University of Alberta

Rural Home-Based Family Caregiving for Persons with Advanced Cancer: A Description of Caregivers and Their Caregiving Situations

By

Marilyn Wolff ©

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Dedication

I dedicate this thesis to my family and friends for their support and love: To my husband, Roderick, who inspired me with your strength, love, and belief in the importance of education; To my son, Braden, who gave me a joy and love for life that never had been experienced before; To my parents, Geraldine and Charley Wolff, who provided their love and endless encouragement in achieving my educational goals; And to my family and friends in Edson and Edmonton who deserve special thanks for being there when I need them and for providing support and insights along the way.

ABSTRACT

Currently, over 3 million Canadians are caring for family members with chronic or life threatening illnesses. The challenge of providing effective home palliative care is most notable in rural areas with problems associated with geographic isolation, lack of services, large travel distances, lack of transportation, and few healthcare providers. The purpose of the research was to describe the characteristics of rural Albertans who are providing home-based palliative care to family members. The descriptive/correlational, cross-sectional study utilized questionnaires to collect data from home-based family caregivers of patients with advanced cancer. The characteristics (demographic, economic and health) of caregivers, nature of the caregiving situation and use of health care services were described. Further analysis explored the relationships between characteristics of caregivers and their caregiving situations. This information is crucial to the tailoring of supportive programs for home-based family caregivers.

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CHAPTER 1: BACKGROUND TO THE STUDY

Introduction

Presently, over 3 million Canadians are caring for family members with chronic or life threatening illnesses (Health Canada, 2002). With spiraling healthcare costs, as well as a desire to increase quality of life for patients and their families, increased care is being provided in the home (Coyte & Howell, 2001; Stajduhar, 2002). The challenge of providing effective home palliative care is most notable in rural areas with problems associated with geographic isolation, lack of services, large travel distances, lack of transportation, and few healthcare providers (Andrews, 2001; Bull, Krout, Rathbone-McCuan, & Shreffler, 2001; Burge, Lawson, & Johnston, 2005; Kelley, Sellick, & Linkewich, 2003; Sorensen & dePeuter, 2005).

In Canada, considerable health care reforms have occurred over the past 20 years (Burge, Lawson, & Johnston, 2003). The reforms have resulted in a reduction in the number of hospital beds per capita and in the length of hospital stays (Burge et al., 2003; Dudgeon & Kristjanson, 1995), leading to increased emphasis on the home setting for palliative care delivery (Burge et al., 2005; Coyte & Howell, 2001; Grunfeld et al., 2004). These changes, combined with an aging population and the increasing incidence of cancer, have had the potential to exert greater pressure on families to care for terminally ill relatives at home (Burge et al., 2003; Grunfeld et al., 2004). Although family members may be willing to take on this role, it does not come without personal costs (Stajduhar, 2002).

In a national survey of family caregivers, 35% of unpaid caregivers in Canada indicated that they took on the role because no one else was available, and 25% reported a lack of home care services (Health Canada, 2002). The researchers also found that the most significant predictor of caregiving stress is lack of choice in taking on the responsibility of caregiver (Health Canada, 2002). Family caregivers experience diminished sleep and increased fatigue, depression, physical problems, and isolation (Campbell, Bruhm, & Lilley, 1998; Carter, & Chang, 2000; Cranswick, 2002). It is not surprising, then, that the physical, psychological, social, spiritual, and practical strain of providing end-of-life care in the home can make it difficult to honor a terminally ill person's wish to die at home (Dudgeon & Kristjanson, 1995).

Most home care is provided by informal caregivers (Brazil, Bédard, Wilson, & Hode, 2003; Grunfeld, Glossop, McDowell, & Danbrook, 1997; Stajduhar, 2002). Women, chiefly spouses or daughters, constitute the majority of primary caregivers (Brazil et al., 2003; Davis, Cowley, & Ryland, 1996; Grande, Todd, & Barclay, 1997; Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Kelly et al., 1999; Wyatt, Friedman, Given, & Given, 1999). It is well known that spousal participation in care is a critical factor in influencing how long domiciliary care can be extended (Axelsson & Sjödén, 1998).

Living in a rural area is a barrier to receiving palliative care services in Canada (Burge et al., 2005). With limited funding, lack of service availability, cultural diversity, and relatively high concentrations of older people, the provision of adequate palliative care services is difficult (Andrews, 2001; Kelley et al., 2003; Watson, 1996). According to Maclean and Kelley (2001), higher hospitalization rates occur because of the lack of specialized formal palliative care services in rural communities. For these reasons, managing and financing the complex health problems of people in rural communities have become more complex (Watson, 1996); therefore, it is imperative to understand the characteristics of primary caregivers and their challenges of providing care in rural communities.

Epidemiology of Cancer and Palliative Care in Canada

The increasing incidence of cancer in the Canadian population has led to an emphasis on palliative care (Coyte & Howell, 2001). In 2003, the Canadian Cancer Society estimated that within the following year 139,900 new cases of cancer would be diagnosed in Canada and that approximately 67,400 people would be expected to die from cancer. Furthermore, as the population ages, this number is expected to increase (Canadian Cancer Society, 2003).

According to the Canadian Cancer Society (2003), current incidence rates show that 38% of women and 41% of men will develop cancer during their lifetimes. Furthermore, cancer is identified as the leading cause of premature death in Canada. It is associated with age, in that among Canadian men, 75 % of new cases and 82% of deaths due to cancer occur at 60 years of age and above. Among women, 63% of new cases and 78% of cancer deaths occur at 60 years and older (Canadian Cancer Society, 2003).

The number of patients who require palliative care will increase as a result of cancer (Coyte & Howell, 2001). Cancer is now the leading cause of death in Albertans, and the number of newly diagnosed patients with cancer is steadily rising (Alberta Cancer Board, 2002). It is projected that mortality rates will continue to rise over the next decade (Alberta Cancer Board, 2002). Lynn (2001) identified three chronic illness trajectories for people at end of life:

1. A short period of obvious decline at the end of life, which is typical of cancer
2. Long-term disability, with periodic exacerbations, and unpredictable timing of death usually associated with chronic organ failure such as chronic obstructive pulmonary, cerebral vascular accident, amytrophic lateral sclerosis, etc.
3. Slowly dwindling course to death with increasing self-care deficits such as frailty or dementia

It is expected that the number of people who will require palliative care in the future will increase as a result of an increasing incidence of cancer and chronic disease and an increase in the elderly population (Coyte & Howell, 2001).

Rural Palliative Care and the Alberta Context

The published health literature most often refers to rural without any qualification or definition beyond an assumption of non-urban. A clear, explicit definition is important for comparisons of findings across studies. For the purpose of this study, nonmetropolitan will be defined as *rural*. The Canadian criterion of *census metropolitan area* is a geographic area surrounding an urban core with a population of at least 100,000 (Murphy & Puderer, 2002). According to the 2001 census, Alberta has two metropolitan areas, which encompass Calgary and Edmonton (Murphy & Puderer, 2002). In Alberta, the definition of *rural* would include the entire province with the exception of Calgary, Edmonton, and their surrounding communities. This definition covers a broad range of population densities and is a potential limitation of the study because it groups family caregivers in remote farming communities with those who live in small towns or near small cities. Nonetheless, this definition distinguishes caregivers who lack access to specialized palliative care services from their urban counterparts who have this access to care.

Sorensen and dePeuter (2005) conducted a 10-year census analysis of rural Albertans from 1991 to 2001. The authors reported that Alberta's rural population (24.6%) comprises a slightly larger share of the total Canadian rural population (20.6%). Compared with their urban counterparts, rural Albertans are more likely to be children or seniors, have higher rates of unemployment, lower income, and fewer paid health care providers (Sorensen & dePeuter, 2005).

Current research data suggest that rural communities have higher rates of long-term disability and chronic illness (Andrews, 2001; Campbell et al., 1998; Goins & Mitchell, 1999; Kelley et al., 2003) because of the higher proportion of elderly in rural areas (Andrews 2001; Bull et al., 2001; Sorensen & dePeuter, 2005). Nearly one third of Canadians over the age of 65 live in rural areas, and the high number of elderly and disabled persons living in these regions places demands on already declining health services (Sorensen & dePeuter, 2005), further increasing pressure on family caregivers (Campbell et al., 1998; Watson, 1996).

Definition of Home Care and Palliative Care

In order to understand the relationship between home care and palliative care, a description of the philosophy of home care and palliative care services is essential. According to the Canadian Home Care Association (CHCA) (2003), *home care* is defined as an array of services enabling Canadians who are partially or completely incapacitated to live at home, often with the intent of preventing, delaying, or substituting for long-term care or acute care alternatives. The delivery of home care is patient-centred and must be integrated with the resources of family and informal caregivers. Home care services are delivered through a multidisciplinary care team with the aim of restoring and/or maintaining a patient's level of health or providing consultation and education for the patient and family who are coping with problems in the home and community settings (CHCA, 2003).

Palliative care is a philosophy of care and a system of services offered to individuals and families who are living with the effects of advanced disease (Ferris & Cummings, 1995). Palliative care focuses on the comprehensive management of the physical, psychological, social, and spiritual needs of patients and families facing incurable and progressive illnesses (Kelley et al., 2003). The central aim is to enhance quality of life and relieve suffering (Ferris et al., 2005). The following definition of palliative care was developed by the Canadian Hospice Palliative Care Association (CHPCA) (Ferris & Cummings, 1995):

> Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social, and spiritual expectations and needs, while remaining sensitive to personal, cultural and religions values, beliefs and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care. (p. 12)

Palliative care is appropriate for patients living with a life-threatening illness regardless of prognosis and age. The above definitions demonstrate the relationship between home care and palliative care services (CHCA, 2003). Palliative care service, as used in the context of this paper, is a program of care that is interdisciplinary, focused on quality of life, control of pain and symptoms and attends to the psychological, spiritual experiences of patients and their families in adapting to advanced illness and preparing for life-closure (Ferris et al., 2005). Palliative home care services are considered to be time limited and narrowly focused and are intended to improve the quality of life of terminally ill patients and their families by proving symptom management, pain relief, psychological care and bereavement support. Both palliative and home care aim to meet the needs of patients and families in a comprehensive manner, going beyond addressing their physical care needs to include social, psychological and spiritual needs.

Model of Hospice Care

Conceptual Framework

The "Square of Care" model of hospice care (see Appendix A), developed by the Canadian Hospice Palliative Care Association (Ferris et al., 2005), provides the conceptual framework for this study. Within the "Square of Care" model, patients and their families are treated as the unit of care (Ferris et al., 2005). The family and patient are located in the central section of the "Square of Care." The vertical axis is comprised of the following domains: disease management, physical, psychological, social, spiritual, practical, end of life care/death management, and loss/grief. The following section describes the components of these domains to be addressed by the study. The horizontal axis of the conceptual model represents steps in the process of providing care (Ferris et al., 2005). Although they are important to the provision of palliative care, these components will not be addressed by this study.

Disease Management Domain

In the "Square of Care" model, disease management addresses cancer diagnosis, treatment, palliative care and the effect of these activities on caregivers. In this study, disease management focuses largely on the use of professional services (e.g. nurses, family physicians, and specialists).

Physical Care Domain

The physical domain in the "Square of Care" focuses largely on symptom management, an important focus of family care (Peruselli et al., 1999; Sach, 1997; Taylor, Ferrell, Grant, & Cheyney, 1993). In their systematic literature review, Evans, Stone, and Elwyn (2003) found that more attention to adequate pain control is needed. In this study, caregivers are asked to identify the major caregiving problems. It is anticipated that the problems identified by family caregivers will include those in the physical domain.

Psychological Domain

The psychological domain involves the psychological morbidity experienced by families, including depression, anxiety, anger, guilt, fatigue, lack of sleep (Axelsson & Sjödén, 1998; Grunfeld et al., 2004; Nijboer et al., 1998; Werth, Gordon, & Johnson, 2002), and restrictions in social and sexual functioning (Nijboer et al., 1998). In this study, caregivers are asked to report changes in sleep patterns and the level of fatigue experience due to their caregiving.

Socio-Economic Domain

These domains include role changes and costs associated with caregiving. Numerous studies have identified the social and economic problems of patients and families (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Grunfeld et al, 2004; Jepson et al., 1999).

Practical Domain

The practical domain involves assistance with tasks that patients would normally do for themselves. In this study, the practical domain includes types of care (activities of daily living), amount of time spent on direct care, and transportation activities. Changing physical care needs can cause additional demands for family caregivers (Brazil et al., 2003) and place the patient at increased risk for hospitalization unless community home-based services are provided (Burge et al., 2005).

The domains of care illustrated by the "Square of Care" model provide an organizing framework for characterizing the needs of dying patients and their families. Health care providers, to be effective at relieving suffering and improving quality of life, must respond to complex and multiple issues faced by patients and families (Emanuel et al., 2000). Further research is needed to determine the particular components of care for family caregivers that need to be addressed clinically.

Summary and Purpose of Study

Limited research has been undertaken to understand the impact of terminal illness on rural families in the home and the role that palliative care services might play in meeting families' and patients' needs (Weitzner, Haley, & Chen, 2000). More attention to the health of family caregivers, particularly those in rural areas, is required in order to guide future action.

Rural caregivers have fewer health care resources in general than their urban counterparts (Andrews, 2001; Burge et al., 2005; Kelley et al., 2003). Presumably, this lack of resources also extends to palliative care services. As well, little is known about the characteristics of rural caregivers and their caregiving situations.

Therefore, the purpose of this study is as follows:

1. Describe the characteristics of home-based family caregivers of persons with advanced cancer in rural Alberta.
2. Describe the relationships between demographic characteristics (gender and health status) and caregiving time spent on these tasks.
3. Describe the family caregivers' costs associated with caregiving.

CHAPTER 2: LITERATURE REVIEW

Introduction

The purpose of this chapter is to review the palliative care research literature that focuses on rural family caregivers providing care for persons with advanced cancer. The databases used in the literature review included *Medline, CancerLit, Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, and PubMed,* from 1995 to October 2005. Reference lists in published reports were scanned, and additional relevant references were retrieved and reviewed. The following search terms were used to retrieve appropriate references: family caregiving, family caregivers, caregiver experiences, care receivers' characteristics, care receivers, care recipients, caregiving responsibilities, caregiving tasks, hospice care, dying and death, terminal care, terminal cancer, terminal illness, terminally ill palliative care, direct care, home-based care, community, end of life care, rural, and remote.

The results of the literature search were somewhat disappointing. Empirical literature on rural palliative care worldwide is limited, and Canadian data on rural palliative care is extremely limited. Evans et al. (2003) conducted a systematic literature review on the organization of rural palliative care services and the views of professionals located in rural areas. They found a total of 26 empirically-based papers, only five of which focused on rural family caregivers (Crawford, 2000; Freeman, Ramanathan, Aitken, Dunn, & Aird, 1998; McRae, Caty, Nelder, & Picard, 2000; Moorhouse, George, & Smith, 2000; Wilkes, White, & O'Riordan, 2000). Only one of the 26 studies (McRae et al., 2000) had been conducted in Canada. The McRae et al. (2000) study was the only Canadian study reported in another systematic literature review by Hughes, Ingleton, Noble, and Clark (2004). Their review focused on the needs of the patients and caregivers in the delivery of cancer and palliative care in rural areas. They found a total of 20 papers. Of these, 11 focused on needs of patients or carers. The other papers focused on place of death or end-of-life care and on service provision. More recently, Burge et al. (2005) and Brazil, Howell, Bédard, Krueger, and Heidebrecht (2005) have conducted studies examining rural cancer patients and the family caregivers.

Brazil et al. (2005) conducted a longitudinal study investigating care of terminally ill patients in Ontario, Canada. Their study included both urban and rural patients. Unfortunately, the only demographic data reported on rural patients was the proportion of patients living in rural vs. urban areas. Burge et al. (2005) conducted a secondary analysis of population-based administrative health data files in Nova Scotia, Canada, from 1992 to 1997. The purpose was to determine the association between rural locales and out-of-hospital deaths of cancer patients. Findings showed that, compared to their urban counterparts, patients in rural areas were less likely to die out-of-hospital.

Because of the limited body of empirical literature on rural palliative care and the near absence of Canadian data, this literature review will incorporate research on urban palliative care and on non-Canadian populations as necessary. The "Square of Care" model will be used to organize the literature review.

