professional at all about the home death? What that would look like?
FCG: No, no. And I had talked to Dr. [family doctor] about, you know, wanting [husband], you know whichever one of us went first, we wanted a home death. And he understood that, that was ok, but then it wasn’t discussed. You know (FCG 11).

This same FCG described how her lack of knowledge regarding the dying process, the problems she might face, and the potential solutions that may be available affected her ability to ask for help. Her lack of knowledge directly affected her ability to keep her promise and keep her husband at home:

Now my thoughts are, if I’d had a clear mind, I would have asked them to put a catheter in. I would have asked for [that]. See I didn’t know [husband] was going to die that fast. [He was only in hospice one day before he died.] I would have asked for help too. I was worried about if I kept him home, we have a queen size bed, I couldn’t turn him, and I was worried that he’d get bed sores. Well if I’d known to ask for a catheter, I could have kept him home. So, if somebody had suggested [a catheter] to me, because my mind was not thinking, I could have kept him home. My mind was thinking he needs more than I can give him [heavy sigh] (FCG 11).

Relationships with health care professionals were frequently strained as FCGs reached out for assistance and support, and found their hopes for assistance dashed. For example, they experienced delays in referrals for their family member to the Hospice Palliative Care Program, difficulty accessing the right support and delays in accessing care. One FCG explained her experience when, even after diligent effort at a time of crisis, there were multiple delays in receiving adequate help:

So the next morning I called and I happened to know the nurse. I said, “Look, something has to be done. It has been three weeks and something has to be done. We need a nurse in there now. We need support in there now because you know, this is just falling apart. We are in crisis. And it’s falling apart.” So this nurse came that next morning and saw the
crisis and said, “I am going to do this, this, and this, I am going to get this rolling, I am going to get that rolling.” Phew... he was there for about an hour and a half which we were dumbfounded by, he really saw the crisis. He went back and got the coordinator for the RCAs [registered care aids] to come and see us, but that didn’t happen for 3 or 4 days. And [coordinator of the RCAs] asked us what we needed, asked us what we wanted. We thought that was going to happen and then NOTHING. NOTHING happened (FCG 15).

Another FCG, who was ill herself, described her difficulty with accessing the right support for her situation. Even simple requests for help were unmet.

So, this is what we needed, you know a little bit more care. I was still doing all of his care, but somebody was here observing me. One time, when I was in the hospital, my sister happened to be here. One of the girls (registered care aid), she wasn’t even allowed to open up his cans of food. And (husband) couldn’t bend to get them, they were in boxes. And my sister was here. She says, “Can’t you get that for him?” And no, she couldn’t. And [sister] opened them, and poured it into the container. They weren’t allowed to do that. So, my thoughts were, we didn’t need them. Other than for his bathing, we could have done it all on our own. But I needed somebody coming in to make sure he was okay while I was in the hospital….I did get respite for awhile, but then I felt I had to go out. And I didn’t want to go out all of the time, I was also sick. So for me to go to a shopping centre and wander around for four hours, didn’t make sense either. So I did stop the respite, which was my doing (FCG 11).

Not all FCGs were comfortable with activities normally performed by nurses, such as seeing blood or giving injections or changing bandages on a wound. One FCG shared how she had to call several times before there was a response to her plea for help:

I was able to call a nurse, like there is, a number available for, I forget what they call it. They gave me a number of somebody to call and she would come in and change the
bandages and check on him. I remember calling several times, I need help. I need somebody to come and look at him (FCG 6).

Other FCGs pointed out problems with lines of communication between their family doctor, other health care professionals and themselves. They spoke about how this had affected their ability to access help and the adequacy of help they received. One FCG described an episode between her family doctor and the hospital emergency department staff. She felt the experience “almost killed” her dying husband, and blamed this situation on a combination of factors including poor assessment by the triage nurse and lack of communication between her family doctor and the triage nurse:

He had become extremely weak [pause] and on the 12th I called the GP…. Anyways, it took to the 15th before I could take him down to the doctor. The doctor had to see him before he could get him into the emergency. We had an appointment to see the doctor at 1:30 [in the afternoon] and the doctor called the emergency right away. He asked us to come back home and wait for the emergency room at the hospital to call us to tell us when to come. We waited in emergency waiting room from 4:30 in the afternoon until after ten o’clock in the evening before they took him in and he was sinking in his wheelchair…. This man was rapidly failing and [the triage nurse] couldn’t see it ….I think that that emergency wait was almost deadly….I think the GP should have triggered the emergency triage nurse that this is moving very fast, you need to do something pronto. He might have done it but he didn’t get the message to the triage nurse [regarding admission to hospital]. I don’t know what could have gone wrong. But my dear husband was sinking so fast, I must have grown grey hair overnight, within hours. I was petrified (FCG 5).

As can be seen in the situation described above, the ‘help’ FCGs received was often significantly delayed and inadequate, putting them and their dying family member in a position
of increased suffering. The help received was not the help they wanted or needed. There was often a critical mismatch of needs and resources that was illustrated above when care aides could not open a can of nutritional supplement. Another example was given by a caregiving daughter who described how home support workers were available to help bathe, dress and feed her father, but her father did not want this. He only wanted his wife to do these kinds of personal activities. The help she needed was with the making of meals, housework and laundry and this was not available to her. She explained:

My father, because my mom is a nurse and because I’m a nurse, wanted, this was his desire, and he wanted only my mom or me to touch him. In fact he only wanted my mom to touch him, in terms of his care…. My mom was doing 24/7 work. She needed support, so I had said to these powers that be, which came into the house, “Look, she needs the support to support him. So can you not [clean] his bathroom and can you not [make] his bed area and can you not hand him a meal, and do respite?” [They said] “Well, yes we can do those things.” But that never happened. We only ever got respite. We got people to come and sit….And he didn’t want to be watched anyway. He was a dignified person, he didn’t want to be just sat there, watched, make small talk with somebody he’d never met before (FCG 15).

Desperate to get support with their caregiving, this FCG shared her frustration regarding the lack of availability of community nurses to respond to urgent care needs. She was informed by the community home care nurses that help would be available if she and her family should run into a crisis and required guidance or assistance. However, her calls to the nurses were often unanswered. When the calls were answered, most of the time the nurses were too busy and unable to come to the home on short notice. Instead, she was directed to take her father to the hospital. She explained how:
[Her mother] couldn’t phone anybody else [frustrated laugh] because she had already been turned away once [by the nurses]. And all it takes really is once to get, I am too busy, take him to the hospital. So, we don’t ask again (FCG 15).

Thus, in addition to extremely challenging caregiving demands, there were the additional burdens of broken promises from health care professionals, dashed hopes, and feelings of isolation.

However, not all interactions with health care professionals were characterized as ineffective. One FCG marvelled at how the family physician kept her informed in all aspects of her sister’s care. The community nurses also encouraged and supported her. She stated:

Well they [nurses] were my support. [The nurse] were there, like how am I doing? They would check on my sister, do whatever was needed to be done there and then they’d come and sit in the living room. “Now I’m concerned about you,” she would say. “Now tell me how are you doing?” Well that would take a little bit of time, because, well how am I doing? You tell me how I’m doing, you know. My job is in there. And yet no, she would take care of my well being. She was the one who talked to her [sister’s] husband, and took time with him. I thought that was very good. She took time with my husband to make sure he was doing okay, and the kids and very supportive. Like I always felt supported and I always felt that if there was anything that I needed, they would be there in an instant if it was at all possible (FCG 13).

Another FCG experienced a sense of appreciation for the care received and explained how she took comfort in knowing that the health care professionals communicated between each other about her family member:

They obviously know what was going on there. And they talked amongst themselves about various patients I guess. And I just felt like we were in the best hands we could ever be in. I couldn’t say enough good things about them (FCG 9).
Another FCG had the opportunity to discuss his brother’s wishes and the types of help that were available with the community nurses:

So the nurses were involved in coming over, meeting, making some notes, if you need us, call us. Yes, it was, there was no aggressive or, not trying to talk us into anything, or anything like that. Just offering help, [discussing] the types of help that they could provide. They gave us brochures [so] we understood what palliative care was and they asked us if we wanted to have an in-home passing or you know whether you wanted to go to hospice care. So there were discussions all about that, like we wanted to have it at home and lots of information (FCG 17).

FCGs worked hard to keep their family member at home until death; however, they were often disappointed with their interactions with health care professionals. Although, there were some positive experiences with health care professionals, over time the help they received was not enough to aid them in their promise in keeping their family member at home.

### 4.2.3. Keeping the Promise: Pushed Beyond Capacity

Under the strain of caregiving, often around the clock, the consequences of being unprepared, and pushed beyond capacity - relationally, physically, and emotionally were acutely felt. FCGs’ trust in the health care system was eroded, and they increasingly felt alone and unsupported. They witnessed the increasing physical suffering of their family member and this took a huge emotional toll. In addition, some FCGs experienced apprehension regarding their caregiving abilities. One of their biggest fears was that if they revealed how difficult managing at home had become, they would be pressured by health care professionals to have their family member cared for in hospital or hospice. In spite of these circumstances, they were determined to fulfill their promise:

And only I know that when I brought him home from the hospital after the second hospitalization, I confided in a nurse. I said, “I am so scared.” She said, “Why don’t you
tell the doctor that?” I said, “If I do, he won’t let him go home and he wants to go home.”

So I will somehow put my head in its place and make sure that I won’t fail him (FCG 5).

