

THE EXPERIENCES OF RURAL AND REMOTE
FAMILY PALLIATIVE CAREGIVERS WHO COMMUTE WITH
A FAMILY MEMBER FOR ADVANCED CANCER CARE
AT AN URBAN CENTRE

by

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Abstract

Commuting for advanced cancer care represents an important option for rural families who require palliative care. Few studies have focused on the experience of travelling for cancer care, and fewer still illuminate family palliative caregivers' (FPCs) perspectives. The purpose of this qualitative study was to describe the experiences of rural FPCs who supported patients in commuting to a regional cancer centre for palliative care. Semi-structured interviews were conducted with 15 FPCs (27-73 yrs) who were involved in commutes ranging from 24-774 km one way. FPCs in this study had the key responsibility for their family members' personal needs as they sought palliative treatment and consultation. Data analysis revealed important contextual factors influencing FPCs' experiences including the independent nature of rural dwellers, rural support networks, and familiarity with long distance travel. The dedication of FPCs to making the commuting experience as positive as possible for their family members was a central theme. Accordingly, FPCs were involved in extensive preparations for trips, managing the financial implications of commuting, taking extra precautions - just in case, monitoring the impact of travel on both the patient and themselves, and providing comfort and support during commutes. The work of commuting was stressful, tiring, and sometimes pushed FPCs beyond comfortable limits. Despite these challenges, FPCs spoke of the importance of "making the best it" by taking full advantage of the time spent with their family member and incorporating other activities to make each trip worthwhile. Participant recommendations for supporting FPCs involved in commuting for care targeted the importance of self care. Practice recommendations, therefore, include a holistic assessment of the FPC and the family member and their needs as they continue to commute for palliative care. Policy changes to support financial needs and plan treatment visits that will minimize commuting are indicated. Finally, research initiatives are indicated in order to focus attention on diversity issues such as gender and ethnicity among rural and remote palliative caregivers. Commuting for care as a FPC is still emerging as an area of research study.

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*To my husband, Bill, for his love,
perseverance, and gentle humour
along the way*

ℒ

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ℒ

*To the family palliative caregivers and their loved ones
who shared their stories of travelling,
with such dignity and grace*

Chapter One: Introduction

Evolution can be likened to the cycles of the moon where new and old, life and death, and all phases are ultimately one.

What remains constant is the cycle itself. (Chinn, 2001, p. 9)

Palliative care (PC) captures the essence of evolution and tenuous balance as individuals reach the end of life. The experience of commuting to an urban centre for family palliative caregivers (FPCs) who accompany advanced cancer patients from rural and remote locales for cancer care is largely uncharted. A small body of research on patient experiences of commuting for care suggests the inconvenience and adversity of travel are barriers to accessing required treatments (Payne, Jarret, & Jeffs, 2000). However, even less attention has been directed to understanding the needs of family caregivers of patients who commute for cancer care. Commuting for PC is a reality for many families who do not reside within cities. In this situation, family caregivers have added responsibilities associated with commuting. Only two Canadian studies that describe caregivers' perspectives on traveling for cancer care could be located (Longo, Fitch, Deber & Williams, 2006; McRae, Caty, Nelder, & Picard, 2000). Aoun et al. (2005) describe palliative caregivers as those being at risk for physical and psychosocial morbidity, and economic challenges. FPCs often continue to maintain their role and responsibilities as a family member while they provide care to family members. In addition, they are coping with their own responses to the pending loss of a loved one. The aim of this research study was to examine the experiences of FPCs who commute from rural and remote locales with a family member who was receiving advanced cancer care, and to extend our understanding of the demands of family caregiving in this context.

Research Orientation and Objectives

This study forms part of a larger research study on the experiences of rural cancer patients and their families who commute to an urban centre for advanced cancer care. The larger study was funded through a British Columbia Cancer Foundation- Southern Interior research grant (Robinson et al., 2007). The aim of the overarching study was to examine both the rural and remote patient and FPC experience of commuting to an urban centre for advanced cancer care. The design of the larger study utilized a mixed methods approach.

The research question addressed in this thesis study was “What are the experiences of FPCs who commute from rural and remote areas to urban centres with family members who are receiving advanced cancer care?” The objectives of this project were to:

- describe rural and remote FPCs’ experiences related to supporting their family members with advanced cancer when they commute for PC services away from their home communities
- identify the unique needs and challenges that FPCs encounter when they commute to an urban setting with family members who require PC services
- describe the impact of commuting on FPCs’ health and quality of life
- make recommendations for supporting FPCs who commute from rural and remote settings to urban centres with family members with advanced cancer who receive PC.

Definition of Terms

Palliative Care. For the purpose of this study, palliative care is defined as that which is aimed at relieving suffering and enhancing the quality of life for individuals dying from advanced illness, their caregivers, or those who are bereaved (Canadian Hospice Palliative Care Association, 2008).

Family Palliative Caregiver. For the purpose of this research, a FPC is defined as an individual with key responsibility for ascribed or designated health care, psychosocial support, instrumental and transportation needs for an advanced cancer patient. Specifically, they may be represented as an immediate family member, relation or proxy family member who participates in the care and well being of an individual with advanced cancer who is receiving PC and accompanies them to treatment and consultation visits.

Rural and Remote. For the purposes of this study, rural/remote refers to communities having a population of less than 10,000 people. The Canadian Rural Information Service defines rural as those areas with a population of less than 150 people per square kilometer. Rural and remote is the designated term for those regions that include more than 50% of their population living in rural communities (Government of Canada, 2007).

Significance of Research

A better understanding of rurally based FPCs' experiences, needs, challenges and quality of life is necessary to ensure that they are receiving the support they need. There is strong justification for undertaking this study. Moreover, research that focuses on patient needs does not always include FPCs' needs or concerns.

Estimation of the number of rural residents in Canada indicates that they comprise about 10 million individuals across the country (Rural Health Research in the Canadian Institutes of Health Research, 2000). This represents just under one third of the total population in the country. Life expectancy in rural residents is known to be less than that of urban residents. Concurrently, chronic illness, including cancer and long term disability rates also tend to be higher in the smaller rural areas (Pong et al., 2000). Moreover, our aging population is experiencing increased chronic illness and therefore aging with poorer health. The need for palliative care will increase significantly in the years to come (Robinson et al., 2007). Access to health care is a primary focus for people who live in rural and remote Canadian locales (MacLeod, Kulig, Stewart, Pitblado & Knock, 2004). The Canadian Senate responded to community pressure and developed a Quality End-of-Life Care Coalition with a mandate to work toward availability and access to services for end-of-life care (Government of Canada, 2005). The long distances from rural and remote locations to these services make this mandate challenging to fulfill

When rural and remote families must commute for advanced cancer care, it is imperative that health care providers have a clear picture of their needs. This study examined and qualitatively described experiences of FPCs. The findings provide a foundation for improved supportive care planning.

Chapter Two: Literature Review

In this chapter, a summary of relevant background literature underpinning this research will be provided. First, an overview of the development of palliative care will be provided to situate the focus of this study in an evolving area of health care. Second, the prevalence of cancer will be described to demonstrate the scope of the disease and demands for palliative care. Third, selected research about preferences for place of death will be summarized to highlight the trend for dying at home. Fourth, geographic and social context will be clarified. Fifth, the research on family palliative caregivers will be described highlighting what is known about their needs and quality of life. Finally, the literature related to commuting for advanced cancer care will be highlighted. The chapter will conclude with a summary of the findings of this literature review.

Palliative Care

The modern palliative care movement has been fuelled chiefly by advances in understanding the concept of pain (Seymour, Clark & Winslow, 2005). The emergence of palliative care to address cancer pain can be linked with three contributions. First, the groundbreaking research pioneered by a United States physician Raymond Houde in the mid 20th century led to the development of subjective assessments for cancer pain. Second, the 1953 text by anesthesiologist John Bonica marked the view that pain comprised both a response to and a perception of pain (Seymour et al.). This further expanded the notion of pain subjectivity beyond an emotive and perceptive realm alone. Third, Cicely Saunders published a landmark work as her inaugural contribution to medical science (Seymour et al.). In this article, she laid the framework for a palliative care philosophy and the cornerstones for a rejuvenated hospice movement. Her later work focused on the concept of ‘total pain’ and advocacy for interdisciplinary assessment (Seymour, et al.). These three developments opened the door for viewing cancer pain as an aggregate of many contributing factors and directed attention to better pain management particularly in the advanced stages of cancer and when curative treatments were no longer effective.

The boundaries of palliative care have since expanded beyond pain control to include many facets. Palliative care is seen today as a holistic approach that may include medical, complementary and alternative therapies for physical comfort. Psychological

and spiritual attention provide for both the patient and their family member through counseling and clergy services. Instrumental needs and support are also assessed by social workers and community nursing providers (Canadian Hospice Palliative Care Association, 2003). Palliative care has evolved to a philosophy, body of knowledge and approach to care that seeks to lessen the specific distress and burden of life limiting illness.

Support for the principles of palliative care has been demonstrated on a wide scale. Cancer care is one area where palliative care is deemed to be indispensable (WHO, 2007). Within Canada, a national model to guide hospice palliative care was proposed in 2003 (Canadian Hospice Palliative Care Association, 2003). The thrust of this document was to provide recommendations for family-centred palliative care. This guide included approaches for care, organization, education and advocacy. Three years later, a joint report between the Canadian Hospice Palliative Care Association and the Canadian Home Care Association was released as the Pan-Canadian Gold Standard for Palliative Home Care. This report envisioned both equal access to palliative care and high quality delivery of care (Canadian Hospice Palliative Care Association & Canadian Home Care Association, 2006). Later that spring, a British Columbia Provincial Framework for End-of-Life Care was produced to provide a political position. Seven principles of palliative care are outlined in this document. The fundamental components of palliative care include care that is patient and family centered, ethical, enhances quality of life and end-of-life, accessible, effective, collaborative, adequately resourced and is cost effective in the delivery of services (Province of British Columbia Ministry of Health, 2006). Unfortunately, progress towards many of these goals has not been reached. One of the key stumbling blocks for delivery of palliative care to those living in rural and remote areas continues to be access. The British Columbia Hospice Palliative Care Association (2005) advises that palliative facilities, resources, health personnel and supportive volunteer care must be accessible. Nationally, round-the-clock palliative care access is being spearheaded through advocacy for technology. Preliminary, core clinical and complete palliative care services may only reflect a portion of palliative care services that are provided in a given area. Settings where all palliative care services are provided are designated with a specialized environment classification. The Canadian Hospice

Palliative Care Association (2002) gives examples of this type of palliative care delivery by showing how some settings like residential hospices or palliative care wards may serve several palliative care clients in one location. The level of technological sophistication and expertise in outlying areas together with the shortage of trained health care personnel often means residents may be travelling for some portion of palliative care services.

To gain perspective on the number of individuals with cancer who may require palliative care, it is useful to first look at the disease statistics compiled for cancer. In Canada, from 2004-2005 all new cases of cancer combined accounted for 147,108 individuals across all age groups. During this same time period, British Columbia statistics reported a total of 18,635 cases annually. This represents 12.67% of all cancer cases in Canada (Statistics Canada, 2007).

The Interior Health (IH) region of south central British Columbia services a large rural and remote population. It was projected that a total of 4,046 new cancer diagnoses would occur in the region in the year 2007. These figures are anticipated to increase to 5,515 by the year 2020. Meanwhile, the expected number of new cancer diagnoses in the population over the age of 60 in the same region was 3,008 for the year 2007. By the year 2020, the diagnoses for this older age group are expected to climb to 4,404. These projections are based on population increase estimates alone, and may not account for other factors that may develop over time. Moreover, cancer deaths in this health region by the end of the year 2007 are anticipated to reach 1,931 and 2,950 by the year 2020 (BC Cancer Agency, 2007). These figures suggest the demand for PC services will also climb over time.

Longevity is predicted to increase in the general population, and this reality has implications for cancer rates and the palliative support associated with that occurrence. The median age at death in the IH is forecasted to be 79.9 years in 2007 and is expected to increase to 82.2 years by the year 2022 (Interior Health, 2006). Bearing these statistics in mind, it is apparent that this health authority will have to prepare for the needs of an older population for the delivery of cancer care. Through the tireless efforts of the Senate Subcommittee on Quality End of Life Care, those individuals who face death and require PC care now have an advocate to the legislature for palliative health challenges (Standing

Senate Committee on Social Affairs, Science and Technology, 2000). PC is now a nationally recognized option for the support of those with life-limiting illnesses. As cancer begins to have effects on a largely older population of cancer patients, PC forms an invaluable supportive resource for the families supporting them. Because specialized PC services are concentrated in urban centres, access to PC in rural and remote regions continues to be a challenge in Canada.

Place of Death

Place of death has been a topic of study because of its implications for providing palliative care. In a report on the Proportion of Cancer Deaths Occurring in Hospital in Canada during 1994-2000, hospital based deaths accounted for 77% of all deaths in Canada during this time frame (Allan, Stajduhar, & Reid, 2005). These researchers note that the number of home deaths is not yet available across Canada as there has been a lag in the collection of statistics for home deaths. There is some data to indicate a growing number of home deaths in four provinces reporting home deaths in 2005. A survey commissioned by the Canadian Hospice Palliative Care Association and Glaxo-SmithKline identified that 90% of individuals prefer that they die at home (Ipsos-Reid, 2004). Although statistics for BC were not available, what is known is that there is currently an increased demand for death to take place at home over other settings.