Domains of Family Care

Demographic Characteristics of Family Caregivers

Demographic changes such as aging populations, increased incidences of cancer and other chronic diseases, and changes in family structure have continued to increase the proportion of Canadians requiring and providing care. Sorensen and dePeuter (2005) conducted a t10-year census analysis of rural Albertans from 1991-2001. They reported that rural Albertans tend to be older and have less education, lower average incomes, and higher rates of unemployment and illiteracy than their urban counterparts. Current data also suggest that rural communities have higher rates of long-term disabilities and chronic illness (Andrews, 2001; Campbell et al., 1998; Goins & Mitchell, 1999; Kelley et al., 2003) because of the higher proportion of the elderly in rural areas (Andrews 2001; Bull et al., 2001). The demographic characteristics of age, gender, income, employment, and health status will be discussed in the following sections. The challenges of rural family caregivers of persons with advanced cancer at the centre of the "Square of Care" model (see Appendix A) will be illustrated.

Age.

As Canada's elderly population grows, it is estimated that an increasing number of seniors will require end-of-life care (Coyte & Howell, 2001; Cranswick, 2002; Grunfeld et al., 1997; Ross, Maclean, Cain, Sellick, & Fisher, 2001; Weitzner et al., 2000). The Canadian Cancer Society (2003) reported that the aging of the population is having a dramatic effect on the incidence of cancer and mortality rates. Approximately 75% of all cancer deaths occur in people over 65 years of age (Canadian Cancer Society, 2003). The vital role played by family members in supporting cancer patients is well recognized. However, the concern is that these caregivers may themselves be elderly, with their own health problems limiting their ability to provide care. As the population ages, more people are likely to be functionally dependent and in need of medical and social services. This trend can be expected to increase the pressure on homecare programs and family caregivers.

Canadian studies of family caregivers of persons with advanced cancer have reported mean ages between 53 to 62 years (Brazil, Bédard, & Wilson, 2002; Grunfeld et al., 2004; Strang & Koop, 2003). The care recipients were, on average, older than the family caregivers, whose mean ages ranged from 56 to 71 years (Brazil et al., 2002; Grunfeld et al., 2004).

On average, rural residents are older than their urban counterparts (Andrews, 2001; Bull et al., 2001). Rural communities have a higher percentage of young children and older residents (Andrews, 2001; Sorensen & dePeuter, 2005). This trend places the elderly in double jeopardy: family members may not be available to provide care when needed, and seniors may suffer from chronic illnesses when they are needed as caregivers (Grunfeld et al., 1997). There were no studies linking rural family caregivers' ages and health status with their ability to manage the care required for persons with advanced cancer.

Education.

Education increases opportunities for income and job security and equips people with coping skills, all of which are key factors that influence health (Bradshaw & Casebeer, 2001). Bradshaw and Casebeer (2001) conducted a review of the literature on rural health status and health services utilization (Mistahia Health Services Utilization Projects). The authors reported a lower level of education in rural populations, which is similar to the findings of Sorensen and dePeuter (2005), who conducted a 10-year census analysis of rural Albertans. They reported that, as recently as 2001, 46% of the population of those 20 years of age or older had not completed high school. No studies, however, were found that looked at how education influences caregivers' abilities to cope with the care required for persons with advanced cancer.

Income.

Income usually refers to total family or household income (Bradshaw & Casebeer, 2001). Several studies have shown that incomes are generally lower in rural regions (Andrews, 2001; Goins & Mitchell, 1999; Rupnik, Thompson-James, & Bollman, 2001) and among women (Beck, Jijon, & Edward, 1996; Emanuel et al., 1999). Compared with urban residents, the rural elderly are twice as likely to live at or below poverty levels (Goins & Mitchell, 1999).

Statistics Canada has found that, for the past three decades, rural families have had the lowest average incomes of all Canadians, and those in the most populated areas (100,000 or more) have had the highest incomes (Rupnik et al., 2001; Sorensen & dePeuter, 2005). In 1997, the average income for families in rural areas was $48,850 while in areas with a population of 100,000 or more the average family income was $59,920 (Rupnik et al., 2001).

The Canadian literature suggests that individuals with lower incomes tend to have poorer health and are likely to have a greater demand for a variety of healthcare services (Rupnik et al., 2001). A study conducted by Wyatt et al. (1999) of 124 bereaved caregivers found that their poor health status was positively correlated with health service utilization and negatively correlated with monthly income. Ekwall, Sivberg, and Hallberg (2004) found that a weak economic situation had a negative impact on physical, as well as mental, quality of life. This indicates that health care providers should consider a family caregiver's financial situation and explore how this may impact general quality of life.

Research on caregiving for persons with advanced cancer and its economic impacts has been surprisingly sparse (Haley, 2003). No studies were found on the differences between the incomes of rural caregivers in Canada and their caregiving situations. Healthcare providers need to be aware of the financial barriers perceived by informal care providers and the economic effects on their lives.

Employment.

Family caregivers' employment is often affected by the care required of family members with advanced cancer. Grunfeld et al. (2004) found that, of the employed caregivers, 69% reported some form of adverse impact on their work. In the terminal period of the family member's illness, 77% reported missing work because of caregiving responsibilities. Numerous studies have found that caregivers had to take time off work to care for the terminally ill patient at home (Emanuel et al., 2000; Wyatt et al., 1999). Furthermore, women are twice as likely as men to report lost opportunities for promotion because of caregiving responsibilities (Cranswick, 2002), suggesting that employment effects differ by gender.

In January 2004, the Canadian Federal Government unveiled a new initiative: the Employment Insurance Benefit or Compassionate Leave Plan (Government of Canada, 2004). This plan is available to Canadians to leave work and tend to dying family members. Caregivers who have accumulated 600 insured hours in the previous 52 weeks of employment are eligible to receive the compassionate care plan (Government of

Canada, 2004). This strategy, although a positive and supportive step, leaves out many seniors and women who provide care.

The National Profile of family caregivers in Canada prepared by Health Canada (2002) indicated that women represent 77% of those providing care to an ill family member. The study reported that 31% of these women are homemakers, and 19% work part-time or are self employed, rendering the majority of female caregivers ineligible for Employment Insurance Benefits (Health Canada, 2002). Various studies found that primary family caregivers were mostly unemployed females (Brazil et al., 2005; Jepson et al., 1999; Stajduhar & Davies, 2005). No studies were found which addressed employment status (employed vs. not employed) of rural family caregivers and its impact on the caregiving situation. Further studies are required to evaluate how caregiving of persons with advanced cancer affects employment status.

Gender.

Numerous studies reported that the national shift to community-based care is not gender neutral (Campbell et al., 1998; Carter & Chang, 2000; Thomas, Morris, & Harman, 2002). The label of "family caregiver" has a strong gender bias as the majority of primary caregivers are women (Campbell et al., 1998; Carter & Chang, 2000; Davis et al., 1996; Emanuel et al., 1999; Grande et al., 1997; Jepson et al., 1999; Stajduhar & Davies, 2005; Thomas et al., 2002), and spouses and daughters are more likely to serve as primary caregivers than other family members (Cranswick, 2002; Davis et al., 1996; Emanuel et al., 1999; Grande et al., 1997; Jepson et al., 1999; Kelly et al., 1999; Stajduhar & Davies, 2005; Strang & Koop, 2003).

Health Status.

As Canada's population ages, an increasing number of elderly people will have health problems that influence their ability to care for themselves or others. The aging process is associated with a progressive decline in many organ systems, and this functional restriction can compromise tolerance for stressors. A comparison of the health status of rural and urban adults found that rural residents reported significantly poorer health status than urban residents did (Beck et al., 1996; Bull et al., 2001).

Jepson et al. (1999) conducted an American study and found that 25.5% of caregivers reported having a wide range of physical health problems. The most frequently reported problems were arthritis (51.2%), hypertension (34.1%), diabetes (22%), heart disease (22%), and ulcers (19.5%). The problems increased their risk of psychological morbidity and limited their ability to provide care (Jepson et al., 1999). Strang and Koop (2003) conducted a Canadian qualitative study of family caregivers and found that more than 50% of the participants reported the presence of one or more chronic illnesses.

Campbell et al. (1998) conducted a study in rural Nova Scotia of family caregivers' support needs and found that adults are likely to rate their health as fair or poor and experience chronic illness and subsequent work and physical limitations. Indices of family caregivers' physical health are often measured by reports of major health problems and number of visits to medical practitioners and hospital or emergency room visits, together with respondents' assessment of their health as poor, fair, good or excellent (Schofield, Murphy, Herrman, Bloch, & Singh, 1997). The latter have been found useful in predicting survival among the elderly (Schofield et al., 1997).

Fainsinger, Demoissac, Cole, Mead-Wood, and Lee (2000) conducted a Canadian study on home versus hospice inpatient care. The prospective survey identified factors that helped or hindered home discharge of 100 consecutive patients who did not require further specialist palliative care or acute care. Younger patients with younger caregivers were discharged more often. Brazil et al. (2005) found that younger caregivers and fewer health concerns were strong determinants of the patient's ability to die at home due to their family member's ability to provide care. This finding is important for healthcare providers in rural communities when one considers that relatively large elderly populations have more health concerns.

The health of the caregiver needs to be studied as a predictor of ability to provide care rather than as an outcome (Jepson et al., 1999). No rural family caregiving studies were found that examined the association between the caregiver's health and age and the ability to manage their caregiving responsibilities. Understanding how health issues affect the caregivers' abilities to provide care and cope with changes over time is essential, and more research is needed in this area.

Disease Management Domain

In Canada, with improvements in cancer diagnosis, treatment, and palliative care, cancer patients survive longer; therefore, the length of the caregiving period has been extended from days or weeks to months or years (Weitzner et al., 2000). A cancer and subsequent illness trajectory affect the patient, as well as family and friends. The chronic and progressive nature of cancer suggests that caregivers of cancer patients are likely to face various challenges in different stages of the disease and treatment modalities (Nijboer, Triemstra, Tempelaar, Sanderman, van den Bos, 1999; Weitzner et al., 2000).

As a group, palliative cancer patients present with multiple and varied health problems since patients are affected by various symptoms and functional problems depending on the primary site of the cancer and recommended treatments (Malhotra & Perry, 2003). Illness-related indices such as disease site, stage of illness, prognosis, and duration of illness are considered primary stressors. These illness-related characteristics directly influence the nature of caregiving (Weitzner et al., 2000).

Burge et al. (2003) conducted a retrospective, population-based study of 9714 deaths in Nova Scotia. The researchers examined primary care continuity and location of death for those with cancer in both urban and rural populations. They found an association between patients' dying at home and longer survival times, urban dwelling, and more ambulatory care family physician visits. Brazil et al. (2005) conducted a study of 216 informal caregivers who participated in a bereavement interview and found that the most important determinants of home death were care recipients' statement of preference of home death and home visits by the family physicians.

Disproportionate numbers of the elderly and disabled live in rural communities, and this places special demands on declining health care services and family caregivers (Campbell et al., 1998). Numerous studies confirm that rural citizens are unable to access the same resources and services as their urban counterparts (Andrews, 2001; Beck et al., 1996; Benjamin-Coleman & Alexy, 1999; Maclean, & Kelley, 2001; Sach, 1997). Problems of access to services and health professionals, including family practitioners, nurses and allied health professionals, have been identified as a concern in rural communities (Andrews, 2001). Advancing age is generally associated with increasingly complex health problems, and providers best suited to treat these problems may not be available in rural communities (Bull et al., 2001).

Physical Care Domain

A large body of knowledge exists describing families' perceptions of what is required from health care professionals in order to enable them to feel supported while caring for their family member with advanced cancer (McRae et al., 2000; Sach 1997). Family caregivers in nine rural regions of Australia reported that control of pain and other symptoms (including unrelieved pain, nausea, vomiting, bleeding, wounds) was their first priority from palliative care services (Sach, 1997).

The literature about family caregivers and patients with advanced cancer describes pain as the main symptom to be managed and controlled (Peruselli et al., 1999; Sach, 1997; Taylor et al., 1993). Because approximately 90% of patients with advanced cancer develop significant pain before death (Boström, Sandh, Lundberg, & Fridlund, 2003), it is understandable that family caregivers placed this need as their main concern for patients in rural communities (Sach, 1997). In their systematic review of rural palliative care, Evans et al. (2003) found inadequate attention was given to pain control.

Families play an important role in pain management for patients in the later stages of cancer. Taylor et al. (1993) reported that families faced difficult decisions and conflicts related to medications. They found themselves having to decide when to administer medication and what dose to give (Aranda & Hayman-White, 2001; Taylor et al., 1993; Wilkes & White, 2005). It is important to understand the decisions and conflicts that family members experience in relation to medication administration and symptom management (Wilkes & White, 2005).

There is a large body of knowledge analyzing family caregivers' concerns related to care recipients' symptoms during the palliative phase of illness in the general population. However, further studies are required of rural palliative care to determine if family caregivers with limited palliative care services can effectively manage symptoms.

Psychological Domain

Psychological morbidity experienced by family caregivers has been identified as including depression, anxiety, anger, guilt, lack of sleep (Axelsson & Sjödén, 1998; Grunfeld et al., 2004; Nijboer et al., 1998; Werth et al., 2002), and restrictions in social and sexual functioning (Nijboer et al., 1998). Factors related to caregiver depression include time since diagnosis and type of diagnosis, as well as the patient's age, functional needs, social support, and the quality of relationships (Carter & Chang, 2000; Jepson et al., 1999).

Grunfeld et al. (2004) conducted a longitudinal study of 89 caregivers of women with advanced breast cancer in Ottawa and Hamilton, Ontario. They found substantial psychosocial morbidity in family caregivers. At the onset of the patient's terminal stage of the illness, 30% of caregivers were depressed, and 35% had anxiety. The caregiver's burden and depression increased substantially when the patient reached the terminal stages of the illness.

Based on a Canadian study of family caregivers, Cranswick (2002) reported that 31% had sleep disturbances because of their caregiving responsibilities. Haley (2003) found that female caregivers of patients with advanced stage cancer, age-related dementia, or AIDS had similar levels of depressed moods. However, the caregivers of persons with advanced cancer had more anxiety and trouble sleeping at night.

Jepson et al. (1999) conducted a longitudinal study on a randomized sample of 161 caregivers of cancer patients at a university hospital in the northeastern United States. The research demonstrated that caregivers for cancer patients who have physical problems of their own are at increased risk for psychological morbidity though the onset may be delayed. However, the study illustrated the need for homecare programs to assist caregivers in identifying the realities of long-term caregiving in order to help them prepare for what is to come.

Mental health services are limited in rural communities (Andrews, 2001; Bull et al., 2001; Watson, 1996) and not well funded (Watson, 1996). Recent government cuts in funding have forced rural communities to offer fewer services to even the most seriously mentally ill patients. Furthermore, mental health professionals do not typically receive specialized psycho-oncology training that equips them to meet the educational and support needs of families experiencing cancer (Watson, 1996).

The uncertainty regarding disease course, questions about their ability to provide patient care, the distress of watching the deterioration of their family member, as well as other anxieties, were found to contribute to a family's psychological distress (Nijboer et al., 1999). While families in rural communities felt that their psychological needs were often unmet, their discomfort could have been alleviated by better communication from healthcare providers as they tried to care for a loved one while parenting their own children and fulfilling occupational and other responsibilities (Dudgeon & Kristjanson, 1995; Nijboer et al., 1999). Family caregivers reported that a place to discuss their fears was important for them.

Socio-Economic Domain

The social and economic needs of palliative care patients and their families have been identified in numerous research studies (Emanuel et al., 2000; Grunfeld et al, 2004; Jepson et al., 1999). Social care is of great importance to families providing care for family members with advanced cancer. A humanitarian approach includes sensitivity to role changes and costs associated with family caregiving.

Role changes.

A cancer diagnosis adds considerable stress to an otherwise supportive and stable social network, which may already be taxed by pre-existing family and social problems (Malhotra, & Perry, 2003). It is important for health care providers to assess the characteristics and quality of the patient's support network at an early stage since families often play a crucial role in accomplishing treatment goals (Malhotra, & Perry, 2003). The early identification of conflicts within the family or lack of social support is important as these issues can negatively impact the patient's care and the family's ability to manage the changes.

Rural women and the elderly are especially vulnerable to social stressors, including living in poverty and isolation, functioning in multiple and changing roles on the farm and in the workplace, and managing the serious illness of family members (Bull et al., 2001; Watson, 1996). Roles may expand as family members take on additional roles previously held by the care recipient. No rural family caregiving studies were found that examined the caregivers' socio-economic status and their ability to manage care.

Costs of Family Caregiving.