### 4.2.3.1. Erosion of Trust and Now All Alone

When FCGs received help that was not helpful or found their concerns not taken seriously, this resulted in a significant loss of trust in the health care system and a sense of increased vulnerability. FCGs had no choice but to fall back on their own inner resources to do what needed to be done, and they pushed themselves to try to manage. One FCG shared how in spite of having various professional supports in place she felt isolated in her caregiving. She looked forward to her son’s visits because she felt emotionally all alone and needed moral support. She explained:

> Oh my goodness, I went insane. Mind you, I had not been sitting on my haunches, as I was nursing him I was up and down [the stairs]. There were times where I must have gone up and down [the stairs] 64 times in the day. There was a door bell, there was something else. Doctors coming, palliative care nurses coming, it was just incredible. I stopped thinking of myself as a person because things have to be done.... Even with my son coming, after a 24 hour trip, I didn’t expect anything out of him. I just needed some moral support because I had been struggling on my own entirely with no help, with absolutely no help (FCG 5).

The feeling of being all alone was magnified for those who were in many cases losing their life partner, the person they would normally share their angst, their hopes, and their dreams; the person they would go to when they felt all alone. One FCG described her thoughts on the loss of her father in terms of her mother’s and father’s relationship:

> But when a stressful thing like that happens, and it was very stressful, she was losing her best friend, she’s losing her husband, she’s losing her mate, her partner, her everything. You want to be there for her and watch out for her but not baby her because she needs to
feel all those emotions and go through the process as well…. So, for her it was a tragic incident; she was devastated to lose the love of her life. They were so close. They were best friends all their lives (FCG 7).

4.2.3.2. Witnessing Suffering

The majority of FCGs made reference to witnessing suffering as the most difficult part of caring for their family member:

But there were times when I would be looking after her and I would just be crying inside because she was in so much pain. We had a pump, what do they call it, a subcutaneous pump, for the morphine…. We had that put in; oh I’m not even sure when that went in, but that went probably September, maybe. But she had no muscle, no nothing left even to absorb anything. The only thing that could absorb in there was her skin. And so it really didn’t take away the pain and she would be on 900 mg of morphine, I mean it would have killed me six times over and it wasn’t relieving her pain. Her pain in her back was so horrific as the tumour just kept squeezing the nerves. Oh my goodness, it was just awful (FCG 13).

FCGs felt helpless as they witnessed frightening symptoms of increasing restlessness, personality change, nausea, vomiting, breathlessness, and pain. They became very aware of their own limitations and this pushed them to a place of desperation:

And I think that watching, whoever it is you are caring for, watching them suffer, you do, you feel helpless. You want to make it stop. You want to make them feel good. You want them to feel happy. A lot of the time, you can’t do that. You can do what you can, to ease the situation, and you can distract them a bit. You know you can do little things to distract them so they don’t realize how much they are suffering, but you can’t, especially when someone is terminal with cancer, you can’t take that away. You can be there and do what you can for them, but you can’t take that away. That’s a reality and that’s a hard
thing as a caregiver. I think that was probably the hardest thing for me. Sometimes when it got really, really bad I think, oh, you don’t feel inadequate, but you do in a lot of ways feel helpless, no matter how helpful you are. You do, for sure. It’s a tough one, yes (FCG 7).

4.2.3.3. Exhausted and Desperate

FCGs were available 24/7 to their family members and over time as the magnitude of the work increased they became exhausted and at the same time more desperate to find a way to fulfil their promise for a home death. FCGs spoke of the immense amount of physical care they provided to their family members that filled the days and often the nights. The care they provided included bathing, massaging, transferring, positioning and repositioning, toileting, lifting, and managing medications, wound care dressings, colostomies, and tube feeds. In addition, they managed incontinence, changing bedding, laundry and making meals. They described how when caring for their loved one it did not matter how much time it took or how intense the requirement for caregiving – what mattered was fulfilling their promise.

As family members’ health deteriorated it became progressively important for FCGs to be vigilant for changes for the worse during both the days and the nights. One FCG recounted how she would lie awake in the night listening to her son’s every turn, every footstep and every cough, always ready to offer help, and assistance as required. However, this took a further toll on her health to the point where she could no longer set her own health concerns aside:

And so I would get up every day, I would set the alarm every 2 hours and give him more meds. And sometimes I would sleep downstairs and set the alarm and come up. But you are so conscious of him moving around, you may as well be in the same room. And I think that is why I had this little episode that sent me to the Emerg, just kind of hit the wall, you know, I had numbness and tingling in one hand and I had a dizzy spell, and I
just thought you know, this isn’t right. I need to check this out. As it was, I think it was just God saying, you can’t do this 24/7 (FCG 12).

Another FCG spoke about her silent vigilance and her increasingly grave concerns as she watched her sister begin to waste away to a skeleton of her former self despite best efforts to nourish her. She said, “But it was the hardest thing to see her fade to nothing. Just to nothing. Yes, those last two weeks she didn’t drink anything, she didn’t eat anything, she just faded to nothing” (FCG13).

It was not unusual for FCGs to find themselves burning the candle at both ends until there was nothing left in the middle. They had nothing left to give and it affected all of their relationships:

I was so stretched. I never felt more stretched thinner ever in my whole life as that. Particularly the last four months. I would say that every other relationship suffered. My primary relationships suffered. It certainly suffered with all my children. Who are, two of them are university bound and I have a 12 year old. I did nothing well. I could not be a good partner (FCG 15).

They found themselves existing, numb, and doing what had to be done. One FCG stated, “It was just existing, you know. You don’t really register what you’re doing and you kind of go through it a bit on the numb side” (FCG 16). On top of the increasingly intense work of caregiving, FCGs’ unwavering commitment to their family member and a home death meant that they continually put the well being of their family member before their own. They often tried to ignore signs of exhaustion:

I just wanted to be on top of myself. I did not think about how I felt. That was not the time to feel. That was the time to DO [bangs table with emphasis]. And so that was what kept me going. I said I will do all the crying and all the worrying afterwards (FCG 5).
The constant adjustments made to schedules and routines of life to accommodate increasing needs for care diverted their attention. When they were not providing direct care, their time was filled with taking their family member back and forth to appointments and tests as well as managing the shopping, bill paying, and the work inside and outside of the home. All the while, they were also the main communication link with family, friends and health care professionals. Some FCGs admitted that as caregiving became more intense they no longer paid attention to their own health issues or taking interest in their appearance:

I ignored my own health because I had so much on my mind with [husband]. I ignored tell-tail things that were the matter with me, I put off making appointments to go to the doctor, and I didn’t make appointments to get my hair cut (FCG 11).

FCGs lost also the places in their home where they would have gone to find quiet or solitude and regroup. Their previously private bedroom was now a place of care filled with hospital equipment. Their home was so longer a private sanctuary because it became filled with many visitors coming and going. Their ability to leave the house at will was limited by the care needs of their family member. These experiences contributed to FCGs increasing exhaustion and desperation.

In the context of increasing demands for care, inadequate support, and extremely high levels of emotional and physical fatigue, FCGs’ doubts about their ability to manage another day became more prominent:

I was feeling very overwhelmed by just you know, just having like these interruptions all in the night you know with the falling and, just every, all of those things, I felt like it was a very heavy burden for me and just very emotionally burdensome as well. I felt bad, I felt guilty, but I wanted her to stay in the hospital when we took her there to get checked. And she definitely didn’t…. So that was hard for us, but you know we wanted to respect that. After a couple of days in hospital, we moved her back to the house (FCGs 18).
As caregiving became increasingly more difficult, FCGs found themselves exhausted and began to doubt their ability to carry on. Their ability to keep their promise to ensure a home death for their dying family member became increasingly compromised.

4.2.4. Shattered Promise

All FCGs found themselves in situations where the toll of caregiving became simply too much and the arrival of unexpected events disrupted the FCGs’ ability to keep their family member at home. In hindsight, the unexpected event became the last straw that precipitated a final trip to the hospital or hospice, although it was often not recognized as their last trip at the time.

4.2.4.1. The Last Straw

The events that precipitated transferring family members out of their home to hospital or hospice were unexpected and often influenced by FCGs’ lack of knowledge and ability to cope with increasingly complex and difficult caregiving responsibilities. FCGs did not know what to do in situations such as sudden shortness of breath, constipation or dehydration. They were unsure what to do when their family member collapsed, experienced a seizure, became incontinent, experienced new and/or sudden pain, or their temperature skyrocketed. These were significant changes to their family members’ health status that FCGs did not anticipate or plan for, and for many these changes became the “last straw” in an exhausting struggle to care for and provide a home death for their family member. Scared and worried about their family member, and with no other perceived option to manage urgent problems, they reluctantly reached out and called other family members, 911, the nurse line, or the hospital for help. No one responded with options that would enable the dying family member to receive help and to stay at home. Instead, FCGs were told to bring their family member into hospital or hospice. One FCG explained it this way:
When she was starting to drown in her own fluids, I knew I couldn’t help her. I knew I couldn’t help her, I knew that I had helped her right up to this distance in her path and I knew if I had the suction I probably could do something more, but I couldn’t get that. They didn’t provide that. They denied that to me. And so, I talked to her about that, in her incredible state, I mean she died 15 hours later, so then I felt really bad. I had horrific feelings of letting her down, I talked to her about that, I’m so sorry, I said, “I’m so sorry. I wanted this to be the way you wanted it to be.” And she said, “I know, its fine.” [I said] “I can’t get a suction [machine] and you need help with that.” And she understood, she understood. It was more important to me that she understood than anybody in the family (FCG 13).