The choice of death in a home setting can place heavy care burdens on the lay FPCs because of a lack of support services in rural settings and the need to commute to access specialized PC services. Families supporting a loved one to realize a death at home, and who live in a distant community from oncology care, face unique challenges and often commute long distances in order for their family members to receive PC (McRae, Caty, Nelder & Picard, 2000). One survey of individuals contemplating the palliative care role demonstrated that 64% of those queried felt unable to devote the required time to palliative care (Ipsos-Reid, 2004).

Preferences related to place of death have been investigated. Improved psychological, physical and quality-of-life measures were found to be influencing factors in one study of PC patients who resided at home (Peters & Sellick, 2006). These findings may account for individuals receiving PC to be more receptive to death in their home environment. Brazil, Howell, Bedard, Krueger and Heidebrecht (2005) found that

caregivers' preference for place of death may be variable depending on where care needs can be most suitably met. Among 216 caregivers who participated in bereavement interviews, 77% had a preferred place of death for those they provided care for. A majority of caregivers and care recipients (63%) preferred a home death. Only 14% of caregivers preferred an institutional death, while only 4.7% of care recipients chose institutional care at the time of death. Regardless of where death ultimately took place there was consensus among 92% of caregivers that most individuals ultimately had died in the most appropriate place.

Geographical and Social Context

Geographical and social context factors need to be considered in relation to commuting experiences. Rural regions vary considerably in terms of geography and distance to urban centres. The region in which this study was conducted has unique features. Cancer services are provided from a regional cancer centre situated in the south central region of British Columbia, within the westernmost province of Canada. Area covered by the local health region covers a land mass of 215,346.6 sq. km. with a population density of 3.4 persons per sq. km. The region includes numerous small communities separated by mountainous regions and lakes. In addition to agriculture, forestry, mining and tourism are main industries. The population in this region is projected to increase from the current 732,958 in 2007, to reach 860,636 by the year 2022 (IH, 2006). The majority of the population is concentrated in the south western part of the province. Other surrounding communities in the catchment area for the cancer centre include residences in rural and remote settings. Deaths recorded in BC in 2005 from cancer reached 8,330. Projected diagnoses projected for 2008 in B.C. will reach 20,928. The cancer centre currently serves a population of 600,000 (BCCA, 2009).

In one regional health authority served by the cancer centre the proportion of elderly is expected to grow substantially to exceed 20% in 10 years time (IH, 2006). This shift in population demographics along with a trend toward increased longevity will result in a higher incidence of cancer. Although treatments for cancer have improved, the number of cancer related deaths can also be expected to increase. For those residing in rural and remote communities, there are presently and will continue to be difficulties providing specialized PC services to support home deaths. Therefore, commuting for

specialized PC is likely to become increasingly important. A better understanding of FPC experiences is needed to ensure quality end-of-life care for patients and the families who support them.

Family Palliative Caregivers

There is trend toward shifting the burden of responsibility for managing complex patient needs from skilled health care workers to family providers. As family members take on more complex care, their capacity to meet all demands is challenged. This emerging trend was noted in a literature review focused on palliative caregiver outcomes (McCorkle & Pasacreta, 2001). The provision of PC by family caregivers has been supported through a number of economic and supportive programs. Each of these will be discussed highlighting the benefits and limitations of these programs.

The Compassionate Care Benefits program is a relatively recent Canadian supportive government measure for employed FPCs (Government of Canada, 2007). On the one hand, it provides desperately needed economic support to FPCs who must leave their employment to provide end-of-life care. On the other hand, the program puts the provision of PC squarely in the hands of family members most of whom are unprepared for this role. FPCs may assume the caregiving role in the absence of formal services, or when financial resources to access those services are scarce. Complex care needs may prohibit the assistance of untrained help.

Despite the financial benefits of this program to those who qualify, there are enrollment limitations. The program covers neither retired seniors, nor the unemployed for wages. This omission is clearly at odds with the recommendation by the subcommittee for the national strategy on end-of-life care. Both income security and job protection for FPCs were included in this original initiative (Subcommittee to update “Of Life and Death” of the Standing Senate Committee on Social Affairs, Science and Technology, 2000). As well, the program limits compensation to just a 6 week period per palliative patient. The prediction by families of the most useful period of time to claim benefits is dependent on their ability to forecast the disease trajectory.

Support for the provision of eligible palliative drugs, equipment and supplies through the British Columbia Palliative Benefits Program is another resource that has made it more feasible to deliver palliative care at home (Government of Canada, 2009).

Arrangements can often be made for approval of needed supplies within 12 hours of processing the application. This ensures that waiting time is minimized for families choosing palliative care delivery at home. FPCs in urban centres and communities that offer hospital and inpatient hospice services may be privileged over those in smaller centres if supplies are not readily available. FPCs living in outlying areas must deliver care at home without as wide a range of medical supplies and pharmacies as in urban centres, or relocate their loved one.

Family Palliative Caregivers' Needs. Researchers have begun to describe the needs of FPCs related to their caregiver role, and their personal experiences in coping with a family member who is dying. In these studies the focus has been on understanding these needs from the perspectives of caregivers, patients and health care providers (Clayton, Butow, Arnold, & Tattersal, 2005; Hudson, 2004; Proot et al., 2003; Teno, Clarridge, Casey et al., 2007). Chief among FPC needs were those for palliative resource and information provision, explanation, training from a skilled health professional and access to services. Hudson (2004) further noted a need for personal time. Family caregiver needs are individual, contextual and variable given the unpredictability of the daily course of events.

In the literature on FPCs, researchers have identified major challenges and unmet needs. Andershed (2006) found in her systematic literature review of 94 studies conducted between January 1999 and February 2004 that being a close relative of a palliative patient left FPCs feeling vulnerable because of the increased burden of care. The most important issues for FPCs were good patient care, good listening and communication, good information and the attitude of the health professional. The author of this review suggests that when needs are met the family may feel more secure.

Involvement in the provision of PC is stressful for FPCs and is associated with a wide range of psychological outcomes. The literature reports three main contextual stressors for FPCs in addition to psychological concerns. They include the patient's needs, the impact of events that unfold in the course of end-of-life care, and FPCs' own personal needs. These stressors may surface concurrently and create significant distress. Family communication patterns can also present stressors for FPCs. Difficulties include discussions with children, shielding true emotions from the patient, and existential

dilemmas (Mangan, Taylor, Yabroff, Fleming, & Ingram, 2003). Fear, uncertainty and insecurity represent the psychological responses to stressors most frequently reported by FPCs (Broback & Bertero, 2003; Claravino et al., 2003; Osse, Vernooij-Dassen, Schade, & Grol, 2006; Proot et al., 2003). FPC distress has been related to fear about prognosis, uncertainty about the future, existential distress and anxiety for their own needs. Psychological distress including anxiety, depression, emotional stress and loneliness was also found in four studies (Ekwall, Sivberg, & Hallberg, 2005; Grov, Fossa, Sorebo, & Dahl, 2006; Hudson, Hayman-White, Aranda, & Kristjanson, 2006; Sinding, 2003). In one of these studies of FPCs, loneliness was identified as the primary contributing factor to impaired quality of life in both older caregivers and older seniors (Ekwall et al., 2005). Other researchers report a sense of vulnerability and isolation experienced by FPCs, which was described as acute when undergoing follow up visits (Krishnasamy, Wells, & Wilkie, 2006). This is notable because the premise of this current study was to assess FPCs during a follow up period.

FPCs are also at risk for caregiver burden, a syndrome that is a complex experience of both psychosocial and physical challenges. Chappell (2003) identified that caregiver burden included both subjective and objective stressors. Subjective stressors include low morale, depression or anxiety. Objective stressors refer to external changes to employment, health or daily routine. Three studies concluded that caregiver burden has a major impact on FPC health (Brazil, Bedard, Willison, & Hode, 2003; Centre on Aging, 2006; Skilbeck, Payne, Ingleton et al., 2005). An extensive review of the last 40 years of end-of-life literature indicated that the attribute of stamina is an important coping mechanism (Farber, Egnew, Herman-Bertsch, Taylor, & Guldin, 2003). The increasing and shifting responsibilities that FPCs assume as illness progresses require endurance to meet them. A FPC may be susceptible to caregiver burden without this personal attribute.

FPCs continue as the first-line resource for care delivery and basic needs for terminally ill palliative patients. Supporting the needs of the informal health caregivers is an investment in collective public health. Moreover, the existing literature on rural palliative issues focuses on accessibility to resources and services for patients. Family members who take on palliative caregiving require support so that they can give the best

possible care to the patient. This is a principle of palliative care (CHPCA, 2003). The subjective experience of FPCs regarding their own personal needs has not been completely explored in the context of the PC experience. Furthermore, most of the previous studies of FPCs have not included those residing in rural and remote settings, or those who commute with family members to access care. What is not known, therefore, is how the needs of FPCs are influenced by the experiences and demands that are associated with commuting for PC services.

Family Palliative Caregivers' Quality of Life. One key barometer of FPCs' quality of life is noting the extent to which caregiver needs are met (Fridriksdottir, Sigurdarsdottir, & Gunnarsdottir, 2006). A literature review of 28 studies of FPC QOL conducted in a variety of contexts has been completed (Kitrungroter, & Cohen, 2006). The authors concluded that QOL of the caregiver must be maintained in order to keep the ill family member in the community. Further they suggested that involving nurses in monitoring FPCs and their QOL should be included in the care plan for palliative clients. Evidence suggests that FPCs' ability to continue providing care in the home is contingent on their maintenance of QOL. If home health services are to meet the anticipated future demands associated with our aging population, it is necessary to explore how QOL for FPCs can be maintained or improved. The most important QOL issues that health professionals need to monitor are those that FPCs find to be poorly supported. These gaps could indicate which issues are clear priorities when QOL considerations are assessed (Heyland, Dodek, Rocker et al., 2006). Even if health care and community supports are available and FPCs take advantage of such supports, their ability to attain a sense of well-being may be challenged by the complex phenomenon of PC (Lockie, 2007).

Family Palliative Caregivers in Rural and Remote Settings. An important gap exists in the literature concerning rural and remote FPCs. The experience of carers who provide palliative care in rural and remote settings within Canada remains largely undocumented. Just a few studies that addressed the family palliative caregiver as a participant were located, and some were conducted in very remote communities (MacLean & Kelly, 1997; McRae et al., 2000; Stajduhar, Fyles, & Barwich, 2008). One unpublished literature review demonstrated greater potential risks for physical and

psychological caregiver burden, depending on available resources and locale (Lockie, 2007). An earlier study recommended a model of palliative care in rural Canada which addressed rural PC from the perspective of formal health providers. Imbedded in that model is a component of social support for the family and an acknowledgement of the primacy of the FPC in rural settings. Although the study was published over a decade ago, the authors noted at that time rural areas were ill-equipped to deal with the palliative issues of seniors, HIV/AIDS or cancer patients at the end-of-life (McLean & Kelley, 1997).

Residing in a geographically rural or remote setting still has direct implications for access to resources and services to support home based PC. Most specialized PC services are located in urban centres. Although there are some efforts to bolster rural health services, access remains a problem in most rural settings. The demands of maintaining a rural or remote lifestyle involve activities that may be quite different from those of their urban counterparts (Crosato & Leipert, 2006). Home responsibilities may involve, but are not limited to, the care of farm or ranch. Travel requires planning for extended trips. Although rural palliative care family members frequently assume primary caregiving activities upon return home from cancer treatment, assistance from the health care system may be irregular (Wilkes & White, 2005). Informal family palliative caregiving is frequently delivered by female relatives (Crosato & Leipert, 2006).

The usual financial concerns associated with palliative care can be expected to be exacerbated by additional demands associated with travel. The costs of travel, meals and accommodation can vary considerably depending on distances traveled and length of stays. Uninsured residents may only claim these expenses annually, if their expenses qualify for reimbursement (Government of Canada, 2007).

When rural and remote FPCs commute to an urban centre for advanced cancer treatment, community support is often temporarily exchanged for tertiary services. Depending on the professional and informal supports in place in their home community, some FPC needs may not yet have been identified. Rural and remote communities may be lacking in support groups, counseling, respite help, home health services, physiotherapy and transportation supports. This results in palliative care services that are sometimes only available in urban centres (Bedard, Koivuranta, & Stuckey, 2004).

Consequently, rural and remote FPCs may arrive for PC visits with unmet needs for themselves and their loved one. Regional cancer centres provide specialist palliative care including chemotherapy and radiation interventions as well as counseling services. There is a lack of information in the literature about which services FPCs access or request when they are commuting for PC with family members.

Commuting for Advanced Cancer Care

Published research studies and statistics could not be located that specifically describe the experiences of palliative advanced cancer care patients or their family members who commute for care. This is a significant gap that has far-reaching implications in terms of our ability to deliver quality end-of-life care to individuals and families who live in outlying areas.

Given the trajectory of the last months of life for advanced cancer patients, travel issues may prove to be more difficult as time progresses in the illness. What is poorly understood is the impact of travel on FPCs who transport and accompany their family member to the required cancer care visits at an urban centre. Even less well conceptualized, among all related studies, is the necessary preparation and home outcome experienced by FPCs as they make the round trip journey to the urban cancer care centre.