According to Canadian studies, there has been a dramatic shift from institutional to family care and a resulting increased financial burden to family members (Cranswick, 2002; Grunfeld et al., 1997; Grunfeld et al., 2004; Weitzner et al., 2000). Cranswick (2002) reported profound socio-economic impacts related to the financial consequences for those providing care. One third of younger caregivers cited expenses due to their caregiving duties (42% of women and 38% of men) as did 27% of senior women and 30% of senior men (Cranswick, 2002). Numerous studies of family caregivers of terminally ill patients from around the world revealed substantial economic loss, such as direct out-of-pocket expenses, lost wages related to time off work, missed promotions, and loss of earnings and occupational pensions (Emanuel et al., 2000; Grunfeld et al., 1997; Haley, 2003; Weitzner et al., 2000; Wyatt et al, 1999).

In Canada, Grunfeld et al. (2004) conducted a longitudinal study of 89 caregivers of women with advanced breast cancer in Ottawa or Hamilton, Ontario. They prospectively examined the psychosocial, occupational and economic impact of caring for persons with terminal illnesses. Patients were followed until their death or study completion at three years. The average financial burden reported by families during the patient's illness was higher for those without extended health care insurance ($8,292) than those with extended health coverage ($5,765). No studies were found examining the economic costs of rural family caregivers of persons with advanced cancer in Canada or other countries.

Studies have revealed that patients are likely to experience a home death if they have higher socioeconomic status with access to care (Burge et al., 2003). These families have greater resources available to afford the necessary home support and services. In sum, the overall effects of combining work and caring for older relatives appear to be complex and significantly impact families. Policy makers need to be aware of the positive and negative effects of caregiving, especially the reduction in hours worked, reduced promotion prospects, and financial burdens. When rural caregivers have a lower income and are financially unable to give up work to care for a dependent relative, one might hypothesize that increased care strains may occur.

Practical Domain

The dying patient frequently has important and wide ranging needs. Practical care involves doing for or assisting the ill family member with the tasks independently. This category focuses on caregiving responsibilities including types of care provided, amount of time spent on direct care, and transportation.

The management of personal care has been reported as being most stressful on caregivers (Carter & Chang, 2000). The hours of personal care increase consistently with activities of daily living required by the family member (Brazil et al., 2003). Brazil et al. (2003) reported that physical demands increased substantially during the last three months of life. It is important to understand how gender and health status of the caregivers varies with of the types and amount of care provided.

Caregiving Responsibilities: Types of Care.

As Canada's population ages (Coyte & Howell, 2001; Cranswick, 2002; Grunfeld et al., 1997; Ross et al., 2001), the need for care by family caregivers will increase. The health care provider needs to support and collaborate with informal caregivers to assist them in their coping with care of both physical and emotional needs of the care recipient.

The functional status items in the study were drawn from or patterned after numerous studies of older adults cited in Cranswick, 2002; Norburn et al., 1995; and Wiener, Hanley, Clark, and Van Nostrand, 1990. The functional status items often include basic activities of daily living (BADL), such as eating and getting dressed; mobility activities of daily living (MADL), such as walking and getting in and out of bed; and instrumental activities of daily living (IADL), such as managing money and doing household chores (Brazil et al., 2005; Cranswick 2002; Koukouli, Vlachonikolis, & Philalithis, 2002; Norburn et al., 1995; Rabiner et al., 1997).

Brazil et al. (2003) conducted a retrospective, cohort study of 151 family caregivers in an urban region of Ontario, Canada. The number of caregivers providing assistance in specific functional activities follows: bathing (88%), mobility (81%), dressing and undressing (76%), toileting (67%), and assistance at night (64%). They also reported that they had been providing some form of care for over one year and that the caregiving increased substantially during the last three months of life. As family caregivers provided more assistance with activities of daily living, they were at greater risk of reporting high caregiver burden

Studies have shown that caregiving responsibilities of persons with chronic or end-of-life illness may vary with gender (Cranswick, 2002; Ekwall et al., 2004; Health Canada, 2002). The studies reported that men tend to focus on instrumental activities of daily living, including tasks around the house, outside work, and financial matters. Women are more likely to provide assistance with basic activities of daily living, including the provision of personal care. Ekwall et al. (2004) found that caregivers participating in instrumental activities of daily living had higher levels of physical health.

Some literature suggests reluctance among independent and self-sufficient rural elders to use formal health and human services, even when help is required (Goins & Mitchell, 1999; Rabiner et al., 1997). Rabiner et al. (1997) surveyed 3,485 non-institutionalized older adults to compare functional status and self-care practices of older adults residing in urban and rural communities. The key ideas were to identify differences associated with residential locations. They found that older adults from nonmetropolitan areas were more likely to report being able to perform functional activities but were also more likely to report performing self-care activities in both the presence and absence of disability. They concluded that rural older adults might discount the significance of declining functional status, thus normalizing the trajectory of aging.

Rural elderly are more likely than their urban counterparts to rely exclusively on family caregivers (Goins & Mitchell, 1999; Rabiner et al., 1997). Furthermore, rural cancer patients tend to have lower scores in the functional domain (Goins & Mitchell, 1999), and this increases pressure on family caregivers. Brazil et al. (2003) reported that family caregivers who provided more assistance with activities of daily living were at greater risk of caregiver burden. Research is needed to understand how care recipients and caregivers manage functional limitations that might otherwise necessitate institutional care.

Caregiving Responsibilities: Amount Time Spent on Direct Care.

Time spent on caregiving activities can be measured by the amount of direct care provided and the length of time required for the care. No Canadian studies were found on the time spent on caregiving activities by family caregivers of persons with advanced cancer. Two American studies reported that caregivers provide care for a mean of 9 to 20 hours per day (Carter & Chang, 2000; Wyatt et al., 1999). A Swedish study by Ekwall et al. (2004) examined the gender differences in care provision by informal caregivers of elderly family members. They found that women provided a mean of 19.5 hours per week, and men provided a mean of 15 hours per week.

Length of caregiving trajectory can be measured in length of time since diagnosis with advanced cancer. A qualitative study conducted by Strang and Koop (2003) of home-based family caregiving of persons with advanced cancer ranged from 1 to 11 months (mean of 5.3 months). Carter and Chang (2000) conducted a cross-sectional correlational study of cancer caregivers and found that they had provided care from 3 to 142 months (mean of 48 months or 2 years).

Studies have shown that caregiving is a dynamic, ongoing process for which there are several trajectories (Nijboer et al., 1998). The care tasks, along with caregivers' burdens and caregivers' health, may fluctuate in response to the patients' health (Nijboer et al., 1998). Research that focuses on caregiving patterns involving cancer patients and their caregivers is scarce (Emanuel et al., 1999; Nijboer et al., 1998). Most research has been performed on family members of the frail elderly or cognitively impaired (Ekwall et al., 2004; Haley, 2003; Nijboer et al., 1998). When there is an increase in care tasks, the health of the caregiver may vary both physically and psychologically. It is imperative that studies describe the ongoing health effects of caregiving over the course of illness in order to understand the long-term outcomes associated with providing care (Nijboer et al., 1998).

Adequate and timely professional support is needed if care is not to become an intolerable burden for families (Addington-Hall & McCarthy, 1995). Aranda and

Hayman-White (2001) stated that most terminally ill patients receive approximately one hour of professional service per day. The responsibility of the care rests mostly on the family caregivers. Although work of the family caregivers' has been under-acknowledged, the significance of their contributions is beginning to be recognized.

Transportation.

Rural family caregivers have difficulties resulting from both intra-regional and inter-regional transportation (Andrews, 2001; Beck et al., 1996). Living in a rural area increases the amount of resources that must be spent on transportation (Bull et al., 2001; Hughes et al., 2004; Sorensen & dePeuter, 2005; Watson, 1996) due to the longer distances to services (Sorensen & dePeuter, 2005). As a result, financial cost of travel expenses has been found to be a concern for rural caregivers (Andrews, 2001; Hughes et al., 2004). Further research is needed to capture the range of expenses for rural caregivers and to determine how these costs affect their ability to provide care.

In summary, the differences between and among women and men in different caregiving responsibilities and caring capacities need to be reviewed. Through research, the caregivers' concerns need to be addressed to ensure equitable and effective policies and programs.

Summary of the Major Points in the Literature

Research focusing on the caregiving process involving cancer patients and their caregivers is scarce (Nijboer et al., 1998). Most research conducted has been among family members of the frail elderly or cognitively impaired patients (Nijboer et al., 1998) with relatively little attention paid to the family caregiving of advanced cancer patients. The review of the literature clearly justifies a focus on family caregivers of patients with advanced cancer in rural communities. The gaps identified in the literature demonstrate the specific components of palliative care in rural Canada that require further development.

During the terminal phases of illness, family caregivers face physical, psychological, social, and spiritual challenges to their sense of wholeness. This research seeks to gather practical knowledge about rural family caregivers' needs from their perspective. Their voices are needed if healthcare providers are to help them meet their needs. The data gathered will contribute to a better understanding of caregivers' needs for assistance and support. It is hoped that this improved understanding will ultimately contribute to better interventions and policies that honour the contributions and stressors of rural family caregivers of palliative care patients.

Definition of Terms

The following definitions are essential for understanding concepts related to the "Square of Care" model in order to guide the palliative care process. The definitions can be used as a blueprint to map out the existing literature, identify gaps in knowledge, and suggest research priorities. Unless otherwise indicated, the definitions were obtained from the Canadian Hospice Palliative Care Association (Ferris et al., 2005).

Activities of Daily Living	These are grouped into three different categories: BADLs (Basic Activities of Daily Living), MADLs (Mobility Activities of Daily Living), and IADLs (Instrumental Activities of Daily Living) (Koukouli et al., 2002). The BADL scale includes personal care activities (i.e., eating, dressing, grooming, bathing, toileting, hand care and foot care). IADLs focus on activities of household management (i.e., meal preparation, house cleaning, house and yard maintenance). MADLs include transfers, ambulation, and mobilization.
Family Caregiver	Anyone who provides care without pay because the care recipient cannot care for him or herself due to advanced cancer. Family caregivers may be family members, neighbours, co-workers, or friends.
Family	Those closest to patient in knowledge, care, and affection. The patient defines who will be involved in his or her care and present at the bedside.

	Family may include one or more of the following: • biological family, • family of acquisition (related by marriage / contract), • family of choice and friends.
Formal Caregiver	A formal caregiver is a member of an organization and accountable to defined norms of conduct and practice. They may be professionals, support workers, or volunteers. They are also called *providers*.
Palliative Care	Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social, and spiritual expectations and needs while remaining sensitive to personal, cultural, and religious values, beliefs, and practices. Palliative care may be combined with therapies aimed at reducing the illness, or it may be the total focus of care.
Patient	A patient is the person living with an acute, chronic, or advanced illness. The term patient, as opposed to client, is used in recognition of the individual's potential and vulnerability at any time during the illness. The word patient is derived from the Latin *patients*: to suffer, to

	undergo, and to bear. The patient is a contributing member of the interdisciplinary team. The patient is the central focus of spiritual, mental, and emotional care to promote quality of life.
Unit of Care	A unit of care is made up of those who are the focus of a plan of care. In hospice palliative care, this is typically the patient and family.

CHAPTER 3: RESEARCH METHODS

Research Questions

The purpose of this study was to examine the characteristics of home-based family caregivers of patients with advanced cancer in a rural setting in Alberta and to describe their caregiving situations. The study describes these rural family caregivers in their communities (demographic characteristics) to identify factors that influence how their health and care characteristics co-relate. Another purpose of the study was to describe the specific caregiving tasks and time spent on activities required for persons with advanced cancer. The goal was to describe the nature of their caregiving situations and to explore relationships between the characteristics of caregivers and those of their caregiving situations. The following research questions were addressed in the study:

1. *What are the relationships between age and health characteristics of home-based family caregivers of persons with advanced cancer in rural Alberta?*
2. *What are the tasks that rural home-based family caregivers engage in, and how much time is spent on these tasks?*
3. *What are the relationships between family caregiver characteristics (gender and self-assessed health) and caregiving time for rural caregivers?*
4. *What costs do family caregivers in rural settings report during a family member's illness?*

Research Design

This descriptive/correlational, cross-sectional study of rural Albertans was used to determine relationships between the characteristics of family caregivers (health and demographics) and their caregiving situations. The study was a component of a larger study entitled "Home-based family caregiving for persons with advanced cancer and Alzheimer's disease: A description of caregivers and their caregiving situations" (Strang, Koop, Nordstrom, & Thompson, 2003), which was conducted in an urban setting of Alberta. For this research project, a series of questionnaires was utilized (see Appendix B) to collect data.

Sample

The study was conducted in three rural areas in Alberta including the Aspen, David Thompson, and East Central Health Regions (as of 2004). The regions were chosen to cover a broad geographic area and to reflect the diversity in economics, population density, and distance from major urban centres that exist in rural Alberta.

Power analysis was conducted to estimate the required sample size. The power analysis assumed a non-directional alpha set at 0.05 for the Pearson product moment correlation. A large effect size of 0.40 requires a sample of 46 participants in order to obtain the conventional power of 0.80 (Cohen, 1988).

The 46 family caregivers who participated in this study were accessed through home care centres throughout the three regions. A convenience sample was utilized for the study. The family caregivers met the following criteria for inclusion in the study:

- Able to understand and read English at a grade six level or higher

- Be eighteen years of age or older
- Have provided care for a terminally-ill family member for at least one month

The local nurses who were most familiar with the family made the initial approach to the family to ascertain their willingness to be involved in the study. Family caregivers who were willing to hear more about the study provided permission to release their names and phone numbers to research personnel (see Appendix C).

The researcher contacted family caregivers identified by homecare nurses as potential participants, and described the nature of the research study (see Appendix D). When family caregivers consented to be involved in the study, a mutually convenient time for the interview was arranged. The questionnaire could be administered over the telephone or face-to-face. On the interview day, the purpose of the study was explained again, a written information sheet provided, and written consent to conduct research obtained (see Appendix E).

Method of Data Collection

This descriptive/correlational, cross-sectional study utilized questionnaires (see Appendix B) to collect data from 46 rural home-based family caregivers of patients with advanced cancer. A description of the questionnaires will be provided with details on the reliability, validity and scoring.

General Questionnaire – Caregiver and Care Recipient

The general questionnaire (Appendix B) was utilized to collect family caregivers' and care recipients' demographic data. Specifically, the data from this questionnaire used in this study were the nature of the caregiver-care recipient relationship, whether caregiver and care recipient shared living quarters, community size, marital status, age, gender, religion, education, ethnic background, occupation, employment status (including current and past employment as a result of caregiving), the care recipient's family income, the number of persons depending on the income, income changes, cancer diagnosis, time of caregiving, hours of sleep, reports of fatigue, and the chronic health problems of the care recipient. The sections of the questionnaire included in the larger study that were not included in the rural study included (a) question 20b regarding difficulty in managing the cost associated with caregiving, (b) the Caregiver Reaction Assessment, and (c) the two Caregiver's Burden Scales.

Reliability and Validity

The demographic questionnaire used for the study was originally developed for use with home-based family caregivers of persons with Alzheimer's disease (Strang et al., 2003). Dementia caregivers and caregivers of persons with advanced cancer are acknowledged to have distinct characteristics. Nonetheless, the prior experience with this questionnaire suggests that the order and format of the questionnaire are user-friendly and facilitate data collection.

SF-36® Health Survey

In this study, the SF-36® was used to measure the general health of family caregivers of persons with advanced cancer. The SF-36® is a multi-item scale measuring individuals' perceptions of their health (see Appendix B). It is considered relevant over a broad range of ages, diseases, and treatment groups (Benjamin-Coleman & Alexy, 1999; Mallinson, 2002; Ware, Snow, Kosinski, Gandek, 2002). The questionnaire has been used both nationally and internationally (Mallinson, 2002).

The SF-36® is composed of 36 questions divided among health sub-scales including (a) physical functioning (PF) (10 items), (b) role limitations due to physical health problems (RP) (4 items), (c) bodily pain (BP) (2 items), (d) general health (GH) (5 items), (e) vitality (energy/fatigue) (VT) (4items), (f) social functioning (SF) (2items), (g) role limitations due to emotional problems (RE) (3 items), and (h) mental health (psychological distress and psychological well-being) (MH) (5 items) (Benjamin-Coleman & Alexy, 1999; Ware et al., 2002). The scale offers a number of advantages to researchers. It can be administered by mail or in face-to-face interviews and takes only approximately 10 minutes to complete (Mallinson, 2002; Ware et al., 2002).