For another FCG, it was his wife’s disorientation and attempts to leave the home that was the last straw. He described his experience of struggling to keep her safe.

We had a terrible, terrible night, I was up all night, with my wife, I could not reason with her. Um, I’m pretty sure that was the night that she fell off the toilet as well, but I would try to get her to go to the commode and she would fight that. I’d get her back into bed, and then, she’d be okay for a bit and then she was up and saying, “I’ve got to get out of here, I’ve to get out of here, I don’t want to be here, why are you keeping me here? I don’t like it here, take me home, take me home.” It was just, that’s all she could say. And it was everything I could do to not argue, you know like, but I would say we are home. And she’d [say] “No we’re not, no we’re not” (FCG 17).

He called his daughter for help and his daughter, who had hospice experience, arranged for her mother to be transferred to the hospice:

And I phoned [daughter] and I said I don’t know if I can do this anymore [crying, pause]. And [daughter] came down and she said dad, it’s time to put her in the hospice care [crying]. And I said that I’d be breaking my promise. She said you have no choice dad,
so, we called the ambulance and she died two days later [crying, pause]. We almost got there, but, [pause] at least she was peaceful at the end. I don’t know what we could have done different but, I just, I always tried to honour [wife’s] wishes (FCG 17).

As exemplified in the quote above, even though some FCGs realized that they had reached the limit of their ability to carry on with the help that was available to them, they experienced feelings of unbearable guilt, betrayal, and failure as they began to recognize that they were breaking their promises. Many were devastated by letting their family member down in this way. The distress this caused was vividly recalled several months to 17 years after the events. One FCG described her sense of failure:

I never realized that he would go where I couldn’t look after him like that. So when the nurses came in to give him that suppository that’s when they said I couldn’t do it anymore and that he should go to hospice. And I still was against it. Because I knew that he wanted to stay here [home]. But when I tried to get him on that commode [sighs] I couldn’t [get him onto the commode]. So I told the nurse, she had left, but she came back, because I had to sign something. So she got my husband to agree to go in...and I knew he didn’t want to go. And I felt like I failed him. I still feel that way. We’ve been together almost, well, 49 years. And the one thing, I mean he didn’t ask much of me, and I couldn’t do it [softly crying] (FCG 12).

FCGs did not know what dying looked like. They seemed to have no idea that symptoms such as breathlessness, restlessness and dehydration were common symptoms at the end of one’s life and were critically unprepared. FCGs were unaware of what resources, equipment and supports that might have been available to help them manage to stay at home in these unexpected situations. The majority of FCGs called the hospital or the emergency room directly for assistance and they were told unanimously to come in for an assessment. Other FCGs
experienced nurses coming to the home, assessing the situation, and again unanimously recommending a transfer to the hospice or hospital.

No one was listening to the subtext of the FCGs’ promise to care for their family member at home. FCGs explained that healthcare professionals didn’t give them any choices; the focus was on solving the problem of perceived caregiver burnout and unmanageable symptoms with a transfer to hospital or hospice care. Even when health care professionals acknowledged the guilt FCGs experienced, they continued to recommend taking the family member out of the home into a different environment and did not take into account the profound effect on FCGs when they realized they were breaking their promise:

So as I was talking to her [palliative nurse], she says, I know you’re feeling guilty, but this just has to be done because I just couldn’t look after him anymore. I just, it was hard to explain how, what thoughts were going through. I felt like I was betraying him, I was just turning over, just like I was putting him in prison or something. That’s about the feelings that I had (FCG 9).

4.2.4.3. Leaving Home (Forever)

When there was no other option but to seek care at the hospital or hospice, FCGs found themselves on two different paths albeit with the same ending. The majority of FCGs viewed the move of their family member out of the home as temporary for a variety of reasons. The expectation was for their family member to receive essential help and for the FCG to experience respite from care. Most FCGs fully expected their family member would return home. One FCG describes how her father’s final visit to hospital was viewed as just one more crisis to be addressed that could not be managed in the home. They had experienced several trips to the hospital and each time her father returned home they did not seem to be given the option of extra supports in the home. This final visit was just another crisis similar to other crises which precipitated the previous trips to the hospital:
It was another crisis. Like there were so many crises like that. Going over to that house was a crisis…. The intent was never to go to hospice. [Laughs]….. Yes, the intent was to go back home again. It was just another crisis. Which we had had many times before right? And we always went back home. We always felt, oh my God, what are we going to do with him at home, because every time it was harder. This had been going on for a year now. This was a year that we had been racing him to the hospital, for haemorrhaging or like horrible things, so we were pretty desperate by then. We really needed somebody at home (FCG 15).

Another FCG explained that it was her lack of knowledge about what the final days of life would look like that led her to believe her husband would return home:

Nobody had said to me, “Look we should talk about what you might face in the end.”

That’s a very important thing to tell a caregiver. I was just walking in a dark hall. I expected him back home, oh yes. I did. He always was [a person who said], think in the positive; you don’t think they are dying. You just think, oh he’ll be back. I’ll just pull the covers up and make the bed fresh for him, you know (FCG 9).

A few FCGs struggled with awareness that this would be a permanent transfer to hospital or hospice and their family member would die away from home. Although dying at home no longer seemed to be an option, the idea of breaking their promise brought feelings of guilt and remorse:

And we got him to hospice. I went out of the room as they settled him down in there. I think they preferred that while they settled him, for me not to be there I think. So, as soon as they settled him down there, I came home. But, I had to sign the papers to get him in there. I felt like I was betraying him. I felt like some kind of Benedict Arnold or something that was betraying him. I felt very guilty about having to put him in there, that I couldn’t look after him myself anymore. It felt just horrible (FCG 11).
Along with FCGs’ realization that their family members would die away from home and the painful awareness that they would not be able to keep their promises, was the difficult task of relinquishing caregiving to others. In an effort to continue to demonstrate their love and commitment, most tried to find ways to continue to care for and support their family member in their dying process. For example, they provided some direct care such as helping to get blankets and refreshments. They provided directions to nurses about their family member’s preferences to help ensure they were kept comfortable. They stayed as close to their family member as possible:

I basically washed him, I [did his] peri-care, and I gave him back his oxygen, and all that and resettled his bed, changed his blue pad….And so I set him back up in his bed, repositioned him, and all that and got rid of everything and then I just sat with him (FCG 20).

FCGs whose family member died in hospital shared that their memories of the experience were primarily of tests and interventions. For example, blood work was taken, x-rays were obtained and intravenous therapy was initiated – all precipitated by the unexpected event that prompted them to leave home. FCGs remained close by to help in any way they could, ready to take their family member home when the problem was resolved. Although it was a pattern they were familiar with because they had gone through similar admissions in the past, they began to realize that this time might be different:

When I got there they had started testing him and checking him out, they had him hooked up I believe to the IV, etc. and all the basics. We briefed them as best we could as to all his conditions we could remember and where the cancer was ….. And I think we probably all suspected, including him…something was changing very, very drastically (FCG 7).

Discussion, regarding the imminent death of their family member seldom occurred:
I don’t remember them saying, like taking mom and I and saying, you know, “your [name] probably has, you know 24 hours left,” you know, or something like that, just to sort of give you a clue…. But now when I think about it, just the way they set him up in that room, nobody said anything, but I think in some way we must have known (FCG 8).

Although dying in the hospital was not the ideal, FCGs were grateful the hospital was able to provide a comfortable, peaceful place for dying:

The fact that he had a private room was really important. I felt like we were just together often, we would just sit there and I felt that they really respected our time together. They left us alone.... It was meaningful, just the fact that the people could come and go in his room (FCG 6).

In this study, most of the ill family members died in hospice. For many FCGs hospice was about transitioning from life to death. Hospice was more than a place to take care of the suffering of the human body; it was a time of gathering, of saying good bye, and of continuing to live until the final moment:

So, I just couldn’t say enough [positive things] about hospice. They had a couple of you know needles, they were just sub-q, and if he got gurgley, right away they gave him some of what they do now, I can’t remember. They just kept him so comfortable and we had the music going and people talking. And I phoned his ex-wife, and said you better come up and bring his three sons. They came in that night, just talk to him, and to tell him you are going to be fine. And they all together, and then singly, spent some time with him. And then his two very dearest friends both came in and spent a few minutes with him and he was gone at 2:30, 3:00 in the morning. It was just, it was choreographed (FCG 12).

Although hospice is oriented to family-centered care, unfortunately, the needs of some of the FCGs were not always recognized. As FCGs valiantly attempted to fulfill their promise to
care for their family member until death, albeit with a shift away from home, their efforts were
sometimes minimized:

I’d gone in everyday to see him, but the nurses at the hospice told me, you shouldn't be
coming in so much, because it might be too hard on you coming in so often. Then she
told me to just to limit [the visits] to two or three times a week. Because the nurse says,
he doesn’t really realize that you’re here. But… well I thought, maybe I’ll still come; he
might be a little bit of him still there, for me, for him to know that I’m there (FCG 10).

FCGs were exhausted and varied in their ability and desire to be involved in caregiving;
however, this was often not assessed. For example, in one situation the hospice staff were
focused on the task at hand and, as the FCG recounted, missed the emotional turmoil their
questions provoked:

He was failing when one of the nurses asked me, “We are going to put a catheter on
him.” By that time, I was not myself anymore. I said, “Do what you have to. Don’t ask
me to be present. I can’t take it anymore. [Starts crying softly] I can’t take it.” But these
nurses should of had the common sense not to [taps at the table] put a catheter, put a
diaper on him. That is common sense; you don’t want to indurate the poor man who is in
his final stages. We have seen enough of death to know what terminal stages are like.
You don’t start sticking a catheter into a person at that time. Common sense tells you put
a diaper [crying] but don’t turn to the caregiver for what they are going to do. I couldn’t
for the life of me take anymore (FCG 5).