In the absence of studies that discuss the experience of FPCs commuting for either cancer or palliative care it is useful to include some literature that is available on patients commuting for cancer care. There are important considerations that could influence FPC experiences. Among available studies of patient experiences related to commuting for care there was little data to indicate if the recipient of care was traveling alone or if they were accompanied by family members. The studies demonstrate that when cancer patients commute to receive treatment access, distance, travel time, weather and economic hardship affect care decisions (Celaya, Rees, Gibson, Riddle, & Greenberg, 2006; Chan et al., 2006; Cohn, Goodenough, Roreman, & Suneson, 2003; Davis, Girgis, Williams, & Benney, 1998; Davis, Williams, Redman, White, & King, 2003; Guidry, Aday, Zhang, & Winn, 1997; Fitch et al., 2003; Longo, Fitch, Deger, & Williams, 2006; Meden, St. John-Larkin, Hermes, & Sommerschild, 2002; Stafford, Szcys, Anderson, & Bushfield, 1998). Treatment delays or omissions have been associated with the difficulty in accessing specialist care.

Related studies on rural based cancer patients who commute for cancer care show further detail. In studies that identified travel as an issue for patients there were variable results. A large retrospective study involving 2,220,841 U.S. resident cancer patients highlighted the fact that rural residents were commuting up to three times further than urban residents. Rurality had the dual effect of decreasing the involvement of medical and surgical specialist care while increasing reliance on generalists. This proved true for both cancer and heart patients (Chan et al., 2006). A number of studies were located that focused on transportation and cancer treatment in rural cohorts. Three of these studies involved breast cancer patient populations. Two U.S. research teams assessed travel distance and breast cancer treatment uptake. In both studies it was noted that the distance from a radiation treatment facility together with duration and difficulty of winter travel impacted the choice of treatment (Celaya et al., 2006; Meden et al., 2002). A third study conducted in Australia used a brief telephone survey to conduct a needs assessment in a sample of 80 women with breast cancer who commuted to urban treatment centres (Davis et al., 1998). In a more recent study in rural Australia, researchers have reported that important issues for rural cancer patients receiving radiotherapy in a metropolitan centre were being away from loved ones, maintaining responsibilities while receiving treatment, emotional stress, burden on significant others, choice of radiation as a treatment, travel and accommodation and financial burden (Martin-McDonald et al., 2003). To complete necessary treatment these women spent approximately 6.79 weeks away from their home communities. Social and instrumental needs were noted in 89% of participants. Despite 39% of the participants qualifying for financial aid, 19% of this group reported still struggling to secure financial help. Equitable support and access were key challenges in meeting needs.

In an important Canadian study of rural cancer patients commuting for care there are some interesting observations. Fitch et al. (2003) conducted an in-depth qualitative interview study of 118 Ontario patients who commuted for radiation cancer treatment. Difficulties with commuting related to waiting for the appointments, anticipating the visits, the difficulty and exhaustion associated with travelling as well as the negative aspects of relocation. The researchers concluded that proactive support was necessary to

ameliorate these difficulties for patients (Fitch, et al.). All of these factors have the potential to affect FPCs' concerns on some level.

There are also indications that travel demands have an influence on treatment decisions. Four studies on improving accruals to clinical trials found cancer patients reluctant to travel the distance for studies (Foley & Moertel, 1991), or spend a considerable length of time traveling in order to participate (Avis, Smith, Link, Hortobagyi, & Rivera, 2006; Chan, et al., 2006; Longo et al., 2006). A reluctance among rural and remote patients to solicit assistance for their needs if it involved an urban visit has also been observed (Chan, 2006).

Distance, weather conditions and cost of travel were cited as travel restrictions influencing receipt of care in a survey that assessed decision making for breast cancer treatment in rural North Dakota (Stafford et al., 1998). Economic issues surfaced as well in an Australian study of patients travelling for cancer care. A lack of financial assistance was reported by 53% of those who commuted. Moreover, 13% experienced difficulty obtaining funds, and 10% of these patients felt unable to rely upon the social worker to intervene (Davis et al., 2003). In contrast to these results, are the findings of one UK study. This comparative study found no differences between groups who commuted and those who did not in terms of satisfaction with services. However, an unexpected finding was the increased social support that patients reported when they roomed in overnight (Payne, Jarrett, Jeffs, & Brown, 2001).

Finally, the experiences of parents who commute for cancer care with their children were explored in one study (Cohn et al., 2003). Researchers report that the majority of parents (80%) perceived that additional costs were a burden. In response to this, families instituted austerity programs that included the postponement of vacation plans, activities and entertainment (Cohn et al., 2003). Although this study is not based on adult cancer patients, it demonstrates the effect of financial restraint when commuting for cancer care is not covered with subsidized out-of-pocket expense options. Moreover, it clearly shows a correlation between individual health and family support. Families on budgets of limited means are most at risk.

In summary, the type of treatment chosen, psychosocial issues, financial pressures and lack of professional support affect the viability of care options from the patients'

perspective when travel is necessary. The individual influence of these factors on FPCs providing cancer care is not well understood.

Summary of Literature

The literature on FPCs who accompany family members from rural and remote areas to urban centres for advanced cancer care is limited. While the number of studies on PC is growing, few studies have focused on PC patients and families in rural and remote settings. Specifically, FPCs and the experience of commuting or traveling are absent. Currently, what is known in the literature is that families of cancer patients have reported great benefit in palliative care when they have been able to access it. Hudson (2006) reported that caregivers have found the team approach of multidisciplinary palliative care specialists to be invaluable. Trends toward increasing numbers of cancer patients preferring to die at home have been observed in both urban and rural settings. In order to gain access to PC, patients and their family members often have to commute to regional centres for specialized care. The effects for cancer patients commuting are quite diverse. Time spent and conditions of travel, psychosocial needs, access, economic and practical help were the foremost areas of concern. The FPC who provides ongoing support for the patient during the commuting process warrants a voice in the research literature. In this way, our efforts will support both the patient and the family as advanced cancer treatment is undertaken.

It is important for rural and remote health care regions in Canada, and elsewhere, to begin to identify and collate data that will serve their commuting population of FPCs and the cancer patients, whom they accompany for care. The most significant absence of research studies is apparent in investigations that capture the experiences of the FPC, providing PC in the context of commuting from a rural and remote area residence with family members.

The effect of overlooked economic, instrumental and psychosocial needs among informal FPCs may have an impact that reaches into the extended family and the community. Economic pressure may also be experienced by FPCs who commute for cancer treatments and visits. Two studies reported the financial impact of PC particularly when travel was involved (Claravino et al., 2002; Elting & Ya-Chen, 2004). The

additional burden of commuting for PC is rendered much more challenging when finances are limited.

Chapter Three: Method

This study was nested within a larger mixed method investigation aimed at gaining a better understanding of the experience related to commuting for palliative care. For this masters' thesis project, a qualitative descriptive design was employed. This is an approach that embraces naturalistic study through employing a variety of techniques (Sandelowski, 2000). This method was chosen because it is particularly applicable to the population and research question developed for the research. Little is known about the experiences of family caregivers who accompany their loved ones from rural and remote locales to urban centres for advanced cancer treatment. Therefore, a descriptive qualitative design was used to provide information about the impact of commuting on caregiving from the perspective of FPCs. Specifically, this qualitative descriptive design set aside theoretical perspectives and closely examined the dialogue of the participants. Through attention to the qualitative elements of the experience, the insights of the FPCs were the primary focus of this descriptive study. Study findings generated through this method have been found to be particularly useful for praxis and policy development (Sandelowski, 2000).

Study Setting

This study was conducted in the south central region of British Columbia. The region is served by a regional cancer centre adjacent to a tertiary care facility in a small city. The cancer centre serves a health region of 215,346.6 sq. km. that includes many rural communities (IHA, 2006). The cancer centre is a key resource for palliative care treatments and care. Advanced cancer care services provided at the cancer centre include a range of services such as radiation, and pain and symptom management through the Radiation Therapy Rapid Response Clinic, and a Pain and Symptom Management Clinic respectively. Lodging for out of town patients and family members is provided at a nearby lodge. This supportive housing facility provides families with information, accommodation, transportation and cancer support services.

Sample

This research study utilized purposive sampling to recruit 15 FPCs. Family members who met the following inclusion criteria were recruited: a) actively involved in providing care to a family member with advanced cancer, currently or within the past two

years, b) involved in commuting from a rural or remote area for the purpose of accompanying a patient who was receiving advanced cancer care at the cancer centre, and c) English speaking. For the purpose of this research individuals were eligible if they commuted from a rural and remote community that was located in the study health region and had attended a referral at the Cancer Centre for palliative care for their relative. All participants provided informed consent. All but one FPC was currently involved in commuting with a relative who was receiving advanced cancer care. Efforts were made to maximize variation in the sample to ensure a wide spectrum of experience was captured. Accordingly, attempts were made to recruit FPCs who differed with respect to gender, commuting frequency and distance. FPCs accrued to the sample were represented by caregivers who were spouses, partners, adult children and one participant who had been designated as a family member, in the absence of other relatives by the ill family member. This sample reflected the characteristics that define and qualify individuals for benefits as described by the Compassionate Care Benefit Program for end-of-life caregiving (Government of Canada, 2007).

This study excluded minor children under the age of 18. Neighbours and friends who commuted with a patient were also excluded from the study, unless designated as a family caregiver by agreement with the ill family member. Individuals who declined to participate in the study were also excluded.

Recruitment and Screening Procedures. The sample was recruited through the cancer centre. A recruitment brochure was developed for the overall study. Each week potential participants were flagged based on rural postal code and palliative status. A cancer centre volunteer who had received special training approached each of the identified ill family members and FPCs at a convenient moment near their appointment time, in order to let them know about the study and ask if the patient and FPC were interested in more information regarding the study. These individuals received a copy of the recruitment brochure, a Letter of Introduction (Appendix A) and a Consent to Contact form (Appendix B) from the volunteer. A signed Consent to Contact form or verbal consent to contact triggered a follow up contact by a Research Assistant, who provided further information to about the study and obtained informed consent (Appendix C) if the FPC wished to participate. Recruitment of both ill family members and FPCs occurred

simultaneously. Due to the personal nature of the data collected about the family member receiving palliative care, it was considered an ethical obligation to decline FPCs as interview participants if the family member was not in agreement with the interview. In this study, all of the ill family members did agree to participation by FPCs even when they did not participate themselves.

Recruitment and retention issues with FPCs did arise because of unstable health conditions of the palliative care patients they supported. In some cases, participation was declined. Moreover, in several cases, the availability of telephone interviews may have been a deciding factor for participation. Rural and remote families who had a family member in to receive advanced cancer care were at times unwilling to stay for a personal interview at the end of a long day of travelling. However, most FPCs stated that they were pleased to take part in the study. Interviews generally took place as soon as possible after consent had been signed, or within the first two weeks of contact at the latest.

Data Collection

Initially, participants were asked to complete a brief questionnaire gathering demographic information. This information was collated to form a summary profile of the participants which appears as Table 1 in the Findings section of this thesis. The primary means of data collection was through in-depth, semi-structured, interviews that were either face-to-face or by telephone. These interviews were digitally audiorecorded. The interview guide used with FPCs is included in Appendix D. Open-ended questions were used to facilitate narratives from the FPCs, and probes were used to explore shared experiences in more depth. In practice, this type of questioning invited participants to share experiences and concerns that they deemed most important. Polit and Tatano Beck (2004) describe this technique as typical of semi-structured interviews.

The environment for the FPC interviews varied based on family preference. Interviews were held in the lodge, resident homes and by telephone. Efforts were made to decrease interruptions and provide a quiet atmosphere for discussion. Maintaining privacy during the interview was an ongoing process that required vigilance for both minor and major interruptions in all settings. Attention to environmental ambience was important. To conduct the interviews, room temperature was assessed and adjusted if

necessary. Comfort measures such as an afghan or blanket, tissues, supply of water, juice or hot beverage were located and used if indicated. These gestures were intended to provide for a more relaxed, inviting interview space. Moreover, some of these families had often travelled the same day from rural and remote areas, and appreciated the consideration and care.

Fifteen participants entered the study by signing the informed consent. This consent was verbally revisited as a process consent throughout the interview if indicated. With open ended time parameters, interviews ranged from approximately 30 minutes to almost three hours in one case. Family caregivers who appeared exhausted, unwell, or unable to continue for any reason, sometimes requested to reschedule the interview. There were no FPC participants who refused to complete the study interview entirely after they had begun. One FPC was unable to return demographic measures by mail. Telephone interviews were offered to all participants as an alternative and five FPCs chose this option. These sessions were offered to FPCs who consented to participate, but were unable to attend a personal interview. Field notes were recorded and included participant code number, date, start time, ending time, location of participants' home, pre-interview goals for interview, location of interview, people present, description of environment, nonverbal behaviour, content of interview (summary), researcher's impressions, research analysis, technological problems, and interviewer's own reaction to interview (adapted from Morse & Field, 1995). The study was designed to conduct only a single interview with each participant and fifteen interviews were completed. Sessions were occasionally halted and resumed at the family member's discretion. An honorarium in the amount of \$20.00 was provided to each participating family member to acknowledge their contribution to this research.