The standardized assessment method can be used to elicit information regarding function and well-being in a standardized way. The tool is utilized for monitoring the results of care (Benjamin-Coleman & Alexy, 1999). The measurement of family outcomes will become even more important as quality of care and cost control receive more emphasis.

Reliability and Validity

The reliability of the eight scales and two summary measures has been estimated using both internal consistency and test-retest methods. Published internal reliability statistics have exceeded the minimum standard of a Cronbach's alpha (α) = 0.70 recommended for measures used in group comparisons, and most have exceeded (α) 0.80 (McHorney, 1996; Ware et al., 2002). A review of 15 published studies revealed that the median reliability coefficients for each of the eight scales was equal to or greater than 0.80, except Social Functioning, which had a median reliability across studies of 0.76 (Ware et al., 2002).

Standard errors of measurement with 95% confidence intervals for individual scores, distribution of change scores from test-retest, and one-year stability studies have been published (Ware et al., 2002). Estimated sizes required to detect differences in average scores of various magnitudes have been documented in five different study designs for each of the eight scales (Ware et al., 2002).

The validity of the SF-36® has been established due to its widespread use across a variety of applications, and, therefore, evidence of all types of validity has been determined relevant (McHorney, 1996). Evidence to support the empirical validity includes studies that correspond well with other health measures, discriminate between well and sick populations, and are sensitive to disease severity (McHorney, 1996). Studies to date have addressed content, concurrent, criterion, construct, and predictive validity (Ware, 2002).

Scoring

The SF-36® questions utilize Likert scales, ranging from "not at all" to "extremely"; “yes limited a lot” to “no, not at all”; “none” to “very severe”; “all of the time” to “none of the time”; and “definitely true” to “definitely false” (Ware, 2002). The five sub-scales (physical functioning, role limitations due to physical health problems, bodily pain, social functioning, and role limitations due to emotional problems) define health status as the absence of limitation or disability. The highest score of 100 indicates no limitations or disabilities (Benjamin-Coleman & Alexy, 1999; Ware, 2002). Three of the sub-scales (general health, vitality, and mental health) are bi-polar in nature and measure a much wider range of negative and positive health states (Benjamin-Coleman & Alexy, 1999; Ware, 2002). For these scales, a mid-range score indicates no limitations or disability (Benjamin-Coleman & Alexy, 1999; Ware, 2002), and a high score indicates a positive health state (Ware, 2002).

The SF-36® measures the general health of caregivers. The univariate calculations included frequencies, mean, and range. Scoring of the SF-36® requires three steps: (a) item recoding, (b) computing the scale score by summing across items in the same scale (raw scale score), and (c) transforming raw scores to a 0-100 scale.

The Karnofsky Performance Scale

The patient's functional status was measured using the Karnofsky Performance Scale (KPS) (see Appendix B), which was first developed in 1948 (Anderson, Downing, Hill, Casorso, & Lerch, 1996). Several cancer agencies have utilized the tool for many years (Anderson et al., 1996). The scale provides healthcare professionals with assessments of functional performance status and provides a framework for measuring progressive decline in palliative patients (Anderson et al., 1996).

Reliability and Validity

The KPS has an interrater reliability of r = 0.89 and has reasonable test-retest reliability of r = 0.66 (1 week, home versus clinic) (Richmond, McCorkle, Tulman & Fawcett, 1997).The relevance of the KPS when utilized in the community is limited due to the reference of need for hospitalization as the KPS score goes down (Anderson et al., 1996). For example, a rating of 30% states that hospitalization is indicated, and 20% states that hospitalization is necessary. Therefore, the reference to hospitalization may provide a limitation of application in communities where the goal is to provide home-based care for as long as possible. The scale, however, has been utilized to predict patient survival (Anderson et al., 1996). According to Lassauniere and Vinant (1992), a KPS of

10 to 20% has been reported as indicating an average length of time to death of 17 days, suggesting a need for constant care.

Scoring

Scores on the Karnofsky scale range from 0 = dead to 100 = normal. The score increases in increments of 10. The KPS scale provides ratio measurements due to the fact that the scale has a rational and meaningful zero (Polit & Beck, 2004). The total score was used to measure the care recipient's functional status.

Caregiving Responsibilities: Types and Amount of Direct Care

The caregiving responsibilities (type and amount of direct care) scale was derived from a number of sources. The lists of caregiving tasks for the study were modified in consultation with expert palliative care nurses and in review of the literature on functional assessments cited in Cranswick, 2002; Norburn et al., 1995; and Wiener et al., 1990. The home-based caregiving responsibilities section of the questionnaire has the following five main subscales (see Appendix B):

1. Instrumental Activities of Daily Living: activities of household management-meal preparation and cleanup, house cleaning, laundry, sewing, house maintenance and repair, grocery shopping, banking, transportation, and medication administration
2. Basic Activities of Daily Living: personal care-dressing, eating, grooming, bathing, toileting, hand care, and foot care.
3. Mobility Activities of Daily Living: walking inside and outside of the house and transfers.
4. Monitoring at home: telephone calls and general surveillance

5. Emotional support: keeping up spirits, confiding in someone, helping through the difficult time, giving reassurance, giving encouragement, and someone with whom to laugh and cry

Reliability and Validity

The Caregiving Responsibilities Scale was developed for the purpose of this study because no existing scale measuring type and amount of caregiving could be found in the literature. The validity and reliability of the questions have yet to be explicitly tested.

Scoring

The caregivers were first asked whether or not they had engaged in a specific caregiving tasks. If the answer was "yes," then estimated time spent on that task was calculated, using whatever metric seemed most appropriate. For example, caregivers could estimate daily time spent on some tasks (e.g. meal preparation), weekly on other tasks (e.g. laundry, shopping for groceries), and monthly on still other tasks (e.g. paying bills). These estimates were re-calculated into weekly estimates. The total amount of time for each subscale was then calculated. Some caregivers insisted that they provided care 24 hours a day and seven days per week. They especially found it difficult to estimate time spent on emotional support. When that happened, we calculated times spent on emotional support by subtracting time spent on other forms of care and time spent sleeping from total time (24/7=168/week).

Costs of Caregiving

Family caregivers were asked to estimate the total amount of money spent and not refunded on the following items: (see Appendix B): drugs, patient care supplies, equipment (walker, wheelchair, hospital bed, and commode), and personal care (home care aides, nursing staff, homemakers, and sitters). Open categories for "other" were included to capture items identified by family caregivers.

Scoring

The caregivers were asked to indicate the "total" amount of money spent and not refunded on the items listed during the family members' illnesses. Content analysis was performed for the "other" categories collected in the questionnaire. Data were grouped into mutually exclusive categories according to central ideas expressed by respondents.

Data Entry: Cleaning and Checking

The Statistical Package for Social Sciences (SPSS) program (Norusis, 2002) was used for data entry and analysis. Two research assistants entered data to ensure accuracy. Data cleaning began as data were entered to ensure that systematic errors in data collection, coding, or entry could be corrected before an enormous amount of data were collected (Roberts, Anthony, Madigan, & Chen, 1997). A data codebook was developed before data entry. Instructions on the values assigned to various responses to questions (e.g. categorical variables) were provided on the categories to minimize coding errors.

Random samples of subjects were drawn, and the data entered were compared to data collection forms as recommended (Roberts et al., 1997). The instruments for data collection were randomly sampled to ensure thorough checking. Additionally, each data collector's work was checked throughout the study to ensure accuracy.

Further, data cleaning involved univariate analysis. Depending on level of measurement of variables, measures of frequency, central tendency, and dispersion, minimum and maximum values were used to identify values (Roberts et al., 1997). Any outliers in data were then checked against the data collection forms. Outliers were modified prior to bivariate analysis according to recommended methods. Essential to the study was the use of researchers and assistants who could identify and resolve errors.

Data Analysis

Analytic strategies will be discussed in this section. First, the analysis required for the description of the sample will be described. Following that, the analysis will be organized according to the four research questions.

Description of Sample

The characteristics of rural family caregivers and care recipients were analyzed utilizing univariate analysis. Findings from nominal variables (relationship of care recipients to caregivers, whether or not the caregiver lives with the care recipient, marital status, gender, religion, ethnic background, occupation, current and past employment status, whether or not income has changed, and most common problems associated with caregiving) were analyzed utilizing mode, frequencies, and percentages. Ordinal variables (community size and education) and interval variables (care recipient's family income) were analyzed utilizing mode, median and frequencies. Ratio variables (caregiver's and care recipient's age, estimated time spent on caregiving per week, caregiver's self assessed health, care recipient's nighttime sleep and naps required on a daily basis (current and past sleep/nap patterns), caregivers level of fatigue, SF-36® health domains, and care recipient's Karnofsky score) were calculated utilizing the mode, median, mean, range and standard deviation.

Non-numerical data (e.g. chronic health problems and reasons for visits to physician or emergency room) were subjected to content analysis. Themes were derived, resulting in nominal variables. Also, content analysis was performed on the most common problems of caregiving. Categories were then created based on the domains of care as illustrated in "The Square of Care" conceptual framework. Two researchers independently read through the comments, identifying themes and coding them. Sessions were held comparing coding, reviewing code definitions, creating new codes, and discussing the meaning of comments. Differences in coding by researchers were examined and resolved through clarifying and redefining the definitions of codes.

Further qualitative data in the general questionnaire were obtained through two open-ended questions. One asked about recommended changes to the health care system, and the other asked for descriptions of the experience of providing care. These questions elicited data that might not have been offered in response to closed-ended questions. For the purpose of this study, content analysis was not performed. Direct quotes will be utilized to highlight family caregivers' concerns in the discussion section. Subsequent descriptions of data analysis are organized by research questions.

What are the relationships between age and health characteristics of home-based family caregivers of persons with advanced cancer in rural Alberta?

The first question of "What are the relationships between age and health characteristics of home-based family caregivers of persons with advanced cancer in rural Alberta?" was addressed using age and two measures of health including self -assessed health question and general health domains SF 36®. The self -assessed health question (see Appendix B General Questionnaire number 24) was analyzed utilizing a Visual Analog Scale with anchor labels of 0 = "very poor" to 10 = "excellent." Univariate analysis including mean, range, and standard deviation was conducted to analyze the caregiver's health.

Family caregivers' change in general health was analyzed utilizing the SF 36® question (see Appendix B The SF-36® Health Survey number 2). A Likert scale ranging from "much better than one year ago" to "much worse than one year ago" measured the changes in general health of family caregivers. Univariate analysis was conducted to analyze the change in health including frequencies, mode, and median were calculated.

For the question of "Do you have health problems?" (General Questionnaire number 27) respondents indicate "yes" or "no." Frequencies were calculated for the number of people who answered yes to this question. When chronic health problems were identified, the responses were grouped. Researchers entered responses into a code book, and frequencies were calculated on the types of diseases indicated by the caregivers.

Bivariate analysis was utilized to determine the relationships between characteristics of the caregivers' ages and self -assessed health. If the scatter plot suggested a linear relationship, Pearson's correlation coefficient (r) (two tailed) was calculated (Glass & Hopkins, 1996). Pearson's correlation coefficient (r) is an appropriate statistic to use when the data involve two interval or ratio variables. The magnitude of the relationship is indicated by the absolute value of the correlation coefficient (Glass & Hopkins, 1996). The degree of the relationship can vary from -1.0, through 0, to +1.0 (Glass & Hopkins, 1996). The sign of the coefficient sign shows the direction of the relationship (positive or negative) (Glass & Hopkins, 1996).

What are the tasks that rural home-based family caregivers engage in, and how much time is spent on these tasks?

The second question of "What are the tasks that rural home-based family caregivers engage in, and how much time is spent on these tasks?" was addressed utilizing "Caregiving Responsibilities: Types And Amount Of Direct Care" (see Appendix B). Caregiving tasks were grouped into five main categories: (a) Basic Activities of Daily Living, (b) Instrumental Activities of Daily Living, (c) Mobility Activities of Daily Living, (d) Monitoring at home, and (e) Emotional Support. Univariate analysis was conducted to describe the type of caregiving tasks and amount of time spent on family caregiving. The mode, frequencies, and percentages were calculated for type of caregiving tasks performed (a nominal variable). For each of the tasks performed, estimated time was calculated for the previous week. Total amount of care provided for each category was calculated and descriptive statistics utilized to analyze results (univariate analysis) including mean, range, and standard deviation (Polit & Beck, 2004).

What are the relationships between family caregiver characteristics (gender and self-assessed health) and caregiving time for rural caregivers?

The third question of "What are the relationships between family caregiver characteristics (gender and self-assessed health) and caregiving time?" was analyzed. Bivariate analysis was utilized to determine whether the relationships of caregiving situations varied by gender and self-assessed health of family caregivers. The relationship between self-assessed health of caregivers (ratio variable) and time spent on caregiving (ratio variable) was analyzed first by a scatter plot. If there was a relationship, Pearson's correlation coefficient (r) (two tailed) was calculated (Glass & Hopkins, 1996). The magnitude of the relationship was indicated by the absolute value of the correlation coefficient (Glass & Hopkins, 1996). The degree of the relationship can vary from -1.0, through 0, to +1.0 (Glass & Hopkins, 1996). The sign of the coefficient shows the direction of the relationship (positive or negative) (Glass & Hopkins, 1996).

The relationship between gender and time spent on caregiving was calculated utilizing t-test analysis, which is utilized when comparing the difference of two independent group means (Polit & Beck, 2004). The two groups include male and female caregivers (independent variable) with time spent on caregiving (dependant variable) (Polit & Beck, 2004). An alpha was set at 0.05 ($p < 0.05$) to reject a null hypothesis (Glass & Hopkins, 1996).

What costs do family caregivers in rural settings report during a family member's illness?

The fourth question of "What costs do family caregivers in rural settings report during a family member's illness?" was analyzed utilizing univariate statistics. The family caregivers estimated the total amount of money spent and not refunded on fixed items including drugs, patient care supplies, equipment, and assistance with personal care (see Appendix B). Content analysis was performed for the categories of "other" on the family caregivers' questionnaire. The content data were analyzed for the mean, standard deviation, and range.

Protection of Human Rights

This study was conducted following ethical approval from the Health Research Ethics Board, which administers the ethics review process for all faculty, staff, and students and the University of Alberta Health Sciences Faculties, Capital Health Authority, and the Caritas Health Group (see Appendix F). Then, the study was disseminated to Rural Regional Managers including Aspen Region, David Thompson

Health Region, and East Central Health Region. Approval from regional managers was obtained prior to conducting the study.

The study was discussed with homecare nurses from the various regions. Any questions posed throughout the course of the study were answered in a prompt manner by the research team. The homecare nurses' responsibilities were to obtain the caregiver's permission to release their name and phone number to the research team (see Appendix C). Upon receipt of written permission to contact the caregiver, the research assistant reviewed the study in general terms with each prospective family caregiver. Potential research participants were given an information summary sheet before informed consent was signed. The participants had the option of a telephone interview or face-to-face interview. They were informed of their right to withdraw from the study at any time without any explanation required.

Following data collection, to ensure confidentiality of data, consent forms (which had participants' names) were separated immediately from the questionnaires (which had identification numbers). This was done so that data could not be linked with the identity of the person who provided it. If names were written on questionnaires, they were erased or blacked out to protect the identity of participants.

All questionnaires will be kept for at least five years after study is completed as mandated by the "University of Alberta Research Policies and Services Manual" sections 5.2 and 7.5. The data will be kept in a locked filing cabinet. The questionnaires only have an identification number on them. The consent form, which has name of the participant, will be kept separated from the other documents.

CHAPTER 4: RESULTS

The Rural Home-Based Family Caregivers research findings will be discussed in this chapter. The sample demographic characteristics will be reviewed first, followed by the four major research questions.

Family Caregiver and Care Recipient Characteristics

The sample consisted of 46 family caregivers of persons diagnosed with advanced cancer. The participants were accrued utilizing a convenience sample from the Aspen, David Thompson, and East Central Regions in Alberta, Canada. These areas are mostly rural regions within the province. Nurses from the regions contacted eligible family caregivers of patients and sought their permission to be approached for the study. Of the 49 family caregivers approached regarding participation in the study, 3 family caregivers declined to participate, resulting in a response rate of 94%. Of the 46 caregivers who participated in the study, 1 family caregiver was unable to complete the entire questionnaire. No explanation was given.

The interviews were conducted either by telephone or in person at the caregivers' homes or chosen locations. Forty-two interviews were conducted in person and three over the telephone. For one family caregiver, the type of interview was not stated. Of the 46 interviews, 2 were conducted over two sessions in order to complete the questionnaire. The mean time to complete the interviews was 89 minutes (a range of 50 to 150 minutes), including the time to obtain informed consent before the interview and debrief following completion of the questionnaires.