Connection to their dying love one remained of utmost importance and many FCGs
spoke about the importance of physical touch in the dying process. They expressed a strong need
to be physically and emotionally close as they continued walking the journey towards death.
Whether in hospital or hospice, when they talked about the family member’s death itself, if they
were not in intimate physical connection at the moment of death they expressed a sense of deep loss:

I wasn’t doing much else other than to hold him, hold his hand. Yes, they were washing him, they were turning him. When they wanted to wash him, we would just go out, you know [sighs]. I mean it was quite, we would sit there and we’d talk, we’d cry, we’d laugh, we’d remember things. In fact I, when [my husband] did die, I didn’t see him die and I’d been holding his hand. I’d been watching his breathing, and my sister went down to get me some juice and a muffin … she brought me a muffin and juice and I had to turn to take it from her. Just after she gave me the muffin and I was saying thank-you, she say’s, look at [husband] and he was gone. That was the first time I had let go of his hand [sniffles, soft cry] (FCG 11).

4.2.4.3. Living with a Broken Promise

FCGs experienced a profound sense of having personally betrayed their family member because they were not able to keep their promise. No matter how committed they were to caring for their dying family member at home until death, their promise was still broken. Although death in hospital or hospice was perceived to be peaceful and suffering was relieved, it became clear that for FCGs their family member’s death could not be described as a good death. Location of death mattered to the FCG. Regardless of how good and peaceful the death was, the fact was their family member did not die at home. They expressed huge disappointment and loss that their family member died somewhere else:

So, I can’t speak for my mom how that was, but, you know for me, it was a tad of relief [for father to go to hospice] just because I knew he would be well looked after and we could sleep at night and my mom could sleep at night. So again, it was kind of torturous because it felt like we didn’t get to do what we wanted to do with dad, which was to keep
him at home. So we were relieved, but he wasn’t at home. We brought him to the wrong place. It was still really the wrong place (FCG 15).

As FCGs reflected on their experiences they emphasized that the decision to go to hospital or hospice was made in the moment of crisis. They struggled with the reasons they allowed the transfer of their family member to hospice or hospital. Some continued to question if they did the right thing allowing their family member to go to hospice or hospital. They talked about how in hindsight, if only they had been offered an IV, a catheter, a suction machine, oxygen or medications, their family member could have stayed at home. They shared how if they had had the ability to think at the time or had been more prepared for caregiving their family member could have died at home:

Well again I think it was just our circumstances were such that this odd behaviour at the end got us totally by surprise and I wasn’t prepared… I hadn’t anticipated that, that’s the one thing I guess, if I had any inkling that might have happened, then maybe I could have prepared for it. Maybe we would have had her on the proper medication beforehand (FCG 17).

Breaking the promise held deep meaning for FCGs. They felt extreme remorse and regret. They were angry, disappointed and sad with themselves at being unable to keep their promise and have their family member at home. Although initially experiencing profound guilt and despair, over time many FCGs found ways to make a semblance of peace with the situation. FCGs found the experience taught them many things about themselves and about dying. Some FCGs tried to rationalize the experience and shared that when they looked back on the experience, the care given in hospital or hospice was better than what they could have given in the home. They told themselves they had done the best they could under the circumstances. One FCG stated “I did the best I could. And I don’t know what else I could have done. There was nothing else I could do” (FCG 13).
Other FCGs found renewed reasons to be alive and found strength within themselves that they had not known previously existed and others found connection in reciprocity. Many FCGs spoke about not just the giving of care but of the appreciation they received back from their family member. FCGs learned about dying with grace and dignity from their family member, and they learned they were strong, resourceful and capable from the experience. FCGs also learned that in caring for their dying family member, there was satisfaction in knowing that the care they gave was given in love. They learned the importance of living every day while dying:

What did it teach me? Appreciation for every day, looking at the world through his eyes ... every day is a bonus. So it taught me to appreciate life. He handled it so amazingly well, and bravely, and stoically that no matter what happens to me I am not, I look at him as a pattern to be able to deal with stuff. So it taught me the value of life, umm, to stop and smell the roses. That was his thing...Talk about talking and smelling the roses, I mean that was the story of his life (FCG 12).

Although FCGs recounted their efforts in learning to live with their broken promise, many FCGs carried profound sorrow, grief and regret for years afterward. As one FCG poignantly said:

Like there isn’t a day probably that goes by that I don’t think, wow, it’s such a sad thing. You know that he didn’t die where he wanted to die. You know that was his last wish, you know and that didn’t occur (FCG 19).

**4.3. What Would Have Helped: Family Caregiver Suggestions and Advice**

The majority of FCGs participated in the study in memory of their family member and as a way to honour that memory. They appreciated the opportunity to share their experiences in the hopes that they could help others in similar circumstances. FCGs wanted to contribute to make caring for the dying a more positive experience and to be an agent for change as a legacy for their family member. They wanted others to hear about their experiences so they might benefit
from learning about the personal challenges and successes of caring for the dying in the home.

They wanted to be instrumental in preparing others for what might be involved in caring for the dying. One family caregiver shared how she hoped that her “experience going through this might help someone, some husband, at least anticipate that it could happen and what to do if it did (FCG 17).

FCGs were forthright in their recommendations regarding the types of support, resources and information required to support dying at home:

1. The FCG must be recognized as an important and essential part of the dyad – FCG and the family member – in the planning, implementing and evaluation of the care of their dying family member.

2. The FCG must be included in discussions regarding the likely progression of their family member’s disease and anticipated time frame. The FCG requires this information in order to make decisions regarding care.

3. The FCG requires an advocate – a health care professional who knows and understands the situation and the people involved.

4. The FCG desires competence, kindness and compassion in their interactions with health care professionals.

5. The FCG needs to be aware that it takes more than one person to be able to support a home death.

6. The FCG needs to know what is available in terms of support and resources including how to access them.

7. The FCG needs to be prepared for what the last hours and days of life look like and what they can do in the home to provide comfort.

8. The FCG needs educational support to be prepared to care for the physical, emotional and relational aspects of care for their ill family member at home.
Overall FCGs advocated for the provision of both emotional and practical support by health care professionals for other FCGs. They wanted other FCGs to be prepared and to understand what kinds of things were available to help them when planning for a home death of their family member:

I mean, how would it help somebody else, or what kind of things could be brought into the system that could help somebody? I guess you can’t blame the nurses or doctors in the hospital or the homecare worker or whatever, but if I had of been more aware, I would have prepared my own self for what could be. Like you can take a prenatal course [so why not] take some kind of end-of-life review or something. This might help you to know something about what to do or how to do it. For us, it was a pretty helpless kind of scenario; very ignorant on my own part and my mom’s part. It was a very ignorant position to be in and [we were] totally helpless with not knowing what was going on. Like what would you do about it [caring for her Dad at home] and having any kind of anything there; like we had no drugs, no NOTHING (FCG 8).

4.4. Summary

The major themes represented in the FCGs’ experiences revolved around the profound promise to care at home until death. The reality of caring for their family member was physically, emotionally, and relationally more challenging than they expected. In fact, FCGs were pushed beyond their capacity, and struggled to get the support they needed. The final move from home to hospital or hospice occurred in the moment in response to an unexpected event. The move was constructed more often as a temporary measure as opposed to an admission to hospice or hospital until death; either way, the family member died away from home and the FCGs’ promise to care until death at home was broken. The breaking of this promise was significant and FCGs struggled to forgive themselves for not being able to keep their family member at home and for letting them down.
5. DISCUSSION

5.1. Overview

In Canadian society there is an idealized notion that expected deaths should occur at home. This notion is supported by an Ipsos-Reid 2004 survey which reports that over 90% of Canadians would like a home death (The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, 2004). Stajduhar and Davies (2005) identify dying at home as a cornerstone of a good death. The idea that home is the best place to die is also embedded in the minds of many health care service professionals and policy makers (Stajduhar & Allan, 2008). However, much of the research regarding this premise is from the viewpoint of the dying family member and little research has addressed this topic from the perspective of the FCG. This qualitative interpretive description study addressed this gap in the literature. I explored the experience of bereaved FCGs when a desired home death of their terminally ill family member with advanced cancer was not realized and resulted in the death of their family member in either the acute care hospital or hospice.

The study findings detail FCG experiences when they were unable to keep their promise to care for their family member at home until death. The major finding in this study is the significant and long-term consequences to the FCGs when they were unable to keep their promise to care for their family member at home until death. The promise was of vital importance to the FCGs in this study. As FCGs sought to keep their promise, they were pushed beyond capacity to a place of exhaustion, desperation and isolation. They were unprepared for the enormity of the physical, emotional, and relational challenges of caregiving at end-of-life. When health care professionals were unable to meet FCGs’ needs, they lost trust in the health care system. Their promise to care for their family member at home until death was shattered by a series of events which led to the last straw and precipitated a final trip for their dying family member to hospital or hospice. FCGs found it extremely challenging to reconcile with breaking
their promise to care for their family member at home until death and many were unable to do so. There were profound consequences and bereaved FCGs struggled to live with their broken promise. They experienced profound feelings of guilt, betrayal, disappointment, loss, remorse, and regret. Although the death of their family member was described as peaceful; the death could not be described as a good death. Their family member did not die in the place of their choice and the FCGs’ promise to care at home until death was irrevocably broken.