Data Analysis

Coding of the transcribed data was facilitated through the use of software for managing qualitative data using the constant comparison technique (Munhall, 2007). Initial codes were constructed from the data by reviewing one transcript in detail and raising questions about the data. This began a process of analysis that proceeded concurrently with data collection. Using this process, open codes were identified and recorded on the transcript. Open codes were compared and grouped into categories based

on the similarity of experiences reflected in the data, as well as the frequency with which they occurred. Coding proceeded by hand until several subsequent transcripts were coded using the first transcript as a guide. A review by the larger research team resulted in collapsing some codes and refining coding framework. This process provided a preliminary coding framework to capture salient ideas and themes in the data. Coding then proceeded using NVIVO, a data management software program. As additional transcripts were reviewed new categories were added to the initial coding framework and some revisions to existing codes and their definitions were made. This iterative process provides for both subjective and objective researcher responses to the data (Sandelowski, Holditch Davis, & Harris, 1989). Additional questions that surfaced as the data analysis proceeded were incorporated into subsequent interviews. The categories were refined during the data analysis process. It was necessary to recode some data in the process. This often occurs as new relationships are identified in the data (Munhall, 2007). This technique allowed for a rich and full description of points of interest within the study.

Once the electronic coding was completed data was retrieved for each category and compared and contrasted. Internal themes found within FPC narratives were compared. The themes were organized according to primary themes and, subthemes, and patterns of recurrence or frequency were noted. This is an important assessment with qualitative studies (Polit & Tatano Beck, 2004). FPC quotes were identified to provide exemplars for each theme, subtheme or pattern within the context of the study.

Methodological rigor was achieved through a number of strategies. Verification strategies were used throughout the project. Interviews provided ample opportunities to verify and clarify the disclosures. Interviews with subsequent participants were also used to determine whether experiences were common or unique to particular families, and to gather additional details to enrich descriptions. This was facilitated by concurrent analysis with data collection. An ongoing process of discussion and revision of coding with the thesis committee served as one component of the internal audit. This ensured that codes reflected the content accurately. An electronic audit trail of procedures, decisions, possible thematic development and sources of bias was initiated at the McCorkle, R. & Pasacreta beginning of the study and continued until the study was complete. To address issues related to transferability of the findings, the study setting

and characteristics of the participants are described in detail. In this way, insights from the study can be understood in relation to the context in which they arose and comparisons can be made to other settings and family caregiving situations.

Reflexivity was also used by acknowledging the position of the researcher and her influence on data collection process and analysis. Interpretations of the data are supported with direct references to the data. Diversities as well as commonalities are highlighted in the findings. These features provide a rich representation of participant experiences. Taken together, these data analysis measures assist to ensure the scientific quality of the research undertaken and the trustworthiness of the findings (Sandelowski et al., 1989).

Ethical Considerations

Human subject research demands special attention to ethical considerations in the pursuit of enhancing nursing science. The University of British Columbia Okanagan provided ethics approval for the larger study of which this master's thesis forms a part. In this study each participant was briefed on the purpose and aim of the study prior to obtaining informed consent. Preliminary questions from participants were entertained, in order to clarify areas of concern. The consent document included a statement that participation, withdrawal from the study, or refusal to answer questions was at the sole discretion of the participant. Participants were informed that their decision about participating in the study would not influence the palliative care delivered to the patient. Confidentiality was assured through the use of a numerical identifier and selective publication of data without the use of names. A copy the signed informed consent, disclosure of their rights as research subjects, as well as contact names and phone numbers for questions was provided and retained by the participant.

A quiet location was secured for the interview to take place at the cancer centre, lodge or FPCs' home as requested by the participant. Throughout the interview, the researcher remained vigilant to the overall well-being of the participant, and paced the length of the interview to the wishes of the participant. No problems arose in the context of the interviews, however, resources had been put in place should this have happened. These measures for proceeding with interviews follow guidelines for human subjects and

form an integral part of qualitative research methods for health professionals (Morse & Field, 1995).

Basic underlying assumptions about ethical conduct of the research have been proposed (Munhall, 2007) and were adopted for this study. Three dominant views underpin the activities of this study. First, the advancement of nursing research shall not take precedence over the therapeutic goals of nursing. In the holistic practice of palliative care, the immediate needs of the FPC superseded those of the research agenda. This was a guiding principle that facilitated the pace, environment and techniques provided for interviewing. Second, human beings are not treated with expediency in the research activity. This assumption elevated the status of participant to one of collaborator. Finally, informed consent was designated as an ongoing process consent that was revisited whenever necessary. This process consent ensured the highest regard for the human rights of the collaborators. These intrinsic commitments strengthen the foundational premise of nursing research. The vulnerability of the FPC population was weighed against the essential contribution that could be made toward improving rural and remote health in critical illness.

Chapter Four: Findings

The commuting experiences of FPCs are presented in this chapter. First, a description of the study sample is provided. This is supplemented by information about the frequency and type of commuting of the study sample. Next, the contextual factors that provide a backdrop to FPCs' commuting experiences will be described. These include rural life, life including caregiving and rural informal support networks. Experiences related to commuting for advanced cancer care and the efforts that FPCs engaged in to prepare for all possibilities are then outlined. These preparations included readying for the trip, anticipating patient needs and managing time. FPCs experiences on the road include 'doing double duty,' getting into a routine and being in new territory. The participants described both personal and financial tolls that influenced their quality of life. A description of the benefits of commuting as described by participants is included. However, they also shared that by 'making the best of it' and taking a positive outlook, these trips were memorable despite the reason that they travelled. Recommendations provided by participants for other FPCs and health professionals are summarized. A brief summary is provided to recap the findings.

Description of the Sample and Commute

Fifteen FPCs participated in this study. Their average age was 55 years and the majority of them were female. Most of the participants were either retired, caring for family or both. Only four of the caregivers were employed in the workforce. A range of household incomes was represented in the sample. Twelve participants who were partners or spouses of the patient lived in the same home as the patient see (Table 1). Although currently living a rural lifestyle, many of these participants had previously lived in urban or metropolitan settings.

Table 1: Characteristics of Study Sample (n=15)*

| | |
|---|----------------------------------|
| Gender | |
| Male | 6 |
| Female | 9 |
| Age | X= 55yrs (range=27-73yrs) |
| Education | 3 |
| High School Graduation | 7 |
| Technical/Trade | 4 |
| University Degree | |
| Marital Status | |
| Married or living with a partner | 11 |
| Not married or living with a partner | 3 |
| Resident Status (living in) | 12 |
| The same home as the patient | |
| The same community as the patient | 1 |
| A different community as the patient | 1 |
| Income | 0 |
| Under \$11,000 | 1 |
| 11,000-24,000 | 4 |
| 25,000-49,000 | 5 |
| >50,000 | 2 |
| Don't know/prefer not to answer | |

*Demographic missing on FPC 15

The participants in this study all commuted to a regional cancer centre in south central British Columbia. All but one patient commuted for radiation therapy. Some patients also commuted for chemotherapy, surgery or consults. Although the majority of

FPCs returned to their own homes on the same day, others stayed in the urban centre because of long distances and the time required traveling home, frequency of appointment schedules, illness of patient, and weather. The availability of the cancer lodge in close proximity to the cancer centre, and a nearby motel provided options for FPCs and their family members if overnight stays were required. Four participants made use of the cancer lodge for overnight stays and meals, while a fifth family group stopped just for meals there. At the Cancer Centre services such as healing touch and counseling were also provided for family members.

Commuting distances for cancer care varied considerably for participants in this study and ranged from 26.7 to 774 kms. one way (see Table 2). One FPC participant commuted via air travel and the remainder all travelled by car. Two FPCs who did not live in the same community as the patient, undertook the longest commutes and were also parents travelling with children. For example, one FPC travelled 200 km. each way, driving from her own home to pick up the patient, on to the urban centre for the appointment, and then, she returned back to her own home afterward, often on the same day. Efforts were therefore made by staff to coordinate patients' appointments in order to reduce demands associated with commuting, and when possible consolidating appointments on a single day. Several FPCs stated that when appointments were managed in this manner, even though it meant a longer single day for the family, it was preferred.

Table 2: Distances of One Way Commute

| Participant # | Distance (km.) to cancer centre) |
|----------------------|--|
| 1 | 69 |
| 2 | 27 |
| 3 | 103 |
| 4 | 107 |
| 5 | 88 |
| 6 | 200 |
| 7 | 165 |
| 8 | 82 |
| 9 | 76 |
| 10 | 76 |
| 11 | 27 |
| 12 | 103 |
| 13 | 348 |
| 14 | 101 |
| 15 | 774 |

Five FPCs were interviewed following their first commuting visit for advanced cancer care. Among the remaining participants, experiences of commuting ranged from three visits to numerous visits for various types of advanced cancer care over extended periods of time. These ranged from periods of several years to almost 11 years in duration in one case with a patient who had a rare type of cancer. Two of the FPCs

reported that they commuted with their family member for chemotherapy regimes. An additional four FPCs stated that their family members commuted for both chemotherapy and radiation. Three members of this last group noted that the chemotherapy was delivered in another location to other appointments for cancer care which at times required two commutes on the same day. A further two participants commuted with family members who required radiation therapy sessions. One final FPC commuted with a family member who had scheduled appointments for consultation every six weeks. Several participants were accompanying family members whose conditions were very fragile. Increased pain, unpleasant symptoms, and poor tolerance to the discomfort of travel positions were exacerbated for these family members as they approached the end-stage of their illnesses.

Context of Commuting for Care

Participants' narratives in this study reflected a theme of dedication to supporting family members in their need to commute for advanced cancer care. As one participant stated, "I would do anything, I would do whatever it takes." This stance was echoed through many of the interviews. The depth of this commitment was tied to the context in which the commuting took place. There were four important contextual factors that influenced commuting experiences: a) rural life; b) life including caregiving; c) rural informal support networks; and d) cancer services. These factors effectively formed the backdrop for the experiences of commuting for advanced cancer care to an urban centre with a family member.

Rural Life. The FPCs in this study were rural residents whose lives were intertwined in the activities that support living in rural contexts. As such, this way of life figured prominently in FPC experiences of commuting and was reflected in the independent way they took on this responsibility, often finding ways to manage without relying on help from others.

But um, early on, we felt it was somethin' the two of us could do with no help [emphasis, laughs] you know. And you're married 43 years, you figure well okay at the end 43, you figure you can do this. (FPC 1)

As rural dwellers, FPCs drew on the familiarity of established routines associated with regular commuting for shopping and other appointments to help them manage. One FPC

explained, “[City] as the major shopping centre city, the trip in and out is fairly normal for us” (FPC 2). Experience had taught participants to expect challenges in driving extended distances to commute to major centres whether this was related to weather, road conditions, traffic problems, accidents, road construction or unexpected vehicle breakdowns. Most were confident drivers and well prepared for problems they might encounter with commuting.

Despite the challenges of travelling to make appointments for cancer care, the changing landscape along the way provided some enjoyment for both FPCs and their family members. Feeling out of their element in the urban centre, FPCs sometimes worried about the city traffic and looked for places around the cancer centre where they could relax between trips. Not surprisingly, a nearby lakeside park with ducks was a favorite retreat for one couple.

Although all the advantages of rural living were highly valued by participants, living in a rural setting came with a price. There is an added cost to living in rural areas and this figured prominently as a contextual factor in the commuting experience. Goods and services in rural communities are more expensive and there are added costs associated with travel. Commuting for advanced cancer care added additional financial burdens to an already high cost of living for most. Many FPCs expressed concern about the financial impact of commuting for advanced cancer care for themselves, as well as others who might be in the same position. Costs were associated with gas, meals, accommodation, extra vehicle maintenance, parking and sometimes lost wages if FPCs took time off from work for commuting. As one said “It’s hard you know juggling and the financials and you know having to take time off ‘cause I have no coverage. So, financially it’s been a little miserable, yes. To say the least”(FPC 5). Another participant added, “Even though people may have money, I don’t care. It is a costly event” (FPC 1).

Fuel prices topped the list for expenses that were hard for FPCs to meet. One participant stated that with just one local service station “we’re higher than anywhere” (FPC 5). In addition, another participant stated “it’s a lot more stress you know because...I am on [employment] leave so my income isn’t high and when you’re paying 60 bucks in gas, to go out, it get’s pricey” (FPC 6). One other participant justified her

motel stay by stating that the fuel cost for commuting daily would probably have exceeded her accommodation cost (FPC 4).

The financial strain for two participants saw them foregoing a cell phone, entertainment, going out for dinner as well as new clothes and utilizing coupons to save money. One stated “You just do without other things“(FPC 5). Accommodations, airfare and groceries were other areas where expenses were a consideration for some. When hotels were expensive for rural commuters, the lodge provided a helpful alternative. One family also received complimentary meals there on the day of their departure, when their finances ran low. A FPC who lived a considerable distance from the cancer centre chose to fly only when fares were inexpensive. Even providing the recommended nutritious meals became a strain on another family budget. For the group as a whole, the weighing and consideration of expenses was a common preoccupation since direct commuting costs took priority.