The largest group of participants (45.7%) lived in a town or community with fewer than 10,000 people. Only four care recipients lived in a city of 10,000-17,500 people. This finding is in keeping with Murphy and Puderer's (2002) definition of *rural* as a community with a population less than 100,000.

Care Recipients

Care recipients ranged in age from 33 to 87 years old, with a mean age of 63.6 ± 12.3. Twenty-four care recipients were female (52.2%), and 22 (47.8%) were male. Table 1 summarizes the demographic characteristics of the care recipients. Thirty care recipients (65.2%) had a high school education or less (they were junior high school or high school graduates), and 16 care recipients (34.8%) had more than a high school education (some college, trade school or post-graduate programs).

Care recipients had a mix of primary cancer sites. The most common cancer types reported in the study were lung (23.9%), genito-urinary (15.2%) and gastrointestinal cancer (15.2%). These findings are similar to those reported by the Canadian Cancer Society (2003), which reports that lung cancer is the leading cause of cancer death for both genders. Colorectal cancer is the second leading cause of death from cancer (Canadian Cancer Society, 2003).

Care recipients reported an average of approximately 11 physician visits in the past three months. This included family physicians and specialists. They also were asked whether, in the past three months, they had used emergency services including hospital emergency department, ambulance, or police. Fewer than 2% had used emergency services in the past three months.

Table 1

Characteristics of Care Recipients

Characteristics	Frequency (n = 46)			Percent %
Gender				
Female (F)	24			52.2
Male (M)	22			47.8
Age (years)				
<45	2			4.4
45-54	11			23.9
55-64	10			21.7
65-74	14			30.4
74+	9			19.6
(Range)	(33-87)			
(Mean)	(63.8)			
Marital Status				
Married (common-law)	35			76.1
Single (widowed, divorced, never married)	11			23.9
Education (years				
≤Grade 12	30			65.2
>Grade 12	16			34.8
Income				
below $20,000/year	12			26.1
$21,000 - $30,000/year	10			21.7
$31,000 - $40,000/year	3			6.5
$41,000 - $50,000/year	3			6.5
$51,000 - $60,000/year	6			13
$61,000 - $70,000/year	1			2.2
$71,000 - $80,000/year	3			6.5
$81,000+/year	5			10.9
Declined to answer	3			6.5
Cancer Site	**All patients**	**(M)**	**(F)**	
Breast	4	0	4	8.7
Gastrointestinal	7	3	4	15.2
Genito-urinary	7	5	2	15.2
Head & Neck	6	5	1	13.0
Hematology	5	4	1	10.9
Lung	11	3	8	23.9
Unknown Primary	6	2	4	13.0
Karnofsky Score (3 categories):				
Able to carry on normal activity (80-100)	10			21.7
Unable to work (50-70)	33			71.8
Unable to care for self (10-40)	3			6.5

Care recipients' functional status was measured by the Karnofsky Performance Scale (Anderson et al., 1996). The scores ranged from 10 (near death; fatal process progressing rapidly) to 80 (normal activity with effort; some signs or symptoms of disease). The mean score was 47.2%, meaning that the average care recipient required considerable personal assistance and frequent medical care. Table 1 shows the Karnofsky Performance Scale grouped into three broad categories: (a) able to carry on normal activity and to work with no specific care needed (n = 10, 21.7%), (b) unable to work, however, able to live at home and care for most personal needs (n = 33, 71.8%), and (c) unable to care for self, thus requiring the equivalent of institutional or hospital care (n = 3, 6.5%).

When analyzing the family income of the care recipients' family, it is important to understand that there is no official definition of poverty in Canada. Statistics Canada (2005) utilizes low income cut off (LICO) scores to identify those who are substantially worse off than the average family. For the rural population the community low-income cutoff for one person is $13,680, and for two persons it is $17,100 (Statistics Canada, 2005). Nearly half (47.8%) of the caregivers in this study reported a family or household income of less than thirty thousand dollars. This is lower than the average income reported for rural families ($48,850), in 1997 (Rupnik et al., 2001), suggesting that the families in this study are living with a low income relative to other rural Canadians.

Family Caregiver

Family caregivers ranged in age from 19 to 82 years old, with a mean age of 53.9 ± 14.7. Thirty caregivers were female (65.2%), and 16 (34.8%) were male. Twenty-eight caregivers (60.9%) were spouses, and nine were parents (19.6%) of the care recipients. A large number of family caregivers (n = 36; 78.3%) reported living with the care recipient.

Table 2 presents the demographic profile of family caregivers interviewed for the study. Twenty one (45.7%) had high school educations or less (junior high school or high school graduates), and 25 family caregivers (54.3%) had more than a high school education (some college, trade school or post-graduate education). The family caregivers were more educated than the care recipients, perhaps reflecting their lower average age.

Family caregivers reported having provided care for an average of 11.4 months (range 2-60 months). When asked how many hours of care they provided per week, they reported an average of 87.8 hours or 12.5 hours per day. A number of caregivers insisted that they provided care 24 hours/day and seven days per week. For these caregivers, we subtracted the number of hours of sleep from the total to arrive at what we considered a more accurate amount of caregiving time. Approximately 31 (67.4%) caregivers had assistance from other family members and/or friends. Eleven of these caregivers (23.9%) received assistance from one other person, ten (21.7%) from two other persons, six (13%) from three other persons, and four from five or six other persons (8.7%).

The majority of family caregivers (n = 33, 71.7%) reported chronic health problems of their own. The management of these health problems required regular monitoring by health care providers. Approximately 67% (n = 31) of family caregivers required an average of about two physician visits in the past three months. Although this represents fewer visits than required by patients, it suggests that caregivers have significant health care needs, as would be expected, given their chronic illnesses.

Table 2

Characteristics of Family Caregivers

Characteristics	Frequency (n = 46)	Percent %
Gender		
Female	30	65.2
Male	16	34.8
Age (years)		
<45	11	23.9
45-54	13	28.2
55-64	9	19.6
65-74	11	23.9
74+	2	4.4
(Range)	19-82	
(Mean)	53.9	
Marital Status		
Married (common-law)	35	76.1
Single (widowed, divorced, never married)	11	23.9
Education		
≤Grade 12	21	45.7
>Grade 12	25	54.3
Employment Status		
Employed	7	15.5
Not employed	38	84.4
Missing	1	2.2
Relationship to Patient		
Spouse	29	63.0
Parent	9	19.6
Daughter/Son	1	2.2
Sibling	2	4.3
Other	5	10.9
Size of Community		
City (10,000 + people)	4	8.7
Town (1,000 - 10,000)	21	45.7
Village (300 – 999)	3	6.5
Hamlet (fewer than 299)	5	10.9
Farm	5	10.9
Other (acreages)	8	17.4

Family caregivers reported utilizing various services to help with caregiving (Table 3). The most common home support services included bath assist (n = 12; 26.1%) and nursing services (n = 45; 97.8%). Approximately 70% (n = 32) reported seeing family physicians for the care recipients. Although CHOICE is unique to urban settings, Adult Day Programs and respite admission services were available in some of the communities represented in this study. Interestingly, none of the families used either of these Community Support Services.

Table 3

Types of Formal Services

Types of Services	**Frequency of Services (n /%)**		**Mean (hours per week)**	**Range (hours per week)**
Home-Care Home Support				
Home-maker	3	6.5	0.67	0 – 16
Bath assist	12	26.1	0.39	0 – 3
Sitter / in-home respite	4	8.7	0.61	0 – 20
Home-Care Professional Services				
Social Work	7	15.2	0.13	0 – 2
Nursing	45	97.8	2.25	0 – 14
Physiotherapy	4	8.7	0.15	0 – 3
Occupational Therapy	8	17.4	0.08	0 – 1
Community Support Services				
Adult Day Program	0	0	0	0
CHOICE	0	0	0	0
Respite Admission	0	0	0	0
Professional Services				
Family Physician	32	69.6	Not Recorded	Not Recorded
Physician Home Visits	2	4.3		
Specialists	10	21.7		
Oncologists	17	37.0		
Palliative Care Team	2	4.3		

The SF-36® was utilized to measure the general health of family caregivers. One family caregiver declined to complete the SF-36® scale, yielding a response rate of 98%. Ware et al. (2002) recommended that a scale be calculated if a respondent answered at least half of the items on a multi-item scale. The caregiver did not complete 50% of the scale; therefore, the sample size for calculations involving the SF-36® frequency is 45. Table 4 describes the health states associated with the lowest and highest possible scores for each SF-36® scale.

Table 4

Descriptive Statistics and Score Distributions for SF-36® Subcategories

SF-36® Domains	**Frequency (n)**	**Mean (STD)**	**Range**	**Internal Consistency(α)**
Physical Functioning (PF)	45	81.2 (22.7)	20-100	0.91
Role Physical (RP)	45	67.8 (37.9)	0-100	0.79
Bodily Pain (BP)	45	65.4 (26.4)	22-100	0.92
General Health (GH)	45	74.2 (21.3)	15-100	0.86
Vitality (VT)	45	54.0 (19.0)	0-100	0.80
Social Functioning (SF)	45	73.9 (25.7)	0-100	0.75
Role-Emotional (RE)	45	66.7 (36.9)	0-100	0.73
Mental Health (MH)	45	70.0 (17.0)	20-100	0.78

A higher score represents a higher level of functioning
Internal consistency was assessed utilizing the Cronbach's alpha (α)

The internal consistency of variables in the SF-36® was assessed with Cronbach's (alpha) statistic. The internal consistency scores ranged from 0.73 to 0.92. These results exceed the minimum standard of 0.70 recommended for measures used in group comparisons (Ware et al., 2002). The physical functioning scale exceeded the 0.90 standard of reliability, which is considered a minimum standard for comparisons of scores for individual patients (Ware et al., 2002).

Family caregivers utilizing the SF-36® scale generally rated their health favorably. The physical functioning concept measured performance of physical activities such as caring for self, walking, climbing stairs, and engaging in other vigorous activities. Caregivers rated their physical functioning at an average 81.2%, the highest mean of the health concepts.

The vitality concept measures energy and fatigue. Vitality measures feelings of energy, pep, fatigue, and tiredness. Compared to the other health categories, family caregivers rated their vitality lowest at an average 54%.

Sleep deprivation was also measured in this study. Family caregivers reported that, although they required an average of 7.7 hours of sleep each night, they received an average of 5.9 hours of sleep. This represents an average sleep deprivation of 1.7 hours per night. This supports the finding of low vitality mentioned earlier.

Family caregivers' fatigue was analyzed utilizing a Visual Analog Scale with anchor labels of 0 = "not at all" to 10 = "a great deal." The family caregivers assessed their fatigue fairly low, yielding a mean of 3.80 and a range of 0 to 8 (SD of 2.37).

Family caregivers were asked to describe the three most difficult problems of caring for their family member. Content analysis was performed, and the responses were then grouped according to the domains of issues associated by illness as illustrated by "The Square of Care." Table 5 provides a summary of the reported caregiving problems, which include practical care problems, problems related to physical care, disease management issues, as well as psychological and socioeconomic issues.

Table 5

Most Common Problems Associated with Caregiving

Problem Categories	**Frequency (n = 128)***	**Percent %**
Practical Care	53	42.7
Physical Care	37	29.8
Disease Management	14	11.3
Psychological	10	8.1
Socio-Economic	10	8.1

**Note that percentages are based on the number of problems reported.*

The most frequently identified problems (n = 53; 42.7%) focused on practical care issues. These problems involved the caregivers' concerns about doing for and assisting the sick family member with tasks that he or she normally would have done independently. The concerns included assisting with activities of daily living, monitoring, and administering medication.

The second most common category of problems (n = 37; 29.8%) focused on the physical care needs of care recipients. These included the management of pain and other discomforting symptoms, as well as wound management.

Disease management problems were mentioned fourteen times (11.3% of problems identified). For the most part, caregivers who reported problems in this category wanted more information: primary diagnosis, secondary diagnosis, co-morbidities, adverse events that might arise, and allergies. As a group, palliative patients presented with multiple and varied health problems.

Psychological concerns or issues were mentioned ten times (8.1%) by family caregivers. The psychological problems reported by family caregivers included depression, guilt, and mental exhaustion. The socio-economic problems mentioned by family caregivers (n = 1; 8.1%) included role changes, isolation, changing routines, lack of support from a health care provider, poor living environment, and costs associated with care.

What are the relationships between age and health characteristics of home-based family caregivers of persons with advanced cancer in rural Alberta?

Family caregivers' self-assessed health was analyzed utilizing a Visual Analog Scale with anchor labels of 0 = "very poor" to 10 = "excellent." The caregivers assessed their health fairly high, yielding a mean of 7.67 and a range of 2 to 10 (SD of 1.95).

As part of the SF-36®, family caregivers were asked to compare their current health to that of a year ago. The majority (n = 29; 63%) rated their health about the same as one year ago. Approximately 9 (19.6%) rated their health worse now than one year ago, and 8 (17.3%) rated their health as better than the previous year.

When asked whether they had health problems of their own, 33 family caregivers (71.7%) reported one or more chronic health problems (n = 70). The four most common disorders experienced by family caregivers included musculoskeletal (n = 25; 35.7%), cardiovascular (n = 15; 21.4%), endocrine (n = 8; 11.4%) and psychiatric (n = 6; 8.6%).

A bivariate analysis was utilized to determine the relationship between characteristics of caregivers' age and self-assessed health. A scatter plot suggested no linear relationship between caregivers' ages and self-assessed health. Pearson's correlation coefficient (r) was calculated and confirmed the finding of no statistically significant relationship between age and self-assessed health.

The relationship between family caregivers' age was also analyzed using the eight domains of health as measured by the SF-36® (Table 6). Of these eight domains, only the physical functioning domain was significantly related to caregiver age (r = -0.35, p = 0.02).

Table 6

Correlation Matrix for Caregiver Age with Domains of Health (SF-36®)

SF-36® Domains	**Caregivers Age** Pearson's *r*	 Significance *p*
Physical Functioning (PF)	-0.35*	0.02
Role Physical (RP)	-0.24	0.87
Bodily Pain (BP)	-0.11	0.46
General Health (GH)	0.15	0.32
Vitality (VT)	0.02	0.88
Social Functioning (SF)	0.03	0.87
Role-Emotional (RE)	0.03	0.85
Mental Health (MH)	0.09	0.58

* *Correlation is significant at the 0.05 level (2 tailed)*
** *Correlation is significant at the 0.01 level (2 tailed)*

What are the tasks that home-based family caregivers engage in, and how much time is spent on these tasks?

Family caregivers were asked the types of caregiving tasks they perform and how much time they spend on the tasks as a result of the patients' illness. The types of caregiving responsibilities were divided into five main categories including IADL's, BADL's, mobility, monitoring, and emotional support. Table 7 illustrates the proportion of respondents who provided care in each of the task categories, as well as the average amount of time spent on each category.

All caregivers (n = 46; 100%) provided assistance with instrumental activities of daily living. This category included tasks such as meal preparation, shopping, money management, and medication administration. Participants reported spending between 4 and 131 (mean = 47.8 ± 27.9) hours per week on tasks within the category of IADL's. Most caregivers (n = 45; 97.8%) provided assistance with meal preparation.

Approximately 76% (n = 35) of family caregivers sampled reported assisting with basic activities of daily living. This category included personal care tasks such as assisting with dressing, eating, and bathing. Nearly half (n = 22; 47.8%) of the family caregivers within this category reported providing assistance with dressing the care recipient. Only 15.2% (n = 7) provided assistance with eating. Caregivers reported spending up to 52.5 hours per week on basic activities of daily living (mean = 8.3 ± 11.8). Eleven caregivers spent no time at all on tasks within this category, suggesting that approximately one fourth of patients were able to manage their own personal care.

Approximately 89% (n = 41) of family caregivers reported providing assistance with mobility. This category of care tasks included helping the care recipient move around indoors, transferring from bed to chair and back, and transporting to medical appointments. A large number of caregivers (n = 39; 84.8%) provided assistance with transportation. Approximately 26.1% (n = 12) provided assistance with indoor mobility, 56.5% (n = 26) with outdoor mobility, and 23.9% (n = 11) with transfers. Caregivers reported spending up to 26 hours per week on mobility activities (mean = 6.5 ± 6.2).

Monitoring at home for family caregivers included calling family members to make sure that they were all right and visiting in the home. This category was difficult to calculate for the family caregivers who lived with the care recipient. They reported providing monitoring with all aspects of care. Approximately 70% of caregivers not living with the patient reported providing monitoring. Caregivers reported spending up to 98.5 hours per week on monitoring their ill family member (mean = 19.6±27.8).