In this chapter, the key findings of FCGs’ experiences associated with the broken promise to enable a home death will be discussed in relation to the existing literature and our current understanding of family caregiving in palliative care. This will be followed by discussion of the implications of study findings for practice, policy and research, and the significance of the study.

5.2. Promises for a Home Death: Ideal vs. Reality

The archetype regarding dying is about relationship; enjoying last days and hours through quiet conversation and finally dying peacefully and comfortably with all the family present. It was within this picture perfect archetype that FCGs in this study made the promise to care for their dying family member. The ideal of a home death was one that FCGs could easily identify with and they promised to support a home death in response to their dying family members’ expressed wishes. Others have also described the loving promises made by individuals to care for their dying spouse at home that are based on desires to be together and to experience closeness and security in maintaining everyday life (Fisker & Strandmark, 2007; Stajduhar & Davies, 2005). Although promises to provide a home death can be made when both partners are well or before the reality of advanced terminal illness becomes apparent, they reflect strong commitments. For example, Stajduhar and Davies (2005) described FCGs’ promises to care for their family member at home until death in the context of making marriage vows. The findings from the current study also point to the strength of these promises, and the high level of distress
that resulted when FCGs realized they would not be able to keep their promise to provide a home death.

This study found that the promise to care for a family member at home until death was made in the moment with little reflection. FCGs wanted to honour their dying family member’s wishes and felt a deep sense of love and responsibility when making this commitment to care. There was little evidence of FCGs thinking the promise through before making the decision to care. Even so, the promise demonstrated remarkable commitment. Stajduhar (2003) describes how FCGs in her study experienced lack of choice in caring their dying family member; instead, it was perceived to be an obligation. At least some of the participants in this study were influenced by a sense of obligation, but, for most, it was a sense of commitment that underpinned their promises.

Regardless of the basis of promises to provide caregiving, the results of this study indicate that FCGs had little idea of what would be involved. There was virtually no discussion with health care professionals regarding what caregiving may look like at the end-of-life either at the outset of caregiving and throughout the experience, or the potential effect on FCGs if they were unable to care for their family member at home until death. Underlying the stories told by FCGs were the assumptions that FCGs were capable and competent to take up the job with little involvement by health care professionals. It seemed that everyone, the FCG, the dying family member, and the health care professionals expected and took for granted that FCGs would care for their dying family member at home regardless of the cost, and with minimal preparation and support. While providing care to their dying family member was extremely meaningful to the participants, they acknowledged that the burden was high. Yet, we know that one of the primary goals of dying persons is the alleviation of burden for the family (Kuhl, 2002). The findings of this study raise numerous questions in relation to expectations of family members to become caregivers and the decision to support a home death.
The study findings point to the critical need for families, including both ill member and caregivers, to receive support from knowledgeable health care professionals around decision making, caregiving, and preparing for death. The study participants experienced a lack of health care professional involvement in decision making that seriously impeded their ability to make informed choices about caregiving. Appropriate and timely information is clearly needed to provide the basis for decisions about caregiving. The consequences of taking for granted FCGs’ ability to provide home deaths without adequate information, preparation and support are clearly demonstrated in this study. Although FCGs made sincere and committed promises to provide a home death, the reality of keeping these promises became increasingly difficult when they often single-handedly struggled to manage complex and often unpredictable caregiving needs. Although FCGs held intimate knowledge of their family members’ preferences for care, they recognized they lacked essential knowledge and skills to provide symptom management as well as the information they required to recognize and support active dying. Without the support of health care professionals, they found themselves in situations where they could not provide the ideal home death they were striving for.

It is disturbing that FCGs remain unprepared for caring for the dying in the home given the consistency of research findings and clear recommendations on this topic that have been published over the last few years. Many authors cite the importance of health care professionals having conversations with FCGs regarding disease progression, what to expect, and how to care for their family member at home (Cherlin et al., 2005; Herbert, Schulz, Copeland, & Arnold, 2009; Holmberg, 2006; Kristjanson & Aoun, 2004; McLaughlin, Sullivan, & Hasson, 2007; Mangan et al., 2003; Proot et al., 2003). Farber and colleagues (2011) note that health care professionals are doing a disservice and are disrespectful when these conversations are not valued as an expected part of care and this is certainly evident in the narratives of the participants in this study.
This study raises questions regarding the ideal of a home death and whether it is an attainable goal even when FCGs are deeply committed to providing a home death. The disconnection between the ideal of a home death and the reality of the FCGs’ experiences has been reported in other studies (Fisker & Strandmark, 2007; Stajduhar, 2003), and it appears that little progress has been made in reducing this gap. In clinical discussions about home deaths, questions need to continue to be raised about who will provide caregiving, and assumptions challenged about the ability of FCGs to provide care to dying family members at home without adequate support.

5.3. Experiences of Caregiving

The findings in this study concur with the existing literature that FCGs face many challenges which lead to exhaustion and desperation (Singer, Bachner, Shvartman, & Carmel, 2005). The need for constant vigilance, being available 24 hours 7 days a week, along with the physical work of caregiving that were added to FCGs’ usual household and family responsibilities have been described in other studies (Fisker & Strandmark, 2007; Hudson, 2004; Proot et al., 2003; Stajduhar et al., 2008). Furthermore, the toll on FCGs of this extraordinary work has been recognized (Proot et al., 2003; Sutherland, 2009).

What was interesting in these findings was how, even with little or no preparation regarding the actual caregiving involved with supporting a home death, many FCGs knew what they needed. Unfortunately, for the most part they could not get it. They knew they needed someone to listen to them, hear them, and help them anticipate difficulties. McLaughlin and colleagues (2007) addressed the need for health care professionals to increase awareness by talking with patients and families about the types of supports that are available. Similar to the findings in this study, McLaughlin and colleagues found that too often professional support and advice was offered much too late, generally after the FCGs has reached the point of exhaustion,
or only in the immediate period of active dying. In this study, the lack of relatively simple but critical resources such as a catheter, commode, or subcutaneous medication administration route, actually prevented a home death.

5.4. Fear of Caregiving Being Taken Away

When considering the reasons why FCGs may not have initiated the conversations necessary to find out what was entailed to support a home death, it is important to keep in mind the context of the promise FCGs made to care for their dying family member at home. In this study, the promise to care for their family member at home was based on an idealized picture of what that would look like including the comfort of home and the loving presence of family and friends. Little thought was given to death itself and how to live in ever shifting sands as their family members’ conditions deteriorated. Farber and colleagues (2011) alluded to the ever changing environment experienced by FCGs and the importance of health care professionals having conversations that seek to understand the values and goals of both the person who is dying and the FCG. What has not been adequately described in the literature is the finding that FCGs were hesitant to discuss concerns or raise questions with health care professionals. Similar to Holmberg (2008), the FCGs in this study thought that if they asked questions it might reveal their struggle in caregiving and result in health care professionals transferring their family member out of the home. They were worried that revealing vulnerability jeopardized their ability to keep their promise to care until death at home. FCGs often did not want to take this chance, so instead tried to manage the best they could on their own. At times of crisis, FCGs had no choice but to call on health care professionals. At these times, FCGs were consistently advised to bring their family member to hospital. This practice appeared to reinforce FCGs’ fears that they might not be able to fulfil their promise if they disclosed too much or asked too many questions and, ultimately, this proved to be the case.
5.5. Caregiver Burden

Family caregiving at the end-of-life is hard work, and there is a continuous balancing between care burden and the ability to cope (Proot et al., 2003). In this study, FCGs acknowledged the importance of self-care and although they had little time for themselves, many initially found time to maintain their exercise and prepare healthy meals. However, as their family member’s illness progressed and caregiving became more than a full-time endeavour, self-care became non-existent. These findings are supported by Hudson (2004) whose participants found they had no time for themselves and, in fact, were no longer able to leave the home, which resulted in them feeling trapped and isolated.

Witnessing their family members’ suffering was the hardest part for FCGs. Indeed, unrelieved physical suffering was the tipping point for FCGs that led to leaving the home for care and their broken promise. Others have recognized the psychological anguish FCGs may experience when witnessing their family members’ distress and the helplessness they feel when they are unable to relieve their family members’ suffering (Kristjanson & Aoun, 2004). When FCGs are poorly prepared for their role, their ability to comfort and aid in relieving suffering is markedly decreased (Hudson, 2004). However, there is evidence that caregivers’ ability to care for themselves may be a stronger predictor of their caregiving efficacy irrespective of the difficulty of the caregiving situation (Merluzzi, Philip, Vachon, & Hietzmann, 2011).

The importance of these findings related to FCGs’ diminishing ability to care for themselves is also underlined by research that demonstrated that ability to engage in self-care behaviours is highly related to caregiver stress and perceptions of burden and that improving FCGs’ ability to care for themselves may be critical to enhancing caregiver efficacy and preventing caregiver burnout (Lu & Wylke, 2007; Merluzzi et al., 2011).
5.6. Good Death: From Whose Perspective?

The majority of FCGs in this study described their family member’s moment of death as peaceful and their dying family member as comfortable. From an outsider’s viewpoint, these deaths looked like good deaths. Society tends to look at a good death or a bad death solely from the perspective of the dying person. Shiozaki and colleagues (2008) described a good death as a situation where there are no regrets, particularly for FCGs who will continue on. However, the majority of FCGs in this study came away from the death of their family member with intense feelings of regret despite having given their all in providing care. Their family member did not die in the place of their choosing. They had broken their promise. Even though months, and sometimes years, had passed since the death, the majority of FCGs had not made peace with the fact that they had broken their promise and their family member had died outside of the home. They comforted themselves with the knowledge that the death had been peaceful and comfortable, but from their perspective, it was not a good death. These findings emphasize the importance of taking the family perspective into account when making judgements about ‘good’ vs. ‘bad’ death and the support that is necessary in bereavement follow-up.