Life Including Caregiving. Responsibilities associated with supporting family members’ commute for advanced cancer care were typically added to the already active lives of FPCs, and as such were an important contextual factor in the commuting experience. FPCs were involved in a wide range of roles and responsibilities, in addition to taking on caregiving responsibilities. Six FPCs reported significant family responsibilities. Four FPCs noted that they had dependent children in their care, including an infant in one case and two others had their adult children living with them. Six FPCs were employed outside the home or worked as volunteers, and two others were on leave from their jobs.

On top of these responsibilities, FPCs were also involved in providing palliative care for their family member including acting as a personal care assistant by assisting with activities of daily living, transportation, as well as taking responsibility for meal preparation and housecleaning, and providing comfort measures including managing medications, and being responsible for some medical procedures. FPCs found themselves attending appointments as a “second person” to see and hear treatment plans as well.

Rural Support Networks. Rural communities are often known for their strong social networks because of long associations, shared values and strong family ties.

Commuting experiences were therefore influenced by the availability of support in rural settings, as well as whether FPCs accepted the support that was offered to them. For example, all working FPCs in this study who sought flexibility for commuting with their relative for advanced cancer care were able to make satisfactory arrangements for time off at their place of employment. When family members lived close by their involvement in the commuting experience was a common occurrence. Many FPCs could count on family members to assist with driving or childcare as well as attendance at appointments and visitation. However, not everyone felt comfortable asking family members for help, particularly when they lived further away. One FPC stated that she and her husband felt they might be “interrupting” their children’s lives, so chose to manage commuting on their own.

The majority of FPCs did not have close family members living nearby and thus, relied primarily on friends or neighbours in their community. Although not everyone took full advantage of this support network, FPCs knew these individuals could be depended upon to provide meals, be occasional drivers, and provide help and friendship in a variety of ways. Some FPCs noted that their friends and neighbours met with them as a kind of ‘a social club.’ Other friends made telephone calls during commuting visits, and kept in touch with internet email or made personal visitations if the FPC and family member were staying in the urban centre. The broader social network became a valued support for many older couples whose adult children did not live nearby.

Community support also came in the form of financial assistance. Two local community fundraisers were held for a family who had exhausted all other financial resources. This support enabled them to continue to commute to the cancer centre for the next six months. Another FPC knew she could fall back on family members to help out financially if she found herself “completely tapped for cash,” however, at the same time worried about “taking away” financial resources from other FPCs in her family (FPC 6). The onus was, therefore, on these two FPCs to make the best use of all personal resources in order to be financially independent as long possible.

Cancer Services. The cancer centre provided another important context that influenced commuting for care. On the whole, FPCs spoke of the health care staff, volunteers and receptionists as giving compassionate care. They noted in particular that

the friendly and encouraging manner of staff created a community of positive support. The majority of participants described visits that included good humor, smiles and the sense of being remembered between visits, by both staff and volunteers at the cancer centre and the cancer lodge.

Family Palliative Caregivers' Experiences of Commuting

FPC experiences of commuting are described in the following section. FPCs were highly committed to commuting despite the additional responsibilities. The task was taken in stride as “just something that had to be done” (FPC 11). This was clearly reflected in the following narrative:

And you make it work. It's not a problem. That worked for us... it just somehow it's something that you fit in. It's like if you have a kid that's playing soccer, somehow you fit the soccer game in. You're, you're there. If you thought about it, you'd think oh gee, I got my laundry to do. Or I got to do dishes or something. But you don't. You put it on the back burner and you go and see your kids play, you do whatever. Oh coming here is the same thing. It's something that has to be fit in. (FPC 11)

Four themes capture important aspects of FPCs' experiences of commuting: 1) planning ahead: preparing for all possibilities; 2) experiences on the road; 3) the toll of commuting; and 4) making the best of it.

Planning Ahead: Preparing for all Possibilities. FPCs went to great effort to support the commuting requirements of their family member. Planning ahead to prepare for all possibilities was one of the most important methods that they used to ensure the commute went as smoothly as possible. This involved a tremendous amount of preparation, making arrangements, and being aware of their family members' needs. Initially, FPCs did not question the necessity for the trip and managed to accept the inevitability of the journey and take it in stride. Next, came the myriad of preparations that were necessary to undertake for leaving home and travelling with an ill family member. In order to ensure a safe trip, it was necessary for FPCs to anticipate the family members' needs in advance. Participants described how their ability to manage time actually facilitated visits to the cancer centre.

FPCs were motivated to plan ahead in order to avoid missing or rescheduling appointments. They had to ensure that even when patients were not well they would both be prepared to undergo the trip. One FPC observed “that’s not really conducive to cancer treatment at all...you know, he’s throwing up on the road or whatever, you still have to go” (FPC 5). Hence family caregivers took on their responsibility to support commuting seriously and were committed to doing everything in their power to ensure that family members received the treatments they needed. A 36 year old FPC who drove his mother for care stated, “You just make, whatever you have to do, you make, make it happen...with work or anything...Family is everything” (FPC 7). Strategies that supported FPC planning included preparing for the trip, anticipating patient needs, and managing time. Each of these is described below.

Preparing for the trip involved attention to a range of practical issues that needed to be managed in order to facilitate commuting for advanced cancer care, and FPCs took these on single mindedly. These arrangements included getting time off from work, making sure that the car was in excellent running order, packing clothes, medications and equipment for the trip, occasionally arranging for a second driver, and monitoring weather and highway conditions. Concern about the weather had one participant staying overnight in the urban centre (FPC 1). To accommodate for the time commitment required for commuting, FPCs needed to plan ahead to book time off from work, reschedule or exchange shifts with co-workers, make arrangements for childcare and care of pets. Not only did they need to consider the possibility of traffic delays, condition of the roads and weather, they also planned for contingencies in case of breakdowns. To prepare for each trip, FPCs needed to attend to every detail.

Anticipating family member needs was the second major planning activity undertaken by FPCs in order to be sure family members were as comfortable as possible during commutes. Gathering together a wide range of supplies in a “just in case” bag was common for FPCs who were preparing for the trip. Supplies included such things as drinking water, an ice cream pail with lid (in case of vomiting), a change of clothes for the patient, baby wipes, medications (analgesics, antiemetics, regular medications), peppermints for dry mouth, travel pillows and blankets, bandaids, a cold pack and ileostomy supplies. Collectively, participants also found that bringing their own snacks

and other foods (e.g., soups, or meals) was important to ensure that family members had food that they enjoyed and was of better quality than restaurant food. This was also a cost saving measure.

In their efforts to anticipate their family members' needs during the commute, FPCs carefully and continually monitored family members' health to be alert for any impact health changes might have on the journey. They watched over family members to assess their sleep, activity and energy levels, changes in appetite (and associated changes in weight), as well as adherence to medication regimes. Changes in level of debility over the course of commuting for treatment challenged FPCs to provide more vigilant monitoring.

Assessing pain was one of the more difficult monitoring tasks that FPCs took on to guide their planning. "It's tough [the] physical...also mental [pain]...[and] taking inventory as to where the pains are" (FPC 9). One caregiver observed that pain control was "big" and you had to "take lots of breakthrough doses" for the trip (FPC 1). To emphasize the importance of this monitoring task, FPCs reported that they had driven in with their family member who had intractable pain before even leaving home. The length of time spent on commuting trips became an important consideration because of this reality.

Managing time was the third main planning strategy used by FPCs. The nature of the commuting experience for rural and remote families travelling for advanced cancer care, was such that a high degree of flexibility and advance planning was needed to be sure that there was sufficient time to pack equipment and supplies, make necessary arrangements for being away from home, and to get to appointments on time. Participants reported that they always left early and would plan far enough ahead in order to allow "extra time." For a one way trip of 90 kilometres "you have to allow at least two hours" according to one participant who noted that it "would be a lot easier if we were only 20 minutes away" (FPC 11). Another husband planned the trip to get his wife there 15 minutes beforehand so she could "get into her gown...because there is an anxiety that can come with being rushed" (FPC 10). It took extra planning to ensure that an extra cushion of time was built into each activity.

Managing time also involved a great deal of flexibility. FPCs needed to plan for “an all day affair” as well as very short radiation treatments. One participant spoke of her surprise: “How quick it went!” [laughs] (FPC 1). In this circumstance, the FPC barely had time for a hot drink before heading out on the road again. Unlike paid caregivers, FPCs did not get breaks from the responsibilities associated with commuting. Rescheduled appointments with little notice further complicated time management for FPCs. In other situations FPCs found that waiting for appointments was difficult to do. One FPC travelling with her spouse spoke of their own approach as being one that “when we arrive here we just put it into a slower gear” (FPC 12). FPCs found that being receptive to changes in appointment times was sometimes required. The concept of time and time management as discrete knowable entities was replaced by the idea of time being a more fluid commodity for FPCs as they commuted with their family member.

In summary, planning ahead required considerable work on the part of FPCs. This work included making preparations ahead of time including planning for the unexpected, assessing pain for the length of the journey, and managing time. Planning was a complex task influenced by a number of factors including weather.

Experiences on the Road. Data related to FPCs’ experiences on the road captured the unique experiences of commuting for advanced cancer care. Themes that were identified included a) doing ‘double duty’; b) getting into a routine; and, c) dealing with unfamiliar territory. Each will be described in more detail in the following section.

The multiple roles that FPCs took on while travelling can be described as doing ‘double duty.’ The demands of commuting for FPCs were most clearly reflected in their experiences on the road where FPCs took responsibility for getting their family member to their appointments safely and on time, in addition to other caregiving responsibilities. During commutes FPCs remained vigilant and responsive to variations in their family members’ needs while skillfully managing the driving, accommodating to unexpected weather conditions, traffic congestion and remaining alert for animals and other obstacles on the road.

So if you go off the road or hit a deer then you've got to be prepared...because then you have to take into consideration the person with you, is compromised system in general, so they get cold faster you know, they need their medicine. It's like you know, they're just not able to do the hike or walk that far, or stand for three hours hitchhiking, or whatever the case may be, right? So you always want to make sure that if that happened, that one person was able to stay in the vehicle and stay warm, then the other person could go for help or gas or whatever. (FPC 5)

FPCs provided ongoing monitoring of their family member during the course of the trip through talking with them about their emotional distress, watching to see if their physical tolerance was maintained and encouraging them for upcoming treatments. Driving safely was also a priority and FPCs were particularly cautious because they did not want to create any additional difficulties for their sick relative. In addition, for some patients sitting in the car for lengthy intervals became difficult due to pain or 'bounces' because of rough roads. FPCs watched for these changes and did their best to make the commute as comfortable as possible for their family members. However, this part of the job became more difficult as the disease progressed and family members experienced increasing pain and fatigue, as well as side effects from their treatments.

Family members who became increasingly compromised in their ability to travel, created additional caregiving challenges for FPCs during the commute. Three FPCs spoke of discontinuing the appointments if their family member could not tolerate the travel. Finding the right balance between supporting the family members' engagement in activities associated with commuting (including activities they enjoyed when they were in the city such as shopping and going out for lunch) and protecting them from doing too much was difficult at the best of times for FPCs.

Managing the range of emotions ill family members experienced in relation to commuting for cancer care was also a challenge on the road. During the drive, for example, FPCs responded to family member anxieties related to upcoming appointments, reluctance to travel, disappointments with having to return for additional treatments, and loss of independence associated with advancing disease. When ill family members were experiencing discomfort, there were extra challenges. Some caregivers, for example

found it difficult to motivate family members to begin the trip in for more treatment when they were experiencing nausea and vomiting that might be made worse by travelling a long distance by car. In another demonstration of the range of support exercised, one FPC found himself coaching his wife during the commute as to how to manage her claustrophobia during radiation treatments by using images to distract her:

Trying to imagine what it was going to feel like laying there. You know, when you can't move your head, right? And what sort of things can you see that are going to help you deal with that? So, we talked about what she would try and imagine. Like her garden, or walking the dog, or on a particularly nice day in the fall, walking the dog and it's nice and sunny and the colours are out, and it's cool and sunny. (FPC 10)

This FPC noticed that over the course of several radiation sessions that this technique enabled his wife to undergo the treatments with much less anxiety than at first. These experiences demonstrate how seriously FPCs took their responsibility to provide comfort and support when commuting to appointments at the cancer centre.

Getting into the routine is the second theme used to capture FPCs experiences on the road. Acquiring a routine was common experience among participants who commuted frequently. These participants began to feel as though they were on "autopilot." One male FPC commented, "There was days...Holy cats, here we go again, right? And one more thing. Pretty soon the truck would go by itself" (FPC 10). The regularity of the commute helped FPCs to manage the additional responsibilities. Over time, however, these trips became tiring. For other families routines were quickly disrupted when appointments were unexpectedly changed and when ill family members experienced difficulty keeping track of their appointment schedule. One FPC who assisted her mother in commuting for advanced cancer care, described this situation when appointments were inadvertently booked with her mother who was sick, instead of another family member:

Appointments all over the calendar...in different cities and in different things...so much going on, so much, you know it just keeps happening. And it's appointment after appointment you kinda get scrambled on what you're supposed to do...and then with the cancer the brainwaves are not normal already. (FPC 6)

Experiences related to the unfamiliar territory associated with commuting was the third theme identified in FPC experiences of being on the road. The additional stress, arrangements that supported commuting such as arranging for occasional drivers, paying for extra fuel, and packing equipment and supplies including wheelchairs for the trip took commuting for advanced cancer care outside the realm of customary travel. Taking on the chore of driving long distances was new to two participants. The role reversal as a primary driver created a stressful trip to the city for one wife, who had not driven that distance before. She opted to leave home a day early, when the traffic was decreased. As well, local volunteer drivers provided assistance with transport to the centre during her stay. Another FPC undertook an extended drive across the border with a relative to practice her long distance driving skills in the event that they would be needed on her commuting trips. Her comfort zone as the driver had previously been to local communities only.