Nearly all (n = 44; 95.7%) of family caregivers reported providing assistance in the form of emotional support. The most common emotional support activities, reported by 42 (91.3%) family caregivers, were keeping up spirits, helping through difficult time, and giving reassurance. Family caregivers reported spending up to 78 hours per week on emotional support (mean = 13.9 ± 16.21).

In total, family caregivers reported providing care for an average of 87.8 (± 42.1) hours per week. Numerous family caregivers (n = 16; 34.8%) reported providing care 24 hours per day. The time spent on direct care translated into an average of 12.5 hours per day.

Table 7

Caregiving Responsibilities: Types of Caregiving Tasks and Time Spent on Direct Care

Activity	**Frequency (n / %)**		**Range (hours per week)**	**Mean ± STD**
Instrumental Activities of Daily Living	46	100	4 - 131.0	47.8 ± 27.9
Basic Activities of Daily Living	35	76.1	0 - 52.5	8.3 ± 11.8
Mobility	41	89.1	0 - 26.0	6.5 ± 6.2
Monitoring	32	69.6	0 - 98.5	19.6 ± 27.8
Emotional Support	44	95.7	0 - 78.0	13.9 ± 16.2
Total Care	46	100	15.4 - 190.0	87.8 ± 42.1

What are the relationships between family caregiver characteristics (gender and self-assessed health) and caregiving time for rural caregivers?

The relationship between self-assessed health of caregivers and time spent on caregiving was analyzed using a scatter plot. A linear relationship was not apparent, and this was confirmed by calculating Pearson's correlation coefficient (r).

Bivariate analysis was done to examine whether caregiving responsibilities (caregiving time) varied with gender. The relationship between gender and caregiving time was calculated utilizing an independent samples t-test analysis (two-tailed; alpha set at $p \leq 0.05$). No significant differences were found between gender and time spent on caregiving. Table 8 shows the mean time spent on caregiving by male and female caregivers.

Table 8

Comparison of Time Spent on Caregiving Activities by Gender

Activity	CG Sex	N	Mean	STD	Std. Error Mean
Instrumental Activities of Daily Living	Male	16	41.1	30.0	7.5
	Female	30	43.7	27.2	5.0
Basic Activities of Daily Living	Male	16	4.4	7.6	1.9
	Female	30	10.4	13.1	2.4
Mobility	Male	16	5.0	3.8	1.0
	Female	30	7.3	7.1	1.3
Monitoring	Male	16	21.1	28.2	7.1
	Female	30	18.7	28.0	5.1
Emotional Support	Male	12	14.2	20.8	6.0
	Female	29	13.8	14.3	2.7
Total Care	Male	16	77.5	42.7	10.7
	Female	30	93.2	41.4	7.6

*Note the mean difference utilizing independent samples t-test analysis was not significant

What costs do family caregivers in rural settings report during a family member's illness?

Finally, the rural family caregivers were asked about costs incurred over the course of the patient's illness and not refunded. Analysis was performed using univariate statistics. The majority of caregivers (98%) reported out-of-pocket costs to provide care for their family members in the home. Caregivers reported paying for a wide variety of expenses in caring for their family member. Table 9 depicts the costs reported.

Table 9

Out of Pocket Expenses Incurred in Caring for Family Members

Expenses (n = 45)	**Range($)**	**Mean($) ± STD**	**Median($)**
Medications	0.00 - 30,000.00	2,155.66 ± 5,066.06	600.00
Patient Care Supplies	0.00 - 2,000.00	257.24 ± 520.82	37.00
Equipment	0.00 - 1,700.00	95.44 ± 294.66	0.00
Personnel Care	0.00 - 30,000.00	1,113.89 ± 4,525.44	0.00
Transportation	0.00 - 10,000.00	1,435.28 ± 2,127.29	750.00
Complementary and Alternative Medicine	0.00 - 12,471.52	886.72 ± 2,428.42	0.00
Other	0.00 - 6,000.00	704.82 ± 1,283.40	228.00
Total Cost	240.00 - 76,900.00	6,347.51 ± 12,186.55	2,800.00

The average out-of-pocket expense for family caregivers was $6,347.51, with a range from $240.00 to $76,900.00. The most commonly reported costs to family caregivers were those in the category of "medications." The items described by families included over the counter medications, prescription medications, and chemotherapy.

Transportation was the second most common expense that family caregivers reported. The average cost was $1,435.28, which included gasoline, parking, and car repairs. Family caregivers reported traveling long distances to health services. These results echo those reported by Hughes et al. (2004).

The costs reported in the category of other included food supplements, clothing, home alterations/renovations, communication devices (cell phones, telephones, two-way radios), long distance phone calls to health care providers/pharmacists, diagnostic testing (CT scan) not covered by health insurance, oxygen (equipment and rental), and accommodations. These costs were a direct result of the care recipient's illness.

Summary

Research findings were presented in this chapter. The family caregiver and care recipient characteristics were described, followed by the findings from the four major research questions. The following chapter contains a discussion of the findings.

CHAPTER 5: CONCLUSIONS

In this final chapter of the thesis, the importance and relevance of the study findings will be discussed. The findings are interpreted in the context of existing literature of family caregivers of persons with advanced cancer. The chapter is divided into two major sections: the findings in the first section are organized according to the domains of family care as discussed in chapter two, and the second section focuses on the implications of these findings for further research.

Major Findings and Discussion

Characteristics of Family Caregivers

In this study, the demographic characteristics of family caregivers were similar to those found in other palliative care research in relation to age, gender, and health status. The majority of caregivers (n = 30; 65.2%) were women; this is similar to previous study descriptions of family caregivers (Campbell et al., 1998; Carter & Chang, 2000; Davis et al., 1996; Emanuel et al., 1999; Grande et al., 1997; Jepson et al., 1999; Stajduhar & Davies, 2005; Thomas et al., 2002). Numerous studies showed that spouses and daughters were more likely to serve as the primary caregivers (Davis et al., 1996; Emanuel et al., 1999; Grande et al., 1997; Jepson et al., 1999; Kelly et al., 1999; Stajduhar & Davies, 2005; Strang & Koop, 2003). Similarly, the current study showed that spouses (n = 28; 61%) and daughters (n = 8; 17%) were usually primary caregivers.

The age of the family caregiver ranged from 19 to 82 years old, with a mean age of 53.9 years. Findings from other research studies indicated that the majority of family caregivers of patients with advance cancer mean ages ranged from 53 to 62 years (Grunfeld et al., 2004; Jepson et al., 1999; Strang, & Koop, 2003). The family caregivers within this study fall in the lower range of the mean ages reported. Due to the limited number of rural family caregiving studies, a comparison is not possible.

More than two-thirds of family caregivers reported having one or more chronic diseases. This is greater than earlier cited urban research done by Strang and Koop (2003) and Jepson et al. (1999). Further investigation to compare the health status of rural and urban adults is required considering rural residents have reported significantly poorer health than urban residents (Beck et al., 1996; Bull et al., 2001).

Family caregivers' characteristics (age and health) are described in the current study. Although other authors have reported that, on average, rural residents are older and in poorer health than their urban counterparts (Andrews, 2001; Bull et al., 2001), no studies have addressed the impact of age on caregivers' general health. In this study of the eight domains of general health, as measured by the SF-36®, only age was found to negatively relate to physical functioning. Thus, the higher the respondent's age, the lower the score on physical functioning. The results indicate that as the caregivers age, their physical functioning declines. This limits their ability in activities such as self-care, walking, climbing stairs, and performing vigorous activities, potentially lessening their ability to provide care. Given the older age of family caregiver, further studies are required to analyze how health and age impact caregiving responsibilities.

The finding that a majority of caregivers (n = 29; 63%) did not experience an adverse impact on employment status is not consistent with the result of studies regarding family caregivers of cancer patients (Grunfeld et al., 2004). A possible reason for this difference is that the majority of caregivers reported being retired (n = 15; 32.6%) or not employed (n = 10 21.7%), a result which is similar to that of other North American studies by Brazil et al. (2003), and Jepson et al. (1999).

The Government of Canada (2004) recommends income security and job protection for those caring for dying family members. The current study underscores the importance of implementing this recommendation and providing financial assistance for those who are also homemakers, part-time workers, or self-employed.

Domains of Family Care

Disease Management Domain

All care recipients in this study had advanced cancer. Their cancer sites (predominantly lung, gastrointestinal, and genito-urinary cancers) roughly follow the leading causes of death from cancer (Canadian Cancer Society 2003).

In this study, family caregivers reported having provided care for 11.4 months (range 2 to 60 months) at the time of the study. Since caregiving was ongoing at the time of data collection, their caregiving trajectory was not yet complete. The length of caregiving reflects the chronic and progressive nature of cancer and alerts the healthcare provider to the challenges of caregiving over a prolonged period.

The family caregivers reported concerns about the care recipients' primary diagnosis, along with disease progression. Numerous families reported problems associated with the progressive decline of the individual. One family member stated a need to "improve communication between specialists and family." This member described having difficulty receiving information on staging, prognosis, and treatment at the family's level of understanding.

The majority of family caregivers reported receiving Home Care Nursing services (n = 45; 97.8%); however, the mean average time was 2.25 hours per week. Family caregivers received fewer services from Home Care Aides (including bath assist, homemaking, and respite) (n = 34; 74%; mean time = 1.68 hours); Occupational Therapist (n = 8; 17.4%), and Physiotherapy (n = 4; 9%). Although the problems of accessing rural services and health professionals have been identified as a concern (Andrews, 2001; Burge et al., 2005), further analysis by size of community is needed.

Physical Care Domain

Symptoms that caused families concern included pain, nausea, wounds, as well as other. The families reported facing difficult decisions and conflicts related to medications. They found themselves having to decide when to administer medication and what dose to give, concerns similar to those reported in other studies (Aranda & Hayman-White, 2001; Taylor et al., 1993; Wilkes & White, 2005).

In responding to the open-ended questions regarding possible changes to the health care system and what providing care was like, family caregivers reported a need for sound medical knowledge, including the ability to anticipate healthcare needs and provide the appropriate interventions for the care recipient. One family member reported needing specific information about the disease pathology and death process.

Caregivers feel reassured when clinicians demonstrate sound palliative care knowledge and are able to anticipate healthcare needs and provide interventions and explanations of symptoms. Homecare nurses provide a unique and complementary knowledge of treatments and interventions; they are able to provide an important complement to medical care provided by general practitioners (Sach, 1997). Further analysis to understand the difficulty of decisions and potential family conflicts in relation to medication administration and symptom management is required.

Psychological Domain

The psychological problems experienced by family caregivers included depression, guilt, fatigue, and sleep deprivation. One family caregiver described feeling very isolated: “Life goes on for other people and life has stopped for us.” This person described sadness related to the sudden diagnosis and drastic changes in lifestyle. The changes caused marital difficulties, social isolation, and feelings of loneliness.

Few research studies have examined sleep problems in caregiving (Carter & Chang, 2000). Family caregivers in this study reported a deprivation of nearly two hours of sleep per night. Problems with sleeping frequently are a direct result of the needs faced by the caregivers as the family member’s cancer increases (Wilcox & King, 1999).

Families experienced stress and conflict as they tried to care for a loved one while parenting their own children and fulfilling occupational and other responsibilities (Dudgeon & Kristjanson, 1995; Nijboer et al., 1998). Further analysis of these psychological stressors is required for implementation of effective interventions.

Socio-Economic Domain

Family members discussed role changes as a result of the cancer experience. Both the male and female participants in this study were required to take on roles that had traditionally been the domain of the care recipient.

The family caregivers of patients with cancer reported negative economic consequences of costs related to care. The majority of caregivers reported out-of-pocket costs to provide care in the home (n = 45; 98%). This proportion was higher than the 44%

reported by the National Profile of Family Caregivers (Health Canada, 2002). Numerous family caregivers kept detailed records of their expenses and reported significant financial strain. Caregivers reported spending considerable amounts of money on a variety of expenses to look after their family members with advanced cancer.

In this study, prescription drugs were, on average, the most common financial expense reported. This finding is similar to those in the Canadian study by Grunfeld et al. (2004). The average cost was $2,155.66 over the course of this illness at the time of data collection, which is greater than the cost ($1,402.40) described by Grunfeld et al's (2004) study. For families in the study, the average financial burden incurred during the patients' illness was $6,348 (SD = 1,2187). This finding is similar to the study by Grunfeld et al. (2004), who found the cost to be $8,292 without extended health coverage and $5,765 with extended health care coverage.

Caregivers in this study reported costs associated with alternative therapies or chemotherapeutic drugs not covered by the government, given their disease status. These costs were included in this study because caregivers believed them to be necessary. While governments cannot be asked to cover costs that have questionable merit, other costs such as those involving personal care supplies and medications for the control of discomforting symptoms need to be addressed.

A simple question about general costs incurred during family members' illnesses elicited various concerns on the part of the caregivers. One family member in the study stated that the financial issues were the most difficult to handle: "It's an extremely stressful time for the sick person and the caregiver. The illness is one thing; however, the finances are extremely frustrating." Numerous families reported worrying about the ongoing costs of medications and treatments.

These findings underscore the importance of including valid estimates of costs incurred while caring for persons with advanced cancer. The analysis of informal caregiving costs confirms the significant burden that palliative care places on both families and society.

Practical Domain

The most frequently identified problems by family caregivers focused on practical care issues. Caregivers in this study performed many different tasks including basic activities of daily living, instrumental activities of daily living, mobility activities of daily living, monitoring, and providing emotional support. All of the family caregivers reported that the patient experienced some degree of functional impairment. This is to be expected with an average patient Karnofsky score of 47.2%, in which the care recipient requires considerable personal and medical support.

The number of caregivers offering assistance with specific functional activities was greater than that in the findings by Brazil et al. (2003). Although the caregiving times provided by women (93.2 hours per week) was greater than that by men (77.5 hours per week), the independent samples t-test analysis showed no statistically significant difference. A possible reason for this may be due to the sample size when conducting a t-test. The power analysis assumed a non-directional alpha set at 0.05 for a t-test of a large effect size of 0.40 requires a sample of 78 participants in order to obtain the conventional power of 0.80 (Cohen, 1988).

It seems fair to state that women and men are similarly involved in the subcategories of informal caregiving. Other studies have found women were significantly more involved in monitoring whereas men helped more with instrumental activities of daily living (Ekwall et al., 2004). The men in this study were equally involved in caregiving tasks despite the traditional notion that women engage more often in household activities (Ekwall et al., 2004). The patterns of involvement between men and women need further examination. These findings are especially important since the prevailing attitude is that men are less involved in caregiving than women (Ekwall et al., 2004).

The results show that caregivers maintain their caregiving responsibilities despite their own health problems. Analysis showed no statistically significant relationship between health and time spent, suggesting that, despite the family caregivers' chronic health conditions, they continue to provide needed care.

As the incidence, prevalence, and mortality rate of cancer increases, even greater labor costs of care will continue to fall on patients' families. Given the average time spent on caregiving (90 hours/week) by the 46 participants in this study, the contributions of these families are important and need to be acknowledged. The average hourly wage for Nursing Aides in Canada is $13.60/hour (Department of Human Resources Development Canada, 2003); therefore, the replacement costs for the participants in this study alone would be $56,304 (90 x 46 x $13.60) per week. The caregivers in this study had provided care for an average of 11.4 months, and the length of time they had yet to provide care is unknown. An estimate of 12 months as an average length of caregiving time seems reasonable. Assuming a caregiving career of one year (52 weeks), the caregivers in this study provided care that would otherwise cost society nearly $3 million ($56,304 x 52 = $2,927,808).

Summary of the Conceptual Model

Finally, the “Square of Care” conceptual framework was utilized to guide the discussion of the findings that related to patient and family care. The conceptual model represented multiple domains including disease management, as well as physical, psychological, socio-economic, and practical dimensions. The models of patient and family care, considering the domain of care put forward by a nursing perspective, may be worthwhile to apply to a family approach and respond to the caregiver involved in caregiving.

Study Limitations

The sample size of this study was small; therefore, results must be interpreted cautiously. Since the sample was a convenience sample and not randomly selected, the findings cannot be generalized to the total population of family caregivers at end of life.