5.7. Complicated Bereavement

Bereavement can be described as the experience of losing to death a person to whom one is attached and grief refers to the emotional distress related to the loss (Zhang, El-Jawahri, & Progerson, 2006). Complicated grief is a psychological protest against the reality of the loss and certain aspects of the phenomenon (Zhang et al.). The effect of excessive bitterness related to the death is taken into account, and often involves intrusive thoughts of regret (Shiozaki et al., 2008; Zhang et al., 2006). Kristjanson and Aoun (2004) suggest that memories regarding the palliative care experience may follow family members in the bereavement period and have the potential to complicate their grief and leave them with feelings of regret. It was evident that many of the
FCGs in this study experienced complicated bereavement. This has been noted in other settings where people have traumatic experiences around death. For example, Wright and colleagues (2010) noted that when a person who has been previously identified as terminally ill and palliative dies in ICU, their FCGs have a high risk of post traumatic stress disorder (PTSD). Even when the death of their family member occurs in the acute care hospital, there is a higher risk of complicated bereavement (Wright, Keating, Balboni, Matulonis, & Block, 2010). The findings of Wright and colleagues focus on the acute care setting while the findings of this study focus on home. For these FCGs, it was death away from home that placed them at risk of complicated bereavement. The findings regarding the implications of place of death are not at all conclusive. Some researchers have reported higher caregiver burden (Carlsson & Rollison, 2003) and higher levels of bereavement distress (Addington-Hall and Karlsen, 2000) associated with home versus hospice death. In contrast, others have found more positive bereavement outcomes in relation to home death (Brazil, Bedard, & Willison, 2002a; Grande, Farquhar, Barclay, & Todd, 2004). A recent study exploring the experience of relocation from home to hospice at end of life found that family caregivers took advantage of the opportunity to relinquish the burden of caregiving and shift their focus to their relationship with the dying person, which may have implications for bereavement (Waldrop & Meeker, 2011). Perhaps one of the factors related to the difference in bereavement outcomes for caregivers is whether a promise was made to support death at home. The findings of this study extend our understanding of complicated bereavement in that FCGs may experience trauma when they are unable to keep their promise to care until death at home.

There are good reasons why it is so important to pay attention to the aftermath on the FCG when a promise to support a home death is broken. Based on the findings of this study, it may be important in bereavement care to include an assessment of whether a promise to provide a home death was made and the extent to which this promise was realized. The long-term
consequences for FCGs who are unable to keep their promise to care for their family member at home until death should not be underestimated.

5.8. Does Home Death Equate to Best Death?

Informing many Canadian policies and guidelines regarding hospice palliative/end-of-life care are the findings of the Ipsos-Reid 2004 survey which cites that 94% of Canadians wish to die at home (The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, 2004). The British Columbia Ministry of Health (2006) has developed policies and guidelines based on the premise that over 90% of British Columbians wish to die at home. The Ministry of Health advocates for British Columbians to have the right to die at home and to be supported by the health care system to do so. Preferences have now been translated into rights and home death is viewed as the ‘gold standard.’ Currently less than 25% of British Columbians are dying in their homes and the findings of this study suggest that despite the rhetoric, there is little support to do so (Province of British Columbia, Ministry of Health, 2008). There is a disjuncture between government, health care authorities and individuals promoting and advocating for home deaths and the actualization of this desire.

This study highlights that although people want to die at home and their family members are committed to having this happen, this may be extraordinarily difficult to achieve. Other researchers have noted the discrepancy between FCGs’ expectations regarding a home death and the reality of the care that can be provided by health care professionals (Wennman-Larsen & Tishelman, 2002). In British Columbia, the health care system has begun to organize around the belief that home is the best place to die and the majority of British Columbian’s who think they want this, but necessary supports are not keeping pace. In this context, FCGs’ choice to caregiving may be pre-empted and the wishes of the dying person may be privileged, creating significant burden that lasts beyond death. This is the antithesis of what dying people actually want. It may
be that we cannot adequately support home death for at least some of the people who wish to die at home. As the movement gains momentum and the number of people dying increases over the next few years, this situation will only worsen. Consideration has not been given to the fact that people do not always die easily. It is not like in the movies (Stajduhar, 2003).

5.9. Implications for Practice, Health Care Services Policy, and Research

Thorne (2008) explicates the importance of research advancing the knowledge in a particular field and identifying specific contributions to the existing literature. She describes interpretive description research as a method of scientific inquiry that generates nursing practice knowledge and supports evidence-based change in practice and policy. In this section attention will be given to the contribution of the study findings to practice, policy and future research.

5.9.1. Implications for Practice

The findings of this study have a number of important implications for practice. The FCGs in this study clearly described their experience of making a promise to care for their dying family member to support a home death and their distress at finding themselves unable to keep their promise. Lack of health professional involvement compromised informed decision making. Active involvement of health care professionals with both the seriously ill person and potential FCGs in discussions about values and goals of care, and decisions about caregiving as well as end-of-life preferences for care is essential. Ongoing assessment regarding caregiving and the promise to care at home until death is necessary. Further, for families already engaged in the work of hospice palliative caregiving, assessment to determine whether a promise has been made for caregiving until death at home is important. If a promise has been made, discussion must occur with both patient and the FCG about illness progression, anticipated caregiving needs, how needs may change over time, and how available resources can be mobilized to support the
promise and a home death. Potential limitations in providing needed support for caregiving must be acknowledged so that expectations can be adjusted as needed.

FCGs need to be reassured that the health care system is there to help, and the aim of care is to support caregiving in the home. But only to the extent that is realistically possible. False reassurance added to the burden that our participating FCGs experienced over time. Opening the discussion of what help and support is available provides an opportunity for FCGs to discuss issues and plan for, if the need arises, different courses of action. Acknowledging the significance of the promise FCGs make, the challenges of caregiving, the expectation that they cannot do it alone and unsupported, and the importance of early intervention through anticipating and addressing problems as they arise are integral components of care (Stajduhar, 2003; Sudore & Fried, 2009). These discussions provide an opportunity for FCGs to reframe their promise to acknowledge and plan for circumstances that may make a home death no longer a desirable or achievable outcome.

Health care professionals should acknowledge that it is common for FCGs to struggle at times and that when this occurs help can be provided through a variety of resources such as the family physician, palliative care nurse, local hospice houses, nurse help line, or the hospital. At the same time, it is vital to acknowledge that FCGs may require reassurance that accepting assistance does not mean their family member will be removed from the home at the first sign of trouble. The instinct health care professionals sometimes have to take over and quickly solve the situation would be best held at bay. Stajduhar (2003) found that although patients and families received excellent care from health care professionals, there were situations where FCGs felt their roles were undervalued or usurped and decisions were made regarding what was best for their family member without seeking input from the FCGs. These findings were echoed by the participants in this study. It is important that nurses take cues from the family while at the same time, anticipating needs and being realistic about what can and cannot be offered. Time needs to
be allotted to help FCGs work through the situation and opportunity given to determine where the best place for care may be in any given event, be it home, hospice or hospital. To suggest to FCGs that it would be best to bring their family member in to hospital or hospice requires careful and thorough assessment first.

5.9.2. Implications for Health Services Policy

There is an expectation that hospice palliative care can be supported in the home through adequate preparation and resources (British Columbia Ministry of Health, 2006). However, the findings of this study suggest that much work remains to achieve this goal. Policy discussions need to take place on all levels. The assumption that a home death equates to the best death under any circumstances needs to be questioned. The needs and resources of FCGs must be acknowledged. Furthermore, it may be useful to engage communities in discussions of what makes an ideal death that are not limited to the place of death. End-of-life care policy supports individuals in having a choice regarding desired place of death (British Columbia Ministry of Health, 2006). Choice implies that there is discussion and reasonable options, and that there are resources available to support the choices made. According to this study, discussions with health care professionals to support decisions about place of death did not take place, and resources were often not available to support home deaths when they were needed most.

Currently in Canada, only between 16% and 30% of the population access hospice palliative and end-of-life care services although 90% of deaths are expected (Canadian Hospice Palliative Care Association, 2010). With an aging demographic in Canada, the number of expected deaths will only increase. According to the Canadian Hospice Palliative Association, Statistics Canada projects the rate of deaths in Canada will increase by 33% between 2004 and 2020, equating to more than 330,000 per year. In 2004, Canadians estimated that at least 54 hours per week was required to care for a family member in the home and 64% of those polled
indicated they would not be able to commit to these hours of caregiving (The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, 2004). Clearly there is an urgent need to clearly define policies related to supporting home deaths and FCGs who provide care in homes.

5.9.3. Implications for Research

The study findings indicate that prospective studies of the experiences of FCGs who are supporting home deaths are needed to identify both short- and long-term interventions in order to effectively support good death. Documenting the experiences of FCGs who are able to provide home deaths may also be helpful in determining the factors that make it possible for them to fulfill their promises. Effective approaches to support patient and FCG decision making about home deaths are also important. Decision aids have been found to be useful in supporting decisions related to health treatments (O’Conner, Stacey, & Entwistle, 2003). It is possible that similar types of decision aids could be developed to support decision making related to place of death.

