

THE LIVED EXPERIENCE OF INFORMAL CAREGIVERS
OF THE TERMINALLY ILL
IN SOUTH-CENTRAL RURAL MANITOBA

BY

PEGGY DARLENE MARTENS

A Thesis
Submitted to the Faculty of Graduate Studies
in partial Fulfillment of the Requirements
for the Degree of

MASTER OF NURSING

Faculty of Nursing
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ABSTRACT

In the Central Regional Health Authority of Manitoba there are approximately 190 deaths per year from cancer alone (Manitoba Centre for Health Policy, 2002). Many of these persons choose to be cared for at home in the final days, weeks or months leading up to their death. Little was known about the personal experiences of the informal caregivers of the terminally ill (usually family members) in the community. Even less was known about the effect of living in a rural location on this experience. This qualitative study utilized an ethnographic methodology to gain insight into the experience of being a caregiver in rural southern Manitoba. Purposive sampling was used to obtain a sample of nine informal caregivers of the terminally ill in the Central Regional Health Authority of Manitoba. Semi-structured open-ended interviews were tape-recorded and transcribed providing the data. The theoretical framework guiding this study is the Framework for Understanding the Primary Caregiver Experience (Meyers & Gray, 2001).

The findings fit into two general themes; *The Work of Caregiving* and *Coping and Coming Through the Experience*. The struggles and challenges of the experience, the ways and means the caregivers found to cope, as well as the joys and rewards of the experience are framed within the rural context under these two main themes.

The caregivers' stories add to previous information regarding informal caregivers with the additional perspective arising from living in a rural area. Practical recommendations for health care providers, health institutions, programs and policy makers are presented, as are the implications for education and research.

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CHAPTER ONE

BACKGROUND, STATEMENT OF THE PROBLEM, AND PURPOSE

There are increasing numbers of terminally ill patients choosing to die at home (Health Canada, 1999b; Hileman, Lackey, & Hassenein 1992; Pasacrete & McCorkle, 2000). Formal and informal support systems are necessary in order to achieve this choice. While formal supports such as hospice and palliative programs and home care services can do much toward this end, the bulk of the care often falls on the informal caregivers such as family and friends of the patient. While the caregiving experience provides gratification, these informal caregivers are often overwhelmed with burden and stress S psychological, emotional and physical. Caregivers frequently manifest high levels of chronic stress that predispose them to physical health problems. Informal caregivers often are elderly and enter the caregiving role with health problems of their own (Bass & Bowman, 1990; Jacob, 1996; Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Vachon, 1998). Rural caregivers face additional challenges relating to accessing services as well as social isolation because of the remote location (Buehler & Lee, 1992; Long, 1993; Memmott, 1991). A large amount of literature is available about the needs and experiences of terminally ill patients but much less is available addressing the needs of caregivers of the terminally ill. There are few studies addressing the experiences of caregivers in rural locations, and even fewer in the context of the Canadian health care system.

The Central Regional Health Authority (RHA) Palliative Care Program is closely affiliated with other regional palliative care programs and the Manitoba Hospice and

Palliative Care Association. The Central RHA Palliative Care Program attempts to address needs of the terminally ill and their families. This program has a regional director as well as a medical director and collaborates with provincial and national palliative care associations. No formal study has been undertaken in the Central Region to study these needs.

The purpose of this study was to discover how informal caregivers of the terminally ill in the Central RHA understood the caregiving role as they experienced it. It is important for health care providers and program developers to have insight into this experience to both meet the needs of the caregiver as well as strengthen the family unit and help them cope. An ethnographic approach was utilized, as it was well suited to access the experiences of the rural family caregiver. Ethnography is the study of culture and, for the caregivers in the Central Region, living in a rural location defines their culture. The findings are a representation of the day-to-day experiences of the caregivers during the time they provided care.

Assumptions

The following assumptions were made:

1. Most research has concentrated on the experience of death and dying from the patient's perspective. The experience from the perspective of the family member or friend caregiver has not been explored as fully.
2. Culture has a direct effect on how a person interprets their life experiences and views the world. Living in a rural environment affects how caregivers will ultimately view the caregiving experience.

3. Ethnography can provide a reconstruction of the meanings of a person's experience(s) through the filters of their culture. In this study, the common variable of culture is living in a rural area.

4. I believe that the caregivers in the Central RHA will all have unique experiences and interpretations of their caregiving experience. Each experience, while unique, will offer an aspect of the truth and add to the understanding of the caregiving experience. In other words, the reality of the caregiving experience is made up of many truths. I believe that commonalities will also exist between the stories of the caregivers.

Research Questions

This study was designed to answer the following questions:

1. What was it like to care for a dying family member or friend at home in the Central RHA?
2. What was / were the caregiver (s)' understanding of this experience?
3. What were the positive as well as the negative aspects of the experience?
4. What were the caregivers' perceptions of the resources in their rural communities in relation to providing end of life care at home?

Definition of Key Terms

Definitions obtained from the literature of key words provided a conceptual understanding for this study. Keywords to be defined are: *Informal Caregiver*, *Caregiving*, *Palliative Care*, *Caregiver Burden*, *Rural Community* and *Illness Trajectory*.

Informal caregiver refers to an unpaid person who helped the patient with physical care or coping with the disease process (Hileman et al., 1992).

Caregiving is the act of providing for or attempting to meet the physical, social, mental, psychological, emotional or spiritual needs for another person. Caregiving is comprised of numerous complex tasks. The subjective nature of the caregiving experience encompasses both positive and negative elements (Pasacrete & McCorkle, 2000).

Palliative care has been defined by the Canadian Palliative Care Association as the active care of patients whose disease is not responsive to curative treatment” (Lividiotakis, 2002). Palliative care is usually offered to the patient when the terminal diagnosis is made. In Manitoba, a criterion for access to a formal palliative program is a prognosis of less than six months (J.M. Graham, personal communication, 2002; Winnipeg Regional Health Authority, 2002).

Caregiver burden can best be described as the “emotional and physical demands and responsibilities of one’s illness that are placed on family members, friends, or other individuals involved with the patient outside of the health care system” (Vachon, 1998, p. 54).

Rural community will be used to define all communities in non-urban areas. This included small cities (around 10,000 people), smaller towns, villages, as well as individuals living in rural municipalities. These are the same parameters used by Health Canada to define “rural” (Romanow, 2002).

Illness trajectory is defined as path or course of the physical illness. Corbin and Strauss (1988) have identified that not only is *trajectory* referent to the physical unfolding of the disease but also carries with it the *impact* or consequences on the patient and family caregivers. Corbin and Strauss characterize disease trajectories as having a

“fateful” dimension to them. It is as though the end is determined but neither patient nor doctor knows exactly what this will look like.

Significance

This study provides insight and assists in understanding the experiences of informal family caregivers caring for a dying loved one at home. No research had been done in this area in the Central Region of Manitoba. A wide range of persons could benefit from the findings. Informal caregivers might be able to understand their experience better after hearing other caregivers’ stories. It may be possible to provide anticipatory guidance to families going through this experience and offset negative outcomes. Findings will be significant for members of the health care community. Physicians and nurses can use the study results to direct their approach to families and in the provision of care. This study could impact education, nursing, medical and other related professional groups, by preparing professionals for what to expect when caring for those who care for dying loved ones. This study could impact practice as well. Through dissemination of the findings, health care professionals will be able to respond with more understanding to the families of the dying in the Central Region as well as the patient him/herself. Health care professionals play an important role in the support of patients and their families in hospital, hospice, and community