And my [relative] doesn't drive and I'm going, "I never drive, never drove like into the States. And like I've never done anything like that. But I said, you know [patient] is, has cancer and I" and she goes, "Well we don't have to go." And I go, "Yes we do because I've got to learn to do some stuff, right?" (FPC 13)

Dealing with new health care providers and the terrain of advanced cancer care was also part of the unfamiliar territory for all but one FPC. A few FPCs described situations that involved communication problems between staff at the cancer centre that created additional stress for them and family members between commuting visits. Each of these FPCs perceived a lack of clarity regarding prognosis and incomplete information. Travel home was reported as strained or difficult by some FPCs if all questions had not been answered with clarity, and family members relied on them caregiver to interpret the information.

In summary, experiences on the road involved incorporating the caregiving role into the task of driving, establishing routines, and dealing with unfamiliar territory. These experiences capture the unique demands of commuting with family members with advanced cancer.

The Toll of Commuting on Family Palliative Caregivers

Commuting for advanced cancer care had implications for FPCs' own health for most participants in this study. They experienced tolls on both their emotional and physical health, as well as disruption to family life. FPCs found themselves dealing with a range of emotions associated with commuting. Emotions ranged from nervousness, worry or unhappiness to more profound feelings of being scared or fearful. The situations that most often elicited emotional distress related to the lack of familiarity with the cancer centre, lodge, or staff, in addition to concern about which treatments would be undertaken. Participants wanted to know what to expect, who they would be meeting with, the nature of the treatments and options that their family member might have with the course of treatment.

As their family member's disease progressed, seven of the FPC's experienced a range of their own health impacts related to commuting for care. These included the stress of driving, increased worry, anxiety and tearfulness, fatigue, exacerbation of chronic health problems leading to physical discomfort as well as altered sleep and eating patterns. Some FPCs admitted to putting their own health needs aside in order to meet the needs of their ill family member. In one case regular prescribed personal medications were omitted in order for the FPC to feel that she was a safe driver on the road. There were other health-related experiences that had the potential to influence FPCs' ability to take responsibility for commuting visits. One FPC noted that both her sleep and eating patterns had changed to accommodate the patient's needs. FPCs also admitted that they would forget to take pills, "put myself on hold" or "on the back burner" which seemed to indicate that delivering palliative care might be at the expense of their own well-being. One FPC reported that her final commute was particularly "tough," because the pain medication provided for her husband "wasn't enough" (FPC 1). Pre-existing chronic health conditions reportedly worsened for two FPCs and resulted in their increased physical discomfort during the commute. The implications for some FPCs arriving to meet appointments in less than optimum health and well-being themselves are an important consideration on several levels. Those few FPCs that drove while experiencing their own health problems found this a difficult time.

Despite these health issues FPCs commitment to supporting patients on their commute for care did not waver. Their determination was reflected in one participant's firm resolve to continue to drive his wife "as long as I'm able to...number one is family, number two is providing for the family" (FPC 14). For some FPCs, however, this meant pushing themselves beyond comfortable limits. Whereas several other participants reported no ill effects to themselves as a result of commuting for advanced cancer care. These findings reflect the pervasive nature of the burden that the majority of participants experienced, while they commuted to access advanced cancer care.

Disrupted home life was also an important part of the commuting experience for FPCs. A few FPCs who could not stay in the urban centre during treatments because of the need to take care of things at home, found that their own time home alone was unhappy and that they worried about their ill family member. When FPCs spent time apart from the ill family member and they could not be home together as they wished, there was an added layer of strain. Those who stayed with their family members in the city longed for the comforts of home. FPCs found their anxiety about what would occur at the cancer centre, and concern about their family member's well-being, often obscured their own health issues. Whenever FPCs commuted to bring their relative for advanced cancer care they looked for quality time together.

Making the Best of It.

Despite the challenges of commuting, FPCs focused on making the best of commuting. There were examples of FPCs taking advantage of the travel by spending time with their family member, renewing family connections, and taking time to do something different (e.g., enjoying a treat of a restaurant meal, excursion or shopping for something special) in order to make the whole experience as positive as possible. There was a strong consensus among many participants that commuting for advanced cancer care should be enhanced by enjoyable pursuits. However, in addition to this, FPCs also came to appreciate the benefits that commuting offered to them personally and to their relationship with their ill family member.

In particular, the overall commuting time was valued by many participants as an opportunity for meaningful conversation. One FPC noted "I think people just find it easier to talk in a small space...you have that extra time that's just there, just for

you...that, that few hours that you're taking to drive in or out. I think it becomes important" (FPC 11). The idea of the car as an intimate space played out for other families as well. Four FPCs who travelled with spouses and one daughter who drove her mother, spoke about "time together" as a positive outcome of commuting for care (FPC 6). "We're near the end of where we need to, where we are, and so every time for us together is important...but for [patient] and I we need the time together" (FPC 11). A need for talk and discussion about many things including goals, asset protection, relationships and just enjoying private talks together seemed to be facilitated by the close quarters of the car, motel, lodge or airplane that FPCs found themselves spending time within, alongside their family member.

For a few FPCs, the conversation on these drives swung to contemplation about relationships in the future after the patient had died. Both of these conversations were initiated by the patients. For example one FPC recalled:

And he goes, "when I'm gone you'll find somebody else." I go, No I won't. It's like, he's just like "Well you're young, you should you know." And I'm just like. "We're not at that point, would you just cut that out." (FPC 13)

This FPC acknowledged that her husband was more accepting of his own prognosis than she was, and that their expectations were quite different. Commuting appeared to restore a sense of balance that had been lost for some FPCs. Married couples sometimes sought or found a closer intimacy because of the commuting experience. One wife recalled "we'll go back to the hotel and we will crawl into bed and cuddle each other and just hold each other" (FPC 12).

Family Palliative Caregivers' Recommendations for Commuting

Based on their experiences, FPCs had a number of recommendations for other families in similar circumstances and for health care providers. Recommendations for family members centred on various strategies for making the commute comfortable for the ill person. Being well organized, getting ready well in advance, and being prepared for unexpected events were reiterated by the FPCs as important strategies. In addition, they emphasized the importance of asking others for assistance. One FPC advised "[Tell them to] ask people to help them drive, so they're not always doing the drivin' ...[because

the] further out you are and the more often you have to go...just do not depend on the two of you” (FPC 1).

They also had some practical advice for FPCs such as getting a good night’s sleep before the drive, allowing extra time to avoid feeling pressured, and keeping vehicles in good running order. However, the most endorsed recommendations were that FPCs and patients should plan on staying over in the city during treatment to reduce the strains associated with travel.

The commuting experience itself prompted other types of recommendations for FPCs that focused on managing the emotional aspects of commuting with relatives who were receiving advanced cancer care. Two participants stressed that FPCs should “just enjoy it...it’s nice to be there” (FPC 5) and also “take the time to talk about things that matter” (FPC 11). Another FPC who had commuted for years for care had her own recommendation for FPCs: “Don’t think of it as just coming here getting treated...think of something else. Think of it, as a, as a day out...don’t look at the negative part of this” (FPC 11). Yet another FPC recommended that others try to “stay strong...and give what support you can” (FPC 8). One spouse in the study was more somber as he stated that other FPCs should be told:

Take..., what you think [is] the worst thing is going to happen to your partner and double it, triple it... in terms of how they are going to feel. Because it really is quite scary, in terms of how physically beat up individuals get...And they can say, “Yah. You’re doing fine”...And you look at this individual who is just hardly anything there. And there’s no energy, right? It’s just, it is, it’s an eye opener ...Take the good stuff out that you can. Certainly don’t dwell on the down side of it. Enjoy the time with your partner. But relish the moment. (FPC 10)

Other recommendations for coping with the emotional aspects of commuting included using distraction, trying to relax during the waiting times while relatives received treatments, and taking a day to do nothing in order to unwind. The necessity of asking lots of questions was stressed by one participant. Self-care suggestions were what most FPCs wanted to pass along to others who might need to commute with a family member in the future.

FPCs had fewer recommendations for health care providers to support rural and remote families who commute, perhaps because of the satisfaction they experienced with services. The importance of cancer care provision to positive commuting experiences was not discounted. One FPC who was returning to the cancer centre with his mother, after two years away, hoped for good communication, clear information and an acknowledgement of the family member's prognosis. This recent visit met all of his expectations as he explained:

I think the most important thing is that when you arrive, you have a good experience from the doctors, even no matter what's happening with, with the cancer, like you don't wanna drive all that way and go away, either way, you go away disappointed. (FPC 7)

Another FPC thought that staff should know more about the demands of commuting on FPCs and patients including "how tiring it is...how stressful it can be at times...how much of a day [emphasis] it is for them" (FPC 1) and also that it was important to understand the emotions of people who are coming for appointments. Both she and another FPC also believed that more FPCs should be invited "to come in" to observe treatments so that they had a better understanding of the care their family member received and possible implications for commuting (FPC 1, FPC 15).

Specific recommendations for support were directed to health care professionals. There was a recommendation for a "support group for supporters" to share experiences and feelings with others who had first hand experiences with commuting for advanced cancer care. Another FPC thought that volunteers should be available on weekends at the lodge to ensure that when families arrived at the urban centre, that there would be someone to talk with (FPC 15). One FPC stated that she would have welcomed a social services liaison at the cancer centre so that she did not have to apply for these benefits through her small home community with someone "who didn't understand about cancer" (FPC 12).

The FPCs also had a number of other general recommendations for palliative programs providing services to patients and families who commute for advanced cancer care and policy makers. A group of FPCs drew attention to the manner that reimbursements are offered for expenses incurred through travelling for advanced cancer

care. One participant noted tax refunds do not “come anywhere close to matching up to what it cost you to do it” (FPC 2). To address financial implications associated with commuting, FPCs advocated for “compassionate pricing,” rebates for travel costs associated with commuting, and ready sources of funding for basic commuting costs, that should be available right at the cancer centre. FPCs wanted to be present for the palliative care and commuting of their family members, but sometimes were unable to because of the financial outlay that they were not always able to sustain. These comments underscore the investment of time and resources spent on the commute, and the importance of support for FPCs living rurally or remotely where there is more limited access to oncology specialists and supportive care services.

Summary

In summary, the findings highlight the complex nature of individual family experiences while commuting for advanced cancer care to an urban centre. This type of travel is influenced by the boundaries and commitments of rural life, the extent of

travel is influenced by the boundaries and commitments of rural life, the extent of caregiving provided and the specific practical rural support networks that are available and accepted. FPCs planned ahead to prepare for the trip, anticipated patient needs in advance and tried to manage time thoughtfully. FPCs described their experience with these commutes as ‘double duty’ that at times required them to adopt new routines, and take on new skills or competencies in order to provide the palliative care needed for their relative. The demands of commuting had a toll on FPCs health and disrupted their home life. However, they often found ways to make the journey worthwhile, and even found that commuting promoted deep and meaningful conversation with their family members that strengthened their relationships. FPCs’ recommendations for other FPCs, health providers, palliative programs and policy makers provide additional insights into their experiences and directions for enhancing support to families who commute for advanced cancer care.

Chapter Five: Discussion

This thesis concludes with a discussion of the main findings of this qualitative descriptive research study. The chapter will begin with a brief summary of the findings. Following this, the main findings related to FPC commuting experiences will be discussed in relation to existing literature. The study limitations will be presented and recommendations based on study findings will be discussed. Finally, the chapter will end with a conclusion.

Summary of the Findings

The purpose of this qualitative study was to describe the experiences of rural FPCs who travelled with family members in commuting to a regional cancer centre for PC. Analysis of semi-structured interviews with 15 FPCs revealed important contextual factors influencing FPCs' experiences including the independent nature of rural dwellers, rural informal support networks, life including caregiving and familiarity with long distance travel. The dedication of FPCs to making the commuting experience as positive as possible for their family members was a central theme. Accordingly, FPCs were involved in extensive preparations for these trips, taking extra precautions, monitoring the impact of travel on both the patient and themselves, and providing comfort and support during commutes.

Undertaking commuting could be stressful, tiring and sometimes pushed FPCs beyond comfortable limits. Moreover, managing the financial implications of commuting was often an added worry. Despite these challenges, FPCs spoke of the importance of "making the best of it" by taking full advantage of the time spent with their family member and incorporating other activities to make each trip worthwhile. The findings will be discussed in relation to: a) the influence of rurality on experiences of commuting; b) the influence of commuting on FPCs; and, d) unexpected outcomes of commuting for advanced cancer care.