5.10. Study Significance

This study provides a rich description of FCGs’ experiences and provides an avenue for hearing voices that are not often taken into account. In this way the study provides some critically important insights and direction for the provision of hospice palliative care. However, the findings must be considered within the context in which the study was conducted. The interviews were conducted with bereaved family members who were recruited from one health authority; therefore, the findings might be different in a region where there are different supports in place. The sample for this study was relatively small, homogenous and focused on FCGs caring for family members with advanced cancer. The findings may not reflect the experiences of other bereaved FCGs who cared for family members with other life-limiting conditions and
further research may be warranted to explore the experiences of family caregiving within a non-cancer diagnosis. All participants were English speaking and cultural differences that may influence caregiving experiences were not explored. As well, the small sample did not enable considerations of gender as they relate to caregiving.

This is the first study investigating the experiences of bereaved FCGs who promised to support a dying family member at home but were not able to fulfill their promise. Therefore, this study makes a significant contribution to the literature on palliative care and family caregiving.

5.11. Reflecting Back

Interpretive description takes into account multiple realities, including that of the researcher. One aspect of my reality was that I am an experienced palliative care nurse seeking to better understand the complexities involved in the delivery and receipt of hospice palliative care from a FCGs’ perspective. I embarked on this research because of a patient’s wife’s story that profoundly affected me in a way that made me question nursing practice within hospice palliative care. According to Thorne (2008), the researcher’s engagement with the study participants affects the quality of the data, and the researcher’s skill in interviewing and the relief participants may feel in finally being heard must be taken into account. Most certainly my position as a Palliative Care Coordinator working in the same environment that I was researching shaped the way the data was collected and interpreted. Because I was a nurse, participants may have said things to me that they might not have said to someone from another discipline. This excerpt from my reflective journal highlights my own reaction to a participant’s honesty and determination to tell her story from beginning to end, from diagnosis until after death, in spite of the emotion she experienced in the telling:

It is so intimate to hear and witness her story. It is so unbelievably personal and oh so raw. She closes her eyes and she is with him. And when she had points to make she
insisted I write [the points] down…. I left the interview feeling very soulful and introspective….I feel profoundly sad….SOMETHING is seriously missing in the care of the dying…. (Reflective Journal, 2009).

In spite of being an experienced palliative care nurse practicing in the same world as the participants, many of their stories brought me to tears. The experience of data collection, transcribing, and coding was intense as the stories were powerful, raw, and difficult to hear in spite of my vast experience in hospice palliative care. Although I felt privileged to hear and witness their stories it was difficult to do so many interviews back to back in such a short period of time:

- It is another wet, dreary, winter day. So unbelievably dreary. I don’t want to do this. I don’t want to take on anymore stories. I just don’t. I had no idea how utterly difficult this would be to hear dying stories, so intense, so emotional, so close together…. (Reflective Journal, 2010).

Thorne (2008) speaks about the importance of the researcher taking time to step back out of the data, particularly in the analysis and to create some distance from the analytic process. I found that emotionally I needed to take a break and regroup before I approached the next steps involved in the research. These breaks allowed me to create a distance from the process which enabled me to go back into the data and challenge my early assumptions, intellectual linkages, and to take another look at the developing patterns (Thorne). I realized that once I got past my own emotions and the participants’ emotions, I could hear their stories much clearer and was able to move deeper into the analysis phase.

I have been asked what I would have done differently to manage the emotional aspects of being a researcher in this type of research. This was an extremely difficult experience that raised many questions for me about ethical palliative care. I would have ensured debriefing sessions with my supervisory team and initiated professional counselling earlier in the process. I
would have allowed more time between the scheduling of the interviews. What helped me in the research process was my thesis committee supporting me when I needed to take a break from the process. I realized it was important to look after myself and I took time to go outside for walks and hikes, and appreciated quality time with my family.

5.12. Conclusion

This study adds to the small but growing body of research on FCGs who care for a family member dying at home by detailing the experiences of FCGs when they are unable to keep their promise to care for their family member at home until death. The promise to provide a home death was significant and of vital importance to the FCGs in this study. The experiences of FCGs reported in this study illustrate the consequences when they are inadequately prepared for caregiving and did not receive the professional support they needed. However, fears that their family member would be removed from their home if health care professionals were made aware of the difficulties and anxieties they were facing with caregiving, often deterred FCGs from asking for help. FCGs’ despair about not being able to keep their promise for a home death increased the risk of complicated bereavement. The potential of inadequate support leading to increased suffering for dying family members and negative effects on the FCG health cannot be ignored. As hospice palliative care is increasingly shifted into homes and caregiving responsibilities handed over to family members, adequate resources and supports must be in place and accessible at the time they are needed. A commitment to ‘good’ death being home death without an equivalent commitment to preparing and supporting FCGs creates unacceptable suffering and burden for the most vulnerable in our society.
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Have you had the experience of caring for a family member when a desired home death does not occur and happens instead in either the acute care hospital or hospice?

Researchers from the UBC Okanagan are interested in talking with you about your experience.

TO LEARN MORE ABOUT THE RESEARCH PROJECT
Call and leave a message with your contact information at 250-807-8627 or by email topfl@interchange.ubc.ca
Appendix B: UBC Okanagan - Informed Consent Form (Family Caregiver)

Title of Project: When a Desired Home Death does not Occur: Family Caregiver Experiences

Principal Investigators:
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Dr. Joan Bottorff, School of Nursing, University of British Columbia-Okanagan XXX-XXX-XXXX

Co-Investigator(s):
Lorrianne Topf, Graduate Student, School of Nursing, University of British Columbia-Okanagan
Dr. Penny Cash, School of Nursing, University of British Columbia-Okanagan
Cathy Robinson, MSN, School of Nursing, University of British Columbia-Okanagan

Background and Purpose of the Study
This study focuses on gaining an understanding of the experiences of family caregivers when circumstances prevent a desired home death for a family member with advanced cancer. The goal of this study is to identify ways to provide more effective and meaningful support to family caregivers. A family caregiver is defined as the person who provided the majority of the emotional and/or physical care for the family member. This can include immediate family, friends, and neighbours. We will be seeking a total of 15-20 family caregivers for this study.

Study Procedures
You are being asked to voluntarily participate in this study because you have cared for a family member with advanced cancer in the home, who died in either the hospital or hospice, in spite of the intent to support a home death. We are interested in hearing about what this experience was like as well as how it could have been improved. Your participation will involve completing a questionnaire that includes demographic questions and one, possibly two individual interviews. The second interview would be to ensure understanding and clarification, if necessary, from the first interview. The interview(s) will focus on your experiences, and how decisions were made to transfer your family member to the acute care hospital or hospice. We would like to learn about what went well and what did not go well and what this was like for you. The interviews will be face-to-face and will occur in a comfortable, private setting of your choice and at a time that is convenient for you. The total time commitment of your participation will be 2-4 hours depending
on the number of interviews. If an in-person interview is difficult for you, you may choose to participate in the interview by telephone.

The interview will be recorded and typed out by the graduate student, Lorrianne Topf and possibly a transcribing secretary. Interviews will be reviewed and analyzed to describe the experiences of family members when a desired home death of their family member does not occur.

**Risks and Benefits**
Minimal risks are expected from participation in this study. The researcher will have a list of psychological or emotional professional supports available to the participant in her/his region. This list will be provided to participants if needed. As a token of appreciation for participating in the study, each participant will each receive a $5 Tim Hortons gift card for each interview.

**Funding**
This research is partially funded through the Canadian Association of Nurses in Oncology Novice Researcher Grant.

**Confidentiality**
This study is a part of the requirements for completion of a graduate degree (Masters of Science in Nursing; student, Lorrianne Topf) and information from this study will be part of a thesis (public document). Information collected in this study may be used for teaching purposes without revealing any information that identifies you. You will not be identified in any reports of this research.

Your name will not be associated with the thesis document, the audio taped interviews, or the typed transcripts. A code number will be used. The information will be stored in a locked file cabinet and computer files will be password protected. After the study is completed, your information (data) will be stored in accordance with the University of British Columbia (UBC) Okanagan and Interior Health policies and procedures. Data that has had all personal identifiers removed will be stored electronically indefinitely (a minimum of 7 years) at UBC Okanagan in Dr. Robinson's research lab and will be password protected. At the end of the study audio-tapes will be demagnetized, paper copies shredded, and CD's destroyed.

Access to your data will be restricted to the graduate student's masters committee and the Regional Ethics Boards (UBC Okanagan and Interior Health). All who have access to the data will be trained in the appropriate methods of handling and storage of confidential qualitative data. A secretary may be hired to transcribe some of the audiotapes. If so, we will seek an experienced transcriber. He/she will be educated on confidentiality issues and will be required to sign a confidentiality form.

If you agree, information from this study will be used again in a secondary analysis to investigate caregiving experiences to improve advanced cancer care programs and services. This secondary analysis will be subject to a prior review and approval by the Research Ethics Board. You will be invited to sign a separate consent form for this secondary analysis.

**Consent**
Your participation in this study is entirely voluntary. You may refuse to participate or withdraw at any time without any consequences or explanation. If you choose to refuse to participate or
withdraw, you will have the choice of whether the information you have given us will be used in the study or destroyed.

By signing this consent form, you are agreeing to participate in this study and acknowledge that you have received a copy of this consent form for your own records. By signing this consent form, you do not waive any of your legal rights.

If you have any questions or desire further information, you can contact Dr. Carole Robinson at (250) 807-9882 or Dr. Joan Bottorff (250) 807-8627 or anyone on the research team. If you have any concerns about your rights or treatment as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598 and/or the Chair of the Interior Health REB through the Research Office at (250) 870-4602.