The Canadian definition of *census metropolitan area* has been reported in literature as a means of distinguishing between urban and rural populations. Unfortunately, this definition does not differentiate within the broad range of population densities the may exist within rural (non-metropolitan) areas. Although greater than 90% of the sample lived in communities of less than 10,000, this included towns (45.7%), villages (6.5%), hamlets (10.9%), farms (10.9%), and acreages (17.4%). Because of this problem, research findings should be viewed cautiously. Nonetheless, this study offers new information about non-urban family caregiving, thus contributing to a beginning understanding of their unique circumstances.

The form used to calculate caregiving tasks and amount of direct care was developed for this study because no psychometrically sound scale was found. This form was derived from expert sources and through a literature review. The findings derived using this scale must be viewed with caution as psychometric analysis and refinement have yet to be performed. In addition, families reported having difficulty measuring the amount of emotional time involved separately from the other caregiving responsibilities. When family members who reported providing care for 24 hours per day, the hours of care was subtracted from the amount of sleep. Despite these limitations, the research findings are important for several reasons. Family members were able to quantify the amount of care other than emotional support provided in the subscales. The relationships between family caregiver characteristics (gender and self-assessed health) and caregiving time were analyzed. Given the length of time involved in caregiving and the health related concerns, further research is warranted to compare finding to those from other studies.

Implications of the Findings

Implications for Further Research

There is a need for further analysis of some of the data collected in this research and the larger study of which this research was a component. The portion of the study that focused on caregiver burdens requires further analysis. A comparison of caregiver burden and family characteristics would provide valuable insights into the potential stressors of rural home-based family caregivers.

Analysis of the qualitative data collected in this study is required. Insights into what family members recommend for changes to the health care system and general perceptions of what it is like to provide care are required.

A comparison of rural and urban Albertans who are providing home-based care to family members is required. Hughes et al. (2004) reported that many studies on patient and care needs are small. No studies have been done comparing rural and urban home-based family caregivers of persons with advanced cancer in Canada.

Rural providers need to be aware of the barriers family caregivers experience and their ability to provide and access care. Rural dwellers are reported as being impeded in access to care due to poverty and lack of availability of services (Beck et al., 1996; Maclean & Kelley, 2001). An important goal is to determine what strategies will increase not only access to care, but also the perception that care is accessible and acceptable. Little is known about what rural dwellers deem an acceptable level of care. Studies with an emphasis on the evaluation of primary care interventions aimed to meet the needs of family caregivers are critical to assist rural people in improving their health status (Beck et al., 1996).

Finally, there are many questions that can be answered only through longitudinal research. How does health status of family caregivers change over time? What are the relationships between demographic (gender and self-assessed health) characteristics and caregiving tasks/caregiving time? To what extent do health characteristics (existence of chronic illness, well-being, and health-related behaviors) influence the relationship between demographic (age, gender) characteristics and ability to provide care. Longitudinal research could identify how the variables in this study change over time.

Conclusions

The purpose of this study was to present preliminary data on rural Albertans who are providing home-based palliative care to family members. The thesis focused on the demographic, economic, and health characteristics of caregivers. The descriptive/ correlational, cross-sectional study utilized questionnaires to collect data from home-based family caregivers of patients with advanced cancer. The nature of the caregiving situations and the use of healthcare services were analyzed to explore relationships between the characteristics of caregivers and the caregiving situation. The information is crucial to the tailoring of supportive programs for home-based family caregivers.

The research examined rural family caregivers of persons with advanced cancer. As part of the investigation, investigators identified three key themes. First, family caregivers were engaged in numerous caregiving tasks for approximately 87.8 hours per week or 12.5 hours per day. This signifies that family caregivers are providing a tremendous amount of necessary care with limited formal community supports. Further analysis is required to examine how caregiving tasks impact on the caregivers' stress and ability to provide care.

Second, family caregivers are paying for a wide variety of expenses due to their caregiving. The average cost of expenses for family caregivers was $6,347.51 with a maximum of $76,900.00. The most significant costs were medications ($2,155.66), and transportation ($1,435.28). Family caregivers reported financial hardships related to their caregiving costs.

Third, family caregivers reported an average sleep deficit of 5.9 hours of sleep at night. When asked how much sleep they needed, this number was higher, at 7.7 hours, signifying a deprivation in sleep of 1.7 hours per night. The effects of sleep deprivation on the caregivers' health and ability to provide care needs to be studied. When family caregivers are providing care for an average of 11.36 months (at the time of study), the effects of this magnitude of sleep deprivation on their long-term health needs to be studied.

If community-based palliative care services are to succeed, governments must provide essential financial resources for better training, research, and education of all personnel involved in the delivery of palliative care. These personnel include volunteers, support staff, and health professionals. In addition, financial resources must be used judiciously.

The aim of the research was to identify variables associated with family caregivers' needs and concerns in the rural communities. Helping rural family members assume the caregiving role in a way that is sustainable and fulfilling should be the goal of healthcare providers. Through viewing the family as a unit, health care providers are better able to assess and identify potential support for those in need of assistance. Improving quality of care at end of life is now a public, political, and professional priority shared by all health professionals involved in the delivery of palliative care. To improve quality of life, healthcare providers need to develop a substantive body of knowledge that will guide palliative care practice into the future.

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APPENDIX A:

A Model to Guide Hospice Palliative Care

"Square of Care"

Square of Care

PROCESS OF PROVIDING CARE

Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation
History of issues, opportunities, associated expectations, needs, hopes, fears Examination - assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity Goals of care Requests for withholding/ withdrawing, therapy with no potential for benefit, hastened death Issue prioritization Therapeutic priorities, options Treatment choices, consent Surrogate decision-making Advance directives Conflict resolution	Setting of care Process to negotiate/ develop plan of care - address issues/ opportunities, delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions

COMMON ISSUES

Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	**Disease Management**
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking	**Physical**
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	**Psychological**
Cultural values, beliefs, practices Relationships, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues	**Social**
Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	**Spiritual**
Activities of daily living Dependents, pets Telephone access, transportation	**Practical**
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Perideath care of family, handling of body Funerals, memorial services,	**End of life/ Death Management**
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	**Loss, Grief**

Patient / Family

From: Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P.
A Model to Guide Hospice Palliative Care © Canadian Hospice Palliative Care Association, Ottawa, Canada, 2002.

APPENDIX B:
General Information – Caregiver and Care Recipient

1a. Relationship of care recipient to caregiver. You are caring for your…

☐ Husband/wife	☐ Daughter/son
☐ Parent	☐ Sister/brother
☐ Parent-in-law	☐ Other (please specify) ____________

1b. Does the caregiver live with the care recipient? ☐ Yes ☐ No

1c. Size of community

☐ City (10,000+ people)	☐ Hamlet (fewer than 299 people)
☐ Town (1,000 – 10,000)	☐ Farm
☐ Village (300 – 999)	☐ Other (please specify) ____________

2. Marital Status – caregiver	**3. Marital Status – care recipient**
☐ Married	☐ Married
☐ Widowed	☐ Widowed
☐ Never married	☐ Never married
☐ Divorced	☐ Divorced
☐ Common-law	☐ Common-law
☐ Other (please specify) ____________	☐ Other (please specify) ____________

4. Caregiver age ____________

5. Care recipient age ____________

6. Caregiver sex	**7. Care recipient sex**
☐ Male	☐ Male
☐ Female	☐ Female

8. Religion (care giver)	**9. Religion (care recipient)**
☐ Catholic	☐ Catholic
☐ Protestant	☐ Protestant
☐ Jewish	☐ Jewish
☐ Muslim	☐ Muslim
☐ Other (please specify) ____________	☐ Other (please specify) ____________

10. Highest level of education completed (caregiver)

☐ Junior high school or less
☐ Some high school
☐ High school graduate
☐ Some college or trade school
☐ Diploma from college or trade school
☐ Attended university
☐ University degree
☐ Post-graduate degree

11. Highest level of education completed (care recipient)

☐ Junior high school or less
☐ Some high school
☐ High school graduate
☐ Some college or trade school
☐ Diploma from college or trade school
☐ Attended university
☐ University degree
☐ Post-graduate degree

12. Ethnic background (caregiver)

☐ English
☐ French
☐ First Nations
☐ Asian
☐ Eastern European
☐ Western European
☐ Middle Eastern
☐ Other (please specify) ____________
____

13. Ethnic background (care recipient)

☐ English
☐ French
☐ First Nations
☐ Asian
☐ Eastern European
☐ Western European
☐ Middle Eastern
☐ Other (please specify) ____________
____

14. Caregiver occupation (current or former)

☐ Clerical
☐ Labourer
☐ Management
☐ Professional
☐ Home-maker
☐ Other (please specify) ____________
____

15. Care recipient occupation (former)

☐ Clerical
☐ Labourer
☐ Management
☐ Professional
☐ Home-maker
☐ Other (please specify) ____________
____

16. Current employment status (caregiver)

☐ Full-time
☐ Part-time
☐ Paid leave
☐ Unpaid leave
☐ Retired
☐ Not employed
☐ Other (please specify) ____________
____

17. Has employment status changed as a result of caregiving role? ☐ Yes ☐ No
If yes, what was previous employment status? ______________________________

18. Care Recipient's Family Income

☐ below $20,000/year
☐ $21,000 - $30,000/year
☐ $31,000 - $40,000/year
☐ $41,000 – $50,000/year
☐ $51,000 - $60,000/year
☐ $61,000 - $70,000/year
☐ $71,000 - $80,000/year
☐ more than $80,000/year

19. Number of persons depending on family income? _____ adults _____ children

20 a. Has family income changed as a result of illness? ☐ Yes ☐ No

If yes, in what way?

____

20 b. Generally, how difficult is it to manage the costs associated with caregiving?

Not at all difficult										A great deal of difficulty
0	1	2	3	4	5	6	7	8	9	10

Comments:

21a. What is your care recipient's diagnosis? ____________________________

21b. When was your care recipient diagnosed? (date) ______________________

21c. For how long have you been a caregiver? _____________________ **(months)**

22. About how many hours per week do you spend in caregiving? _____________

23. Are there other family members/non-professionals involved in caregiving?
☐ Yes If yes, how many other caregivers are there? _________ About how many hours of caregiving per week in total do these caregivers provide? _________
☐ No

24. Generally, how good is your health?

Very poor Excellent
0 1 2 3 4 5 6 7 8 9 10

Comments:

25. Generally, how much does your health interfere with caregiving?

Not at all A great deal
0 1 2 3 4 5 6 7 8 9 10

Comments:

26. Generally, how much does your caregiving interfere with your health?

Not at all A great deal
0 1 2 3 4 5 6 7 8 9 10

Comments:

27. Do you have chronic health problems? ☐ Yes ☐ No
If yes what are they?

28. Generally, how fatigued are you?

Not at all A great deal
0 1 2 3 4 5 6 7 8 9 10

Comments:

29. Please list the 3 most difficult problems of caring for your family member and tell us how difficult each problem is to manage:

1= extremely easy to manage 4= fairly difficult to manage **2= fairly easy to manage 5= extremely difficult to manage** **3= about in the middle in terms of difficulty**	**1** ☑	**2** ☑	**3** ☑	**4** ☑	**5** ☑
Problem:					
Problem:					
Problem:					

Comments:

30. About how many hours of sleep do you need on a daily basis?

__________ at night __________ in naps

31. About how many hours of sleep do you get these days on a daily basis?

_____________ at night __________ in naps

32. Please note which formal services you are using to help with caregiving. Tell us how many hours per week you get these services and how helpful they are:

1= not helpful at all 4= very helpful **2= a little helpful 5= extremely helpful** **3= fairly helpful**	**1** ☑	**2** ☑	**3** ☑	**4** ☑	**5** ☑
Home-care home support					
☐ home-maker services __________ hours/week (average)					
☐ bath assist __________ hours/week (average)					
☐ sitter/ in-home respite services _________ hours/week (average)					
☐ other _____________________ _______ hours/week (average)					
Professional services					
☐ social work __________ hours/week (average)					
☐ nursing __________ hours/week (average)					
☐ physiotherapy __________ hours/week (average)					
☐ occupational therapy __________ hours/week (average)					
☐ other _____________________ _______ hours/week (average)					
Community support services					
☐ adult day program __________ hours/week (average)					
☐ CHOICE __________ hours/week (average)					
☐ Respite admission __________ hours/week (average)					
☐ other _____________________ _______ hours/week (average)					

33. During the past three months, how many times have you and your care recipient gone to see the doctor for health problems?

Caregiver __________ Care recipient __________

Comments:

34. How many times have you or your care recipient had to use emergency services during the previous 3 months (e.g. hospital emergency department, ambulance, police)? Please comment on what types of services were required and the circumstances under which they were required.

Caregiver __________ Care recipient __________

Comments:

35. Please estimate the total amount of money spent *and not refunded* on each of the following items during your family member's illness:

$ ____________ drugs
$ ____________ patient care supplies
$ ____________ equipment (walker, wheelchair, hospital bed, commode)
$ ____________ personnel (home care aides, nursing staff, home-makers, sitters)
$ ____________ other (please specify) ____
$ ____________ other (please specify) ____
$ ____________ other (please specify) ____

CAREGIVER REACTION ASSESSMENT

☆ *The following items focus on how you feel about providing care for your family member. Put your family member's name in the blank provided. Then answer each statement in terms of how strongly you agree or disagree with it. Put an* ☑ *in the column that best fits how you feel.*

1= strongly disagree **2= disagree** **3= neither agree nor disagree** **4= agree** **5= strongly agree**	1 ☑	2 ☑	3 ☑	4 ☑	5 ☑
1. I feel privileged to care for ______.					
2. Others have dumped caring for _____onto me.					
3. *My financial resources are adequate to pay for things that are required for caregiving.					
4. My activities are centered around care for ______.					
5. Since caring for ______, it seems like I'm tired all of the time.					
6. It is very difficult to get help from my family in taking care of ______.					
7. *I resent having to take care of ______.					
8. I have to stop in the middle of my work to care for ______.					
9. I really want to care for ______.					
10. My health has gotten worse since I've been caring for ______.					
11. I visit family and friends less since I have been caring for ____.					
12. I will never be able to do enough caregiving to repay ______.					
13. *My family works together at caring for ______.					
14. I have eliminated things from my schedule since caring for______.					
15. *I have enough physical strength to care for ______.					
16. Since caring for ______, I feel my family has abandoned me.					
17. Caring for ______, makes me feel good.					
18. The constant interruptions make it difficult to find time for relaxation.					
19. *I am healthy enough to care for _____.					
20. Caring for _____ is important to me.					
21. Caring for _____ has put financial strain on the family.					
22. My family (brothers, sisters, children) left me alone to care for ______.					
23. It's difficult to pay for _____'s health needs and services.					
24. I enjoy caring for _____.					

* These questions are to be reverse-scored

CAREGIVING RESPONSIBILITIES: TYPES AND AMOUNT OF DIRECT CARE

☆ *The following questions address the tasks involved in caring for your loved one and the time these tasks take. Please answer the questions in terms of* ***this past week****.*

Activity	**Yes** ☑	**No** ☑	**Time Spent** (hours)	**Comments**
Activities of Household Management				
Meal preparation (include clean-up)				
House cleaning				
Laundry				
Sewing				
House maintenance & yard work				
Shopping for groceries or other necessities				
Banking and money management (includes preparing income tax)				
Personal Care				
Medication administration				
Dressing				
Eating				
Grooming (hair, shaving, brushing teeth, etc)				
Bathing				
Toileting				
Hand care				
Foot care				
Mobility (movement)				
Indoor mobility				
Outdoor mobility				
Transfers (i.e., bed to chair)				
Transportation (trips to the doctor, dentist etc)				
Monitoring at Home				
Telephone calls to make sure s/he was ok				
Visiting to make sure s/he was ok				
Emotional Support				
Keeping up spirits				
Confiding in someone				
Helping through the difficult time				
Give reassurance				
Give encouragement				
Someone with whom to laugh and cry				

The SF-36® Health Survey

Instructions for Completing the Questionnaire

Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

EXAMPLE

This is for your review. Do not answer this question. The questionnaire begins with the section ***Your Health in General*** below.

For each question you will be asked to fill in a bubble in each line:

1. How strongly do you agree or disagree with each of the following statements?

	Strongly agree	**Agree**	**Uncertain**	**Disagree**	**Strongly disagree**
a) I enjoy listening to music.	○	●	○	○	○
b) I enjoy reading magazines.	●	○	○	○	○

Please begin answering the questions now.