The Influence of Rurality on Experiences of Commuting

Dimensions of rural life figured prominently in the commuting experiences of the FPCs who participated in this study. Although a few studies were located that described the needs of family caregivers in rural contexts (McGrath, 2006; McGrath et al., 2006; McGrath, Ogilvie, Rayner, Holewa, & Patton, 2005; McRae et al., 2000; Wilkes, White,

& O’Riordan, 2000; Wilson et al., 2006), few researchers have taken into consideration the unique nature of the rural environment as a dimension of caregiver experience. The importance of taking into consideration complex rural dimensions of health experiences has been recognized (Harvey, 2007). However, a focus on the social and economic hardships of rural life has often directed attention away from the positive aspects of rural living (Rogers-Clark, 2002) and tensions inherent in rural living (e.g., tension between social isolation and a sense of belonging) (Harvey, 2007). In this study rurality influenced family caregiver experiences in complex ways that enabled commuting, as well as made it particularly challenging. Rural contexts influence the way people relate to one another. As such, FPCs benefited from strong social networks that included both instrumental and emotional support that directly influenced commuting experiences. Familiar routines of regular travel to larger centres prepared caregivers in important ways to assess and modify the commuting approach when palliative caregiving was needed. The rural environment was also viewed as a resource for respite between commutes by participants. However, being in a rural locale also presented challenges for FPCs in the context of commuting for advanced cancer care. The high cost of travel, winter driving conditions, and traffic delays were the most frequently cited worries. In addition, the lack of familiarity and comfort with cancer care facilities where the advanced cancer care was provided created an additional level of stress. These findings add to a growing body of literature that supports the need to recognize the tensions inherent in rural life, as well as the influence of rural environment, distance and climate (Keating, 2008).

Although previous research on rural caregivers has been informative, the influence of rurality has not received much attention. In the only directly related study that could be located, researchers interviewed 13 bereaved Ontario-based FPCs who had the experience of commuting for PC for their family member, often travelling considerable distances to a tertiary centre (McRae et al., 2000). Access to services, quality of services and support and caring predominated as themes in FPCs’ experiences with palliative care services in those rural communities. In contrast to the Ontario study, all but one participant in this current British Columbia study were current commuters. The findings of this thesis indicate that FPCs focused on planning and preparations required for commuting, and monitoring family member needs in order to assure a

positive commuting experience for family members. Access to services was a key concern of FPCs in McRae and colleagues (2000) study likely due to the more remote locations of participants on Manitoulin Island. In contrast, data in this current British Columbia study suggest that length of time involved in commuting was more of a concern than the actual distance travelled for commuters. The FPCs in this current study were concerned about being away from family and friends, and worried about time away from work, stress and anxiety, burden if others drove for them as well as the cost of commuting and staying over. Participants in this current study also expressed concerns about finances, and that their requirement for information from the health care professionals was very important. Similar experiences have been reported among patients who commute for cancer care (Celaya et al., 2006; Davis et al., 1998; Davis, Williams, Redman, White, & King, 2003; Meden et al., 2002; Stafford et al., 1998). Although in these studies participants were in the early stages of diagnosis, not in a palliative stage, their treatment decisions were often affected by travel distance. In this current study, FPCs also appeared to be influenced by travel distances. They spoke of travel time as being an important concern, in terms of their family members' comfort and tolerance. Similar to reports of FCGs in this thesis study, two studies that addressed rural women's needs when travelling for cancer care identified that social and practical support, including equitable financial aid were key concerns (Davis et al., 1998; Davis et al., 2003). Information targeted to specifically assist rural women, comprehensive financial assistance, support for practical and psychosocial needs were also found to be important. In general, there appear to be some common concerns among caregivers and ill family members who commute for cancer care and advanced cancer care in particular.

FPCs in this current study personified dedication as they continually adjusted to accommodate treatment schedules, the declining health of the family members, their own work and family commitments, and the multiple preparations required to commute long distances in all types of weather and road conditions. Only the minority of FPCs involved in this study had close family members living near their community. Most had adult children who lived in other provinces or even out of the country. When immediate family lived close by, it was common that they were involved as a support. However, without family in the community FPCs turned to friends, neighbours and work colleagues

for help, friendship and support. Despite this most of these FPCs chose to make the journey alone as a couple, and rarely asked for an extra driver or companion to come along. This resulted in FPCs 'doing double duty' as they assumed responsibility for driving on top of their caregiving roles. This occurrence may become problematic in the last three months of life, when the aggregate of care needs of palliative patients have been shown to increase sharply (Brazil et al., 2003).

This current study identifies what further demands exist for those who choose to commute for advanced cancer care. There is also a particular pressure on FPCs that involves the increasing awareness of their family member nearing the end of their life. This study describes commuting in the context of that knowledge. Participants were independent, self-reliant, and dependable when it came to commuting, and highly committed to being there at all costs for their family member. The result was a reluctance to ask for help at times, even in the face of their own personal health issues.

The vital role of family caregivers for ill family members with life-limiting illness is well recognized (Andershed, 2006). Despite the multitude demands of caregiving and commuting, FPCs in the current study strove to 'make the best of it' by pursuing meaningful conversation, outings and simple pleasures on their appointment days. Although Hudson (2004) notes that it is important for health professionals to help caregivers realize the benefits in their role, it appears that these FPCs were able to do this on their own.

While commuting is generally an accepted part of rural life, this current study identified additional stressors that result when travel is needed for the advanced cancer care of family members. What is new that this study adds in terms of demands associated with commuting is the extensive preparations that go into such a journey and the measures employed to assist in patient comfort and support. These actions taken together detail the dedication of these resilient individuals as they accompany their family member. This study provides clear descriptions of the investment of time in the FPCs' supportive endeavour. Time spent commuting, rather than distance travelled, appeared as more of an issue.

The specific needs of the commuting population of FPCs who are travelling to access palliative care for a relative are less clear. This current study identified some

concerns surrounding pain and symptom management as well as communication with health professionals. Some participants reported concern with access to sufficient funding. McRae et al. (2000) found similar concerns among palliative caregivers. Stajduhar (2008) found that FPCs are key players that are necessary to the health care system since they often act as advocates for palliative care. This advocacy role becomes particularly important when FPCs are supporting family members who receive advanced cancer care outside their home community and are compromised by their inability to advocate on their own behalf because of deteriorating health. Through extending adequate support to FPCs there is a potential to improve the health of their palliative family member.

The Influence of Commuting on Family Palliative Caregivers

FPCs took on commuting responsibilities and were relatives who already had significant caregiving, work and/or family commitments. Most oncology research on commuting has thus far focused on the recipients of health care. However, the findings of this study suggest that the risks of health effects of commuting for advanced cancer care for the FPCs should not be ignored or underestimated. The tiring and stressful effects of commuting had a direct effect on caregivers' own health. As well, the pain, exhaustion, or illness, sometimes experienced by ill family members were also concerns that affected FPCs while commuting. Hudson et al. (2006) identify the high risk that FPCs face for their own physical and psychological decline due to their caregiving activities. A growing body of research has begun to describe the psychological, occupational and economic aspects of caregiving in this context. For example, Grunfield et al. (2004) report substantial increases in caregiver anxiety and depression as family members entered palliative and then terminal phases of their illness. Caregiver distress was associated with perceived burden. Adverse impacts on employment and income security were also reported in this urban-based sample. The physical, psychological and economic effects that FPCs experience may be magnified when commuting responsibilities for palliative care are added to already difficult caregiving roles. In addition, based on the findings of this study, the challenges of pain and symptom management and the provision of psychological support during commutes also need to be considered as important aspects of caregiving in rural contexts.

In the only other study to examine the experience of both newly diagnosed cancer patients and their families when commuting for radiotherapy treatment (Hegney, Pearce, Rogers-Clark, Martin-McDonald, & Buikstra, 2005), researchers identified five issues associated with commuting: 1) the burden of travel, 2) the difficulties of living in accommodation that is not one's home, 3) the financial burden caused by commuting or relocation to the urban centre for treatment 4) not being close to family and friends, and 5) feelings of being a burden on others. Overall, the findings suggested that the stressful time of a cancer diagnosis may be compounded if travelling is also required. The findings of this study suggest that FPCs who commute with family members for advanced cancer care are also vulnerable in these specific ways. Commuting responsibilities were taken on by FPCs who already had significant caregiving, work and/or family commitments.

Unexpected Outcomes of Commuting for Advanced Cancer Care

Despite the challenges of commuting for advanced cancer care, there were positive and often unexpected benefits associated with commuting for FPCs. Meeting other families and patients who had travelled for treatments offered some FPCs the opportunity to both give and receive support, which eased the cancer journey with their own relative. Many participants also shared stories about engaging in meaningful conversation during the drive. Some even felt that car travel promoted such talks. Several spoke of future plans that they had discussed with their family member in consideration of their relative's end-of-life reality. The intimate time provided during the drives to and from the cancer centre has not been previously described as a feature of commuting experiences. This may be an added advantage, therefore, for both FPC and patients when they travel together rather than using volunteer drivers. Syren, Saveman & Benzein (2006) identify these types of interactions as infused with meaning and key for family well-being. Moreover, Hudson (2004) notes that most FPCs are able to identify positive features about their situation. The inability to do so may signal a need for supportive measures.

Study Limitations

The study findings are based on a relatively small homogenous sample residing within driving distance to a cancer centre in south central British Columbia, Canada. In

circumstances where there is more difficult access to cancer services (e.g., poor road conditions, unreliable transportation, longer distances to travel), experiences of commuting may vary from those described by these study participants. This sample also lacked ethnocultural diversity with many self identifying as Canadian or Caucasian and therefore findings may not extend to diverse cultural groups. Study findings are influenced by the particular characteristics of this rural context. Therefore, FPC experiences may differ in settings where individuals are living in very remote settings, have greater responsibilities associated with rural life (e.g. as might be the case in farming), have more limited financial resources, or when those who support commutes are not family members. This study did not capture the experiences of FPCs who may have had to stop commuting because they or their family were no longer able to manage the travel, or those who chose not to commute at all. Despite these limitations, the study provides some important insights into FPG experiences of commuting that provide direction for healthcare service, policy and future research.

Recommendations

There are important recommendations with respect to the provision of healthcare services, policy and research when FPCs are travelling from a rural or remote locale to access advanced cancer care in an urban centre. The findings of this study provide a beginning framework to share areas of concern and advocate for change.

Recommendations for Practice. In relation to the provision of advanced cancer care to rural and remote communities, FPCs who commute with family members for cancer care may benefit from further support. However, careful assessment may be needed to determine the appropriate measures. In particular, health care professionals at all levels need to be aware of the challenges that FPCs may experience when they take on responsibilities for commuting in addition to caregiving in the context of palliative care. Comprehensive guidelines for supporting FPCs who commute need to include incident pain and symptom management while travelling. Viewing the commuting family as linked in terms of health care needs can point to practice changes that are needed. FPCs who commute with family members from rural and remote communities would benefit from initial and regular assessments that identify their own well-being and support needs.

Family centred care should attend to the caregiver alongside the needs of the family member who is ill and ensure that information is available and readily obtained.

An orientation to the urban cancer centre facility in advance of their first visit may also be helpful. Orientation could be provided through two possible means. One method might be a web site with a virtual tour. This could be delivered by community care providers in rural and remote locations where internet access was readily available. The cancer centre provided an extensive collection of print material and brochures throughout the entry lobby but few were grouped under heading identifiers. This can provide a challenge for access if time is an issue.

For a few families, arrangements may need to be made with the cancer centre to coordinate the delivery of locally scheduled chemotherapy and urban radiation treatments on appointment days. This would avoid dashing between appointments in different locales by utilizing the cancer centre rather than having chemotherapy delivered closer to home as usual. This way, the commuting drive need only be made to one urban centre per day.

Policy Recommendations. Policies that support rural and remote PC families who commute could significantly influence quality of life for those receiving PC as well as their family members. Policy changes are needed to secure methods for timely reimbursement of out of pocket expenses for fuel, accommodation and meal costs for FPCs who commute from outlying areas. Presently, travel expenses to receive medical treatments that are eligible as income tax deductions include mileage expenses (.54 cents per km.), accommodation and meals (capped at \$51.00 per day). Expenses may be claimed for mileage when travel is over 40 km. as well as for meals and accommodations if travel is over 80 km. In British Columbia for the year 2008, the claimants' taxes are reduced by 20.06% of the allowable medical claim (Canada Revenue Agency, 2009). Therefore, even FPCs who meet the requirements to claim expenses may only expect a partial reduction in taxes, not a refund for monies spent. When travel is necessary, policy changes for reimbursement that more accurately reflect the financial outlay would decrease the economic burden on FPCs. The fact that the reimbursement is delayed until income tax time is an added burden for low income households.

The Employment Insurance Compassionate Care Benefits plan provides for some income security and job protection for family members who qualify and are caring for a terminally ill close relative. The plan however, is limited to a maximum of 6 weeks of coverage and stipulates a two week waiting period in addition to evidence that weekly earnings have decreased in excess of 40% among other qualifying conditions. Only family members who are employed may apply for this benefit. FPCs suggested that a means test should enable qualification for palliative assistance. If this type of qualification was legislated, then it would likely have to fall under a different profile than Employment Insurance. Social services, in this case might be more appropriate for Compassionate Care Benefits that are inclusive based on limited means.