I have read the above information and I have had a chance to ask any questions about the study and my involvement. I understand what I have to do and what will happen if I take part in this study. I freely choose to take part in this study and have received a copy of the consent form.

______________________________  ________________________
Participant’s Signature              Date

______________________________  ________________________
Witness Signature              Date

If you choose to participate in this project, please indicate if you would like to receive a project summary and your contact information.

☐  I would like to receive a project summary at the address listed below:

_______________________________________________________

_______________________________________________________

_______________________________________________________

☐ Participant’s Copy

☐ Researcher’s Copy
Appendix C: UBC Okanagan – Interview Guide: Sample Questions

Interview: The Experience of family caregivers when a Desired Home Death does not Occur but Happens Instead in The Acute Care Hospital Or Hospice

Date:
Place:
Interviewer:
Interviewee:
Interviewee:

1. **The Illness Story and the Family Members Involvement (Context)**
   Many family members have cared for their own family through a cancer illness. I am interested in learning about the kinds of thoughts and feelings you experienced when you cared for your [husband, father, mother….] when in spite of the plan to have a home death, your [husband, father, mother….] [passed away / died (caregiver’s language)] away from home.

   Before we begin to talk about that experience, I would like to understand better, what happened for you when your [husband, father, mother….] got very ill.
   a. And then what happened?
   b. What happened next?

   It would be helpful for me to know how you were involved in [his / her] care.
   a. Over what period of time were you involved this way?
   b. What happened next?
   c. And then what happened?

2. **(Home) Wanting to Die at Home**
   I understand from what you have told me the plan was for your [husband, father, mother….] to [passed away / die] at home. Would you tell me more about that?

   When did it become apparent to you that care was shifting from curing the cancer to providing comfort and quality of life?
   a. At what point did you begin to think or talk about dying?
   b. Who most wanted for your [husband, father, mother….] to [pass away/die] at home?
   c. How did you come to know this?
   d. How were things going?
   e. What was going well?
   f. What was not going well?
   g. Then what happened?
3. (Transition) Transfer to Hospice/Hospital: Decision Making
You have gone through this very challenging time and I realize that the decision to support a home death for your [husband, father, mother….] did not go as originally planned. I want to know about your thoughts, feelings, and what you did when all of this occurred.

I would like to know about what it was like for you in the time when the decision was made for your [husband, father, mother….] to transfer from home to [hospice/hospital]. It would be helpful for me to understand how it all unfolded and to appreciate what went well and what did not go well.

a. How were you involved?
b. Could you tell me more about how this was for you?
c. And then what happened?
d. What did you think or feel about that?

When did you realize that it would not be possible for your [husband, father, mother….] to [pass away/die] at home?

a. What else was happening at the time that influenced this?
b. How did this affect you?
c. How were things changing for your [husband, father, mother….] at this time?
d. How were things changing for you?

I am really interested in how decisions were made regarding your [husband, father, mother….] leaving the home to go to the [hospice/hospital]. How did you come to make this decision?

a. How were others involved in this?
b. What helped you in making this decision?
c. What got in the way?
d. When did you know that it was time for your [husband, father, mother….] to go to the [hospice/hospital]?
e. How did this happen?
f. What was this like for you?
g. What was this like for your [husband, father, mother….]?
h. What was this like for the others in your family?

4. Arrival to and the Hospital/Hospice Experience
I would like to learn more about what was it like for you once you and your [husband, father, mother….] got to [hospice/hospital] and the time that you spent there? I’d like to know more about what happened and how you were thinking and feeling?

a. Could you tell me more about how this was for you?
b. And then what happened?
c. And then what did you do?
d. What did you feel about that?
e. How did this affect you?
5. **(Consequences) Thoughts and Feelings about Home versus Hospital/Hospice**
How were you involved in the care provided for your [husband, father, mother…] in the [hospice / hospital]? How was this the same as the care you provided in the home? Could you tell me more about that?
- a. Tell me more about how you were involved.
- b. And then what happened?
- c. And what did you do?
  - a. What was the impact on you?
  - b. How troublesome was it for you? (Optional, depends on the other answers)
  - c. How are you managing now?

6. **(Learning Experiences) Challenges and Meaningfulness**
Looking back at this experience of wanting to support a home death for your [husband, father, mother…] and then to find yourself in [hospice / hospital]

- a. What was the most meaningful or rewarding part for you?
- b. What was the hardest or most challenging part for you?
- c. What did this situation teach you?
- d. What did you learn about yourself?
- e. What would you do differently, if anything, if you would do it again?

7. **Caring for Yourself**
We are aware that that caregiving can be hard work. We would like to know more about how you looked after yourself during this time.

What did you do to stay healthy while you were caring for your [husband, father, mother….] at home; during the transition to [hospice / hospital]; and after the transition.

- a. What got in the way of staying healthy / taking care of your own health?
- b. What do you think would have helped?
- c. What would have made a difference?

8. **Looking Back**
Looking back and knowing what you know now, would you still have wanted your [husband, father, mother….] to [pass away / die] at home?

- a. **IF YES** – What would have made this possible?
- b. **IF NO** - Tell me more about this.

9. **Advice for Others**
Knowing what you know now, after having this experience, what advice or suggestions would you give others caring for their family members at home where there is a preference for a home death?

- a. Do you have any other advice or recommendations?
- b. What about for health care professionals?
10. **Anything Else**
Is there anything else you think is important for us to know that I have not asked you about today?

   a. Can you tell me more?

**Other Probes:**

- What do you mean when you say "------"?
- What did you think about that?
- How did you feel about that?
- What happened then?
- Can you tell me more about that?
- Could you please elaborate?
- I am not sure I understand about "------" would you please explain that to me?
- How did you handle "------"?
- How did this affect you?
- Can you give me an example of "------"?
Appendix D: UBC Okanagan – Demographics

<table>
<thead>
<tr>
<th>FCG Demographic Data Sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date: ____________________</td>
</tr>
</tbody>
</table>

1. In what year were you born? ____________

2. Gender: □ Male □ Female

3. How would you describe your ethnic or cultural identity? _______________________


5. Religious Preference: □ Catholic □ Protestant □ Jewish □ Sikh □ Muslim □ Other (specify) ______________________ □ None

6. What is your highest level of education?
   □ Less than high school
   □ High school
   □ Technical and non-university education (college; CEGEP)
   □ University (undergraduate, bachelor’s degree)
   □ University (post-graduate degree, master’s degree, doctorate degree; post-doctorate degree)
   □ Other (specify) __________________________________________________

7. What do you consider to be your main activity?
   □ Caring for family
   □ Working for pay
   □ Going to school
   □ Recovering from illness / on disability
   □ Looking for work
   □ Unemployed and not looking for work
Retired
☐ Other (specify) __________________________________________________

8. What was/is your usual occupation or profession? _____________________________

9. In general, compared to other people your age, would you say your health is

☐ Excellent?
☐ Very good?
☐ Good?
☐ Fair?
☐ Poor?

10. How were you related to the person you cared for?

☐ Spouse
☐ Parent
☐ Partner
☐ Sibling
☐ Child
☐ Other relative
☐ Daughter-in-law/son-in-law
☐ Friend

11. When did you first learn of your family member’s diagnosis of cancer?

__________________________________________ [month/year]

12. When did you first decide to support a home death for your family member?

__________________________________________ [month/year]

13. How long did you care for your family member at home before she/he was transferred to the acute care hospital/hospice? ________________________________

14. What was the length of time your family member was in the acute care hospital or hospice on their final admission? ________________________________

15. In what community do you live? ________________________________

16. Where did you live at the time you cared for your family member?

☐ In the same home as the person you cared for
☐ In the same community as the person you cared for
☐ Other (specify) __________________________________________________
17. Did you register for and/or receive any community or home care nursing services while you cared for your family member? Please tick all services that were received.

- Palliative Care Program
- Community Care Nursing
- Home Care Nursing
- Home Support Workers
- Bath Assist at Home
- Bath Assist away from Home
- Occupational Therapy
- Physiotherapy
- Social Work
- Respiratory Therapy
- Dietician Support
- Integrated Care Coordinator
- Hospice House Services (Counselling, Library, Volunteer)
- Other (specify) ____________________________________________

18. What is your (FCG) household income in the last year from all sources before taxes?

- Under $11,000
- $11,000-25,000
- More than $25,000-50,000
- More than $50,000
- Don’t know/prefer not to answer
Appendix E: UBC Okanagan – Field Notes
(Modified from Morse and Field, 1995)

<table>
<thead>
<tr>
<th>UBC Okanagan – Field Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>When a Desired Home Death does not Occur: FCG Experiences</td>
</tr>
</tbody>
</table>

**Participant Identification Code:**

**Date:**

**Start Time:**    **End Time:**

**Pre-Interview Goals**

**Locale** *(description of where the interview took place)*

**Location of Interview** *(physical room)*

**Description of the Environment** *(personal environment)*

**People Present** *(interviewer, participant, other people present)*

**Motivation to do the Study** *(of the participant)*

**Content of the Interview** *(key words, topics, phrases)*

**Researcher’s Impressions** *(discomfort of participant with certain topics, emotional responses)*

**Non-Verbal Behaviour** *(tone of voice, posture, facial expressions, eye movements)*

**Emotional Responses** *(people, events, objects)*

**Analysis** *(researcher questions, tentative hunches, trends in the data, patterns)*

**Technological Problems** *(recorder not working, IT services)*