Your Health in General

1. In general, would you say your health is:

Excellent	**Very good**	**Good**	**Fair**	**Poor**
○	○	○	○	○

2. Compared to one year ago, how would you rate your health in general?

Much better now than one year ago	**Somewhat better now than one year ago**	**About the same as one year ago**	**Somewhat worse now than one year ago**	**Much worse now than one year ago**
○	○	○	○	○

3. The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	Yes, Limited a lot	**Yes, limited a little**	**No, not limited at all**
a) **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
b) **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
c) Lifting or carrying groceries	○	○	○
d) Climbing **several** flights of stairs	○	○	○
e) Climbing **one** flight of stairs	○	○	○
f) Bending, kneeling, or stooping	○	○	○
g) Walking **more than a mile**	○	○	○
h) Walking **several blocks**	○	○	○
i) Walking **one block**	○	○	○
j) Bathing or dressing yourself	○	○	○

4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health?</u>

	Yes	**No**
a) Cut down on the **amount of time** you spent on work or other activities	○	○
b) **Accomplished less** than you would like	○	○
c) Were limited in the kind of work or other activities	○	○
d) Had **difficulty** performing the work or other activities (for example, it took extra time)	○	○

5. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

	Yes	**No**
a) Cut down on the **amount of time** you spent on work or other activities	○	○
b) **Accomplished less** than you would like	○	○
c) Didn't do work or other activities as **carefully** as usual	○	○

6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
○	○	○	○	○

7. How much bodily pain have you had during the **past 4 weeks**?

None	Very mild	Mild	Moderate	Severe	Very severe
○	○	○	○	○	○

8. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
○	○	○	○	○

9. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	**Most of the time**	**A good bit of the time**	**Some of the time**	**A little of the time**	**None of the time**
a) did you feel full of pep?	○	○	○	○	○	○
b) have you been a very nervous person?	○	○	○	○	○	○
c) have you felt so down in the dumps nothing could cheer you up?	○	○	○	○	○	○
d) have you felt calm and peaceful?	○	○	○	○	○	○
e) did you have a lot of energy?	○	○	○	○	○	○
f) have you felt downhearted and blue?	○	○	○	○	○	○
g) did you feel worn out?	○	○	○	○	○	○
h) have you been a happy person?	○	○	○	○	○	○
i) did you feel tired?	○	○	○	○	○	○

10. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the Time	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
○	○	○	○	○

11. How TRUE or FALSE is each of the following statements for you?

	Definitely true	**Mostly true**	**Don't know**	**Mostly false**	**Definitely false**
a) I seem to get sick a little easier than other people	○	○	○	○	○
b) I am as healthy as anybody I know	○	○	○	○	○
c) I expect my health to get worse	○	○	○	○	○
d) My health is excellent	○	○	○	○	○

Caregiver's Burden Scale

INFORMATION ABOUT THE PERSON TO WHOM YOU PROVIDE CARE

Please indicate which of the following descriptions most closely reflects the situation of the person to whom you provide care:

	Yes	**No**
1. He/ she can go out and run errands alone and without assistance.	☐	☐
2. He/ she can manage daily activities without help (washing, eating, dressing, etc.).	☐	☐
3. He/ she requires assistance to move around inside at home.	☐	☐
4. He/ she spends more than half of the day in bed or in a chair.	☐	☐
5. He/ she is practically completely confined to bed or chair.	☐	☐

Caregiver's Burden Scale

We would like to know about your experience while caring for an ill person. In the following document, you will find a list of statements that may or may not be part of a caregiver's experience. For each item, please **circle the number** *(from "never" to "very often") that best describes your current situation.*

EXAMPLE :		**Never**	**From time to time**	**Fairly often**	**Very often**
1.	Do you have trouble concentrating?	1	2	3	[✓ 4]

This example indicates that you consider that, very often, you have trouble concentrating.

Don't take too much time responding; your first impression is probably the best!

		How often do you experience this feeling in your role as caregiver?			
	Currently	***Never***	***From time to time***	**Fairly often**	**Very often**
1.	Do you ever find that the tasks required in caring for the sick person are too demanding?	**1**	**2**	**3**	**4**
2.	**Do you ever feel emotionally exhausted?**	**1**	**2**	**3**	**4**
3.	Do you ever feel that you no longer have the strength to care for the ill person?	**1**	**2**	**3**	**4**
4.	**Do you ever feel unable to go on?**	**1**	**2**	**3**	**4**
5.	**Do you feel overwhelmed by everything that has happened to you?**	**1**	**2**	**3**	**4**
6.	Do you feel that you are up to dealing with this situation?	**1**	**2**	**3**	**4**
7.	Do you have the impression that your role as caregiver is making you physically ill?	**1**	**2**	**3**	**4**
8.	Do you ever feel emotionally drained?	**1**	**2**	**3**	**4**
9.	**Do you ever feel that you are no longer capable of caring for the ill person?**	**1**	**2**	**3**	**4**
10.	**Do you ever feel physically exhausted?**	**1**	**2**	**3**	**4**

		How often do you experience this feeling in your role as caregiver?			
	Currently	***Never***	***From time to time***	**Fairly often**	**Very often**
11.	**Do you have the impression that you are in control of the situation?**	**1**	**2**	**3**	**4**
12.	Are you ever afraid that you won't be able to hold out much longer?	**1**	**2**	**3**	**4**
13.	Do you feel like you are at the end of your rope?	**1**	**2**	**3**	**4**
14.	**Are you uncomfortable with the type of care your must provide the ill person with?**	**1**	**2**	**3**	**4**
15.	**Do you ever feel discouraged by all the tasks you have to accomplish?**	**1**	**2**	**3**	**4**
16.	Do you ever think that caregiving is too demanding an experience for you?	**1**	**2**	**3**	**4**
17.	**Do you ever have the impression that you have lost control over your life?**	**1**	**2**	**3**	**4**
18.	Do you ever have the impression that you carry too heavy a burden?	**1**	**2**	**3**	**4**

KARNOFSKY PERFORMANCE SCALE

This scale gives us a sense of how sick your family member is. Please circle the number which best fits with the level of functioning of your family member. Use the left-hand side to get a general sense of the score and use the statements on the right-hand side to find the exact number.

Able to carry on normal activity and to work. No special care is needed.	100	Normal; no complaints; no evidence of disease
	90	Able to carry on normal activity; minor signs or symptoms of disease
	80	Normal activity with effort; some signs or symptoms of disease
Unable to work. Able to live at home, care for most personal needs. A varying amount of assistance is needed.	70	Cares for self. Unable to carry on normal activity or to do active work
	60	Requires occasional assistance, but is able to care for most of his needs
	50	Requires considerable assistance and frequent medical care
Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly.	40	Disabled; requires special care and assistance
	30	Severely disabled; hospitalization is indicated although death not imminent
	20	Very sick; hospitalization necessary, active supportive treatment necessary
	10	Near death; fatal processes progressing rapidly

What changes in the health care system would you recommend to help you and your family member at this time?

Is there anything else you would like us to know about what it is like for you to care for your family member?

Would you like to receive a copy of the report when the research is complete?
☐ Yes ☐ No

Thank you for your valuable co-operation.

APPENDIX C:
Home-based family caregiving of persons with advanced cancer and Alzheimer's disease: A description of caregivers and their caregiving situations

Consent to release name and phone number

I hereby give permission for ______________________________ to give my name and telephone number to Dr. Priscilla Koop. This permission allows Dr. Koop or one of her research assistants to phone me about the study. I understand that this permission does not imply consent to participate in the research. I will have a chance to ask further questions and then decide whether or not I wish to participate in the study.

Name:____

Telephone number:____

Preference for day and time of contact:______________________________________

Signed: ____________________________________

Note: Please fax the form, Consent to Release Name and Phone Number of participants, to (1-780-723-7787)

APPENDIX D:

Home-based family caregiving of persons with advanced cancer and Alzheimer's disease: A description of caregivers and their caregiving situations

Information Sheet for Family Caregivers

The invitation: You are being invited to take part in a research project about taking care of a family member with advanced cancer. We are interested in knowing more about the people who take care of sick family members. We also want to know about the responsibilities that are involved in care giving. We want to know how care giving affects your health.

The researchers: The principle investigator, Priscilla Koop, is a nurse who conducts research at the University of Alberta. Priscilla's research focuses on home-based family care giving. Other researchers on the team are Vicki Strang, Dennie Hycha, Marilyn Oishi and Jacquie Peden. All are nurses who are interested in what life is like for people who take care of family members with cancer at home. Some of the information you give to us may be used for research assistants' master's thesis.

What's involved: Taking part in the research involves filling in a number of questionnaires. The first questionnaire asks general questions about you and the person you are caring for. We will also ask about how you think your care giving affects your finances and your health. We would like to know what you find hard about giving care and about what services you use to help your family member with cancer. Another questionnaire asks about the general well being of your family member with cancer. A third questionnaire asks questions about your health. A fourth questionnaire asks questions about what it is like for you to be providing care. The last questionnaire asks questions about the tasks that are included in giving care and how much time you spend at those tasks. Answering the questions will take about an hour of your time. You have the choice of answering these questions over the phone or in your own home.

What happens if you decide not to take part or if you don't want to answer a question: You are free to choose to take part or not to take part in this research. Whatever you decide is fine with us and will not affect the care that your family member gets. You also have the right to refuse to answer any question. You can withdraw from the research any time you want to and for any reason whatever. All you have to do is to tell the person asking you questions to stop and we will stop.

Risks and Benefits: There are no known risks involved in taking part in this research. Some people, though, feel sad when answering questions about taking care of a family member. If you become sad or distressed, we will offer to take a break or to stop asking questions if you wish. If you need additional help, the research assistant will offer to call your home-care nurse or a member of the Regional Palliative Consultation Team (RPCT) to arrange for an assessment of the caregiving situation. We cannot promise any benefits to you for taking part in the research, although we hope that this information will be used to improve palliative care. Some people find that they feel better after telling a researcher what it is like to take care of a family member with cancer.

What happens to the information? All information will be held confidential (or private), except when professional codes of ethics or legislation (or the law) requires reporting. The information you provide will be kept for at least five years after the study is done. The information will be kept in a secure area (i.e. locked filing cabinet). Data must be stored five years after a study is completed, as mandated by the University of Alberta Research Policies and Services Manual, sections 5.2 and 7.5. The questionnaires will only have an identification number on them. Only the consent form will have your name. The questionnaires and the consent forms are kept separate from each other. Nobody will know your identity from the information you give, except the person asking the questions. We expect to give presentations and write reports about the information you give to us. In those presentations and reports, the information will be given for all participants together and no names will be used. The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

Do you want a copy of this information? If you would like to get a copy of the summary of the information, please tell the person who asks you the research questions and we will add your name and address to the mailing list. As soon as the data are analyzed, we will send a copy of the summary to you.

Do you have questions that haven't been answered? You can ask questions about the research any time during the research process. You can call Priscilla Koop or any of the other team members at any time before you answer the questionnaires or afterwards. All of our telephone numbers are listed below.

What if you have concerns or complaints? If you have any concerns or complaints about the research, you should contact Kathy Kovacs-Burns at 492-3769. Kathy is the Research Administration Officer for the Faculty of Nursing. She can answer questions and address any concerns or complaints you might have.

Research Team:
Priscilla M. Koop, Primary Investigator: (780) 492-2962 (Edmonton)
Dennie Hycha, Co-Investigator: (403) 341-2168 (Red Deer, AB)
Marilyn Oishi, Co-Investigator: (780) 712-6845 (Edson, AB)
Jacquie Peden, Co-Investigator: (780) 679-3093 (Camrose, AB)
Vicki Strang, Co-Investigator: (780) 492-6333 (Edmonton)

I have read the ***Information Sheet to Family Caregivers.***

Initials: ____________ **Initials:** ____________ **Date:** ____________
Family caregiver Researcher

APPENDIX E: Consent Form: Home-based family caregiving of persons with advanced cancer and Alzheimer's disease: A description of caregivers and their caregiving situations

Part 1: Researcher Information

Name of Principal Investigator: Priscilla M. Koop, RN, PhD **Affiliation:** Faculty of Nursing, University of Alberta	**Contact Information:** 780-492-2962
Name of Co-Investigator: Dennie Hycha, RN, MN **Affiliation:** David Thompson Health Region	**Contact Information:** 403-341-2168
Name of Co-Investigator: Marilyn Oishi, RN, MN student **Affiliation:** Westview Regional Health Authority	**Contact Information:** 780-712-6845
Name of Co-Investigator: Jacquie Peden, RN, MN **Affiliation:** Program Consultant Palliative Care	**Contact Information:** 780-679-3093
Name of Co-Investigator: Vicki Strang, RN, PhD **Affiliation:** Faculty of Nursing; University of Alberta	**Contact Information:** 780-492-6333

Part 2: Consent of Subject

	Yes	**No**
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		

Part 3: Signatures

This study was explained to me by: ______________________________ Date: ______________

I agree to take part in this study.

______________________________ ______________________________
Signature of Research Participant Printed Name

______________________________ ______________________________
Witness (if available) Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

______________________________ ______________________________
Researcher Printed Name

* A copy of this consent form must be given to the subject.

APPENDIX F:

Health Research Ethics Approval

Health Research Ethics Board

biomedical research
2J2.27 Walter Mackenzie Centre
University of Alberta, Edmonton, Alberta T6G 2R7
p.780.492.9724 f.780.492.7303
ethics@med.ualberta.ca

health research
3-48 Corbett Hall, University of Alberta
Edmonton, Alberta T6G 2G4
p.780.492.0839 f.780.492.1626
ethics@www.rehabmed.ualberta.ca

August 14, 2002

Dr Priscilla M. Koop
Dept of Nursing
3/F Clinical Sciences Building
University of Alberta

Dear Dr Koop,

Re: Home-based family caregiving of persons with advanced cancer: A description of caregivers and their caregiving situations.

Thank you for submitting the above study to the Health Research Ethics Board (B: Health Research). The board members appreciated the opportunity to learn of the research you are planning to conduct and to provide comments. The reviewers were pleased with your study as presented, and felt the study complied with the *University of Alberta Standards for the Protection of Human Research Participants, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, and Health Information Act.*

If applicable, please note that the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Capital Health, Caritas or other local health care institutions for research purposes. Enquiries regarding administrative approval requirements should be directed to the appropriate organization. (For Capital Health contact Shanie Maharaj, 407-6221; for Caritas, contact Diane Robinson, 930-5908).

Please find enclosed your letter of ethical approval for the above study. Please quote file number **B-110802-NSG** in any future correspondence with the ethics board. On behalf of the Health Research Ethics Board (B: Health Research), I wish you every success in your research endeavours.

Sincerely,

Ishrat Bhatti, BSc, MPH
Administrative Assistant
Health Research Ethics Board (B: Health Research)

University of Alberta

Capital Health

CARITAS HEALTH GROUP

Health Research Ethics Board

biomedical research
212.27 Walter Mackenzie Centre
University of Alberta, Edmonton, Alberta T6G 2R7
p.780.492.9724 f.780.492.7303
ethics@med.ualberta.ca

health research
3-48 Corbett Hall, University of Alberta
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UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES,
CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

HEALTH RESEARCH ETHICS APPROVAL

Date: August 2002

Name of Applicant: Dr. Priscilla M. Koop

Organization: University of Alberta

Department: Nursing

Project Title: Home-based family caregiving of persons with advanced cancer: A description of caregivers and their caregiving situations

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form.

The deliberations of the HREB included all elements described in Section 50 of the *Health Information Act*, and found the study to be in compliance with all the applicable requirements of the Act.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

Dr. Sharon Warren
Chair of the Health Research Ethics Board (B: Health Research)

File number: B-110802-NSG

University of Alberta

Capital Health

CARITAS HEALTH GROUP

Health Research Ethics Board

biomedical research
2J2.27 Walter Mackenzie Centre
University of Alberta, Edmonton, Alberta T6G 2R7
p.780.492.9724 f.780.492.7303
ethics@med.ualberta.ca

health research
3-48 Corbett Hall, University of Alberta
Edmonton, Alberta T6G 2C4
p.780.492.0839 f.780.492.1626
ethics@www.rehabmed.ualberta.ca

Notice to All Researchers

In carrying out this project, remember it is your responsibility to:

1) Submit any changes to the protocol / proposal for HREB approval **prior to the implementation** of the changes.
2) Keep signed copies of the consent forms for 5 years and all raw data (i.e.: tape transcriptions) for at least 5 years following the completion of the study.
3) Ensure that the process of obtaining informed consent is carried out in a way that provides complete information to potential research participants and avoids coercion.
4) Monitor the safety of research procedures and equipment. The HREB must be notified about any adverse events.
5) Preserve the confidentiality of research subjects and store records in a secure area.
6) Ensure that information collected and analysed is complete and accurate.
7) Provide written notification to the HREB when the study is complete or terminated.