Policies should take into account the impact that travel may have over the course of treatment and attempt to minimize commutes overall. Shared access to technology for planning care with rural and remote commuters and their health care providers is also an important tool. This initiative alone has the potential to reduce urban commutes. Through accessing and viewing information about upcoming schedules for diagnostics, treatments and consultations, several planned visits could perhaps be completed together. Taken together, these measures might decrease the frequency and number of appointments that FPCs are making and enhance patient comfort overall.

Research Recommendations. Research is clearly needed to develop our understanding of the factors that influence the experiences of FPCs who commute with family members for advanced cancer care, as well as to determine effective support and respite measures to minimize and address health risks associated with caregiving. In this way, the provision of effective support will rest on a more thorough understanding of the needs of FPCs who commute from outlying areas into the city for care. This recommendation ensures that interventions are developed that are most appropriate to the needs of the FPCs (Hudson et al., 2006).

In order to broaden the scope of future studies, other influences are apparent that provide alternate research avenues. An examination of the influence of diversity in terms of ethnocultural groups, gender influences and socioeconomic status as they relate to the experience of commuting would be useful. Moreover, examining the influence of the frequency and duration of commuting on FPCs' experiences and health outcomes is

important. As well, this study suggested that the separation of family while the patient receives treatment is particularly difficult when the FPC is unable to stay over as well. Research in this area could facilitate supportive measures in both rural and urban communities. It is important to research those individuals who choose not to commute, and why they made that decision. Further research could identify whether or not commuting for advanced cancer care improved QOL measures.

We need to conduct research that identifies the point at which FPCs are stopping the commute. Further, we need to know why the decision may be made to stop commuting.

Finally, through extending research initiatives to other rural populations who also commute for advanced cancer care, our knowledge of how rural contexts influence commuting experiences will be enhanced. Commuting for care studies that focus on rural dwellers can provide direction for improvements to care in these locales. The needs and concerns for these populations are often unique.

Conclusion

This thesis contributes to a small but growing body of information about caregivers' perspectives on travelling for cancer care. It assists in establishing new insights with respect to the experiences of FPCs who commute with a relative for advanced cancer care when they live in rural or remote locales and receive care in an urban centre. Moreover, the results offer a better understanding of the needs, challenges and quality-of-life considerations as experienced by FPCs. A small body of literature on patient experiences of commuting for cancer care indicated that the inconvenience and adversity that individuals faced while travelling could pose barriers to treatment. This study confirmed that the specific challenges of schedule changes, cancellations, traffic, weather and finances were daunting for rural and remote FPCs as well. However, FPCs demonstrated their ability to be resilient, flexible, compassionate and particularly dedicated when commuting with their family member for care. Meaningful conversation and time together were valued as they supported their loved one through palliative treatment. The study findings provide important directions for provision of health care services, policy and research.

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Appendix A: Letter of Introduction
Experiences of Rural Cancer Patients and their Families Who Commute to an
Urban Centre for Advanced Cancer Care

Investigative Team:

| | |
|---|----------|
| Carole Robinson, School of Nursing, University of British Columbia-Okanagan | XXX-XXXX |
| Barbara Pesut, School of Nursing, University of British Columbia-Okanagan | XXX-XXXX |
| Sandra Broughton, BC Cancer Agency Centre for the Southern Interior | XXX-XXXX |
| Gillian Fyles, BC Cancer Agency Centre for the Southern Interior | XXX-XXXX |
| Andrea Mowry, Interior Health Authority | XXX-XXXX |

Date

Dear Mr./Mrs./Ms. _____,

This is a letter of introduction to tell you about a project involving the British Columbia Cancer Agency, Centre for the Southern Interior and the University of British Columbia-Okanagan. The project is focused on what it is like for patients and family members (caregivers) who commute to Kelowna to receive care for advanced cancer. We are interested in hearing about these experiences so that we can make helpful suggestions to improve the services provided.

We are writing to invite you and a family member (caregiver) to be involved in the project. Your participation would include completing a questionnaire with a research assistant as well as an individual interview. We estimate that this will take approximately 1-2 hours in total. Your family member/caregiver will also be asked to complete questionnaires as well as participate in an individual interview. Each participant will each receive a \$20.00 honorarium. It is not necessary for both patients and family members to participate. We would be happy to speak with one or both of you. The information collected in this study will be kept confidential.

Please find enclosed a copy of the consent to contact form. If you would like to get more information about the study, please sign the consent to contact form and drop it off in the enclosed envelope with the receptionist at the BC Cancer Agency Centre for the Southern Interior. Our research assistant will get in touch with you to answer any questions about the project and, if you agree, to set up a time for an interview.

If you have any questions, or would like to give your name and contact information directly to the project Research Assistant, please contact _____ by phone: 250-_____, or via e-mail: tba@ubc.ca. I look forward to hearing from you.

Sincerely,
Carole Robinson, PhD, RN,
Faculty of Health and Social Development
University of British Columbia – Okanagan
E-mail: carole.robinson@ubc

Appendix B: Consent to Contact Form

Project Title: **Experiences of Rural Cancer Patients and their Families Who Commute to an Urban Centre for Advanced Cancer Care**

This is to inform you of a research study involving the UBC-Okanagan School of Nursing and the British Columbia Cancer Agency Centre for the Southern Interior (BCCA, CSI). We are requesting your permission to contact you with more information regarding a pilot study on the experiences of rural cancer patients and their families who commute to the BCCA, CSI for advanced cancer care.

The purpose of the research is to learn about what it is like to commute for care for advanced cancer, including what might be done to improve services. The ultimate goal of this research is to improve services for patients and their families/caregivers who live in rural/remote settings and who require advanced cancer care. We are interested in speaking with patients who have advanced cancer as well as a family member or friend who acts in a care-giving capacity. Interviews may be in person or by telephone at a time and place of your convenience.

At this time, we are asking only for your permission to be contacted to hear more about the study. We ask that you please sign and return this form and we will respond accordingly. If you indicate that you would like to be contacted, we will provide you with more details about the study, at which time, you can make a decision about your participation in the study. Your participation in this study is entirely voluntary. You may refuse to participate or withdraw at any time without any consequence to you or your continuing medical care.

For more information about the study, please contact:
Dr. Carole Robinson, UBC Okanagan, Principal Investigator
Tel: XXX-XXX-XXXX

If you have any questions about your rights as a research subject, please call the UBC Okanagan Office of Research Services, XXX-XXX-XXXX

Please tick one of the following:

- I would like to receive more information about the study.
- I would not like to receive more information about the study.

Patient Name (please print)
Date

Signature

Phone Number

- I would like to receive more information about the study.
- I would not like to receive more information about the study.

Family/Caregiver Name (please print)
Date

Signature

Phone Number

Please return form in the enclosed envelope to the receptionist at the Cancer Centre
Or, if you prefer to call us directly, please phone XXX-XXXX for the Research Assistant

Appendix C: Consent Form (Family)

Title of Project: **Experiences of Rural Cancer Patients and their Families Who Commute to an Urban Centre for Advanced Cancer Care**

Investigators:

| | |
|---|----------|
| Carole Robinson, School of Nursing, University of British Columbia-Okanagan | XXX-XXXX |
| Joan Bottorff, School of Nursing, University of British Columbia-Okanagan | XXX-XXXX |
| Barbara Pesut, School of Nursing, University of British Columbia-Okanagan | XXX-XXXX |
| Sandra Broughton, BC Cancer Agency Centre for the Southern Interior | XXX-XXXX |
| Gillian Fyles, BC Cancer Agency Centre for the Southern Interior | XXX-XXXX |
| Alison Brazier, School of Nursing, University of British Columbia – Vancouver | XXX-XXXX |

Background and Purpose of the Study

This study focuses on the experiences of rural cancer patients and their families/caregivers who commute to the BCCA Centre for the Southern Interior (BCCA, CSI) for advanced cancer care. The goal of this study is to make suggestions to improve advanced cancer care for those who commute from rural areas for treatment.

Study Procedures

You are being asked to voluntarily participate in this study because you are commuting to the BCCA, Centre for the Southern Interior for advanced cancer treatment/services and we are interested in hearing about what this experience has been like as well as how it could be improved. Your participation will involve completing a questionnaire that includes demographic questions and questions on satisfaction with care and needs regarding advanced cancer, and one individual interview. The interview will focus on the needs and challenges you experience in relation to commuting with your family member who is receiving care for advanced cancer, as well as the factors that enhance or diminish quality of life for your family member as well as yourself. The interview will be conducted at a time and place that is convenient to you and the total time commitment of your participation will be 1-2 hours. You may participate in the interview in person, by telephone, or by videoconference. You can participate even if your family member does not wish to participate.

The interview will be tape recorded and typed out by a secretary. Interviews will be reviewed and analyzed to identify important factors that influence both access to care and quality of life from the perspective of family members.

Risks and Benefits

No risks are expected from participation in this study. It is possible that some individuals may experience discomfort talking about challenging experiences. For participating in the study, each participant will each receive \$20 for the interview (\$40/family).

Confidentiality

Your name will not be associated with the audio taped interviews or 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. Only research staff associated with this project will have access to the data. You will not be identified in any reports of this research. Information from this study may be used again for further research to improve advanced cancer care programs and services directed at families, including a secondary data analysis. Information collected in this study may also be used for teaching purposes without revealing any information that identifies you.

Consent

Your participation in this study is entirely voluntary. You may refuse to participate or withdraw at any time without any consequence to you or your family member's continuing medical care. 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 (XXX) XXX-XXXX 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 (XXX) XXXX.

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:

Appendix D: Interview Guide for Family Opening Question

1. Before we talk about commuting for care, I wonder if you could describe your relationship with [patient], so that I understand how you are connected with one another.

Probes if necessary-

- How would you say that [patient's] diagnosis of cancer has changed your daily routine?

Follow-Up Questions

2. What do you see as your role in [patient's] care?

Probes if necessary-

- What is important?
- Do you have other supports (services, family/friends)?
- What will/would you need to do for [the patient] while at the BCCSI?

3. As you know we are interested in peoples' experiences when they have to travel to Kelowna to get the care they need. Tell me the story about your experiences [this time/your most recent time]? [If necessary: Go back to when you first knew you needed to come to Kelowna this time for care and then tell me how it went from then on...]

Probes if necessary-

- Can you explain to me how you planned this? What did you need to consider?
- What were your responsibilities? Was any rescheduling needed?
- Were there any difficulties or concerns for you or [patient]?
- What helped?
- What did you need and how did you get this?
- Is there anything that you needed that you didn't get?
- How has it been for you?
- You told me what it has been like for you, what do you think it was like for the [patient]?
- Has coming away from your home for this care affected anyone else we should know about?

4. Thinking back, how has this visit to Kelowna been different than other times?

Probes if necessary-

- Changes related to weather, sickness [caregiver or patient, other family members], availability of transport, etc.

5. What did you think would be the most difficult part of traveling to Kelowna for care for you and [the patient]. What did you hope for?

Probe if appropriate-

- Did you get this?

6. We are interested in hearing about your experiences when you were/are in the Cancer Centre at Kelowna. What brought you here? How did it go?

Probes if necessary-

- What expectations did you have? What surprised you about your experience?
 - Did it make any difference that you were from out of town? If so, how?
 - Based on your experience, what was the most important thing that made this a positive experience for you? And for [the patient]?
 - Did you encounter any negative experiences that you want to share?
 - How long will you stay at the BCCSI this trip and what services have you used during your stay
7. [If patient is at home or has had another recent visit to Kelowna for PC and returned home] What is it like for you after you get home from a visit like this? What about for [the patient] or others in your family?
 8. Based on your experience, what advice would you have for other people who need to travel for care?
 9. What advice would you have for nurses and doctors at the Cancer Centre for providing care to out of towners?
 10. Is there anything else about your experience that we haven't asked about- that you would like to tell us?
 11. What is the most important thing you have told us today?

Thank you

Appendix E



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL- MINIMAL RISK RENEWAL

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|--|--|--------------------------------------|
| PRINCIPAL INVESTIGATOR: Carole A. Robinson | DEPARTMENT: UBC/UBCO Health & Social Development/UBCO Nursing | UBC BREB NUMBER: H07-01789 |
| INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT: | | |
| <small>Institution</small> | <small>Site</small> | |
| BC Cancer Agency | Southern Interior BCCA | |
| <small>Other locations where the research will be conducted:</small> Interviews may be conducted in other locations that are private and meet the patient/family preference, including: Canadian Cancer Society Southern Interior Rotary Lodge, patient/family hotel or motel room, participants' homes (telephone interviews), and at the university if amenable to the participant. Focus groups will take place at the British Columbia Cancer Agency, Centre for the Southern Interior. | | |
| CO-INVESTIGATOR(S): Barbara K. Pesut Joan L. Bottorff Sandra Broughton Gillian M. Fyles | | |
| SPONSORING AGENCIES: British Columbia Cancer Foundation | | |
| PROJECT TITLE: Experiences of Rural Cancer Patients and their Families who Commute to an Urban Centre for Advanced Cancer Care. | | |

EXPIRY DATE OF THIS APPROVAL: August 1, 2009

APPROVAL DATE: August 1, 2008

The Annual Renewal for Study have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board
 Dr. M. Judith Lynam, Chair
 Dr. Ken Craig, Chair
 Dr. Jim Rupert, Associate Chair
 Dr. Laurie Ford, Associate Chair
 Dr. Daniel Salhani, Associate Chair
 Dr. Anita Ho, Associate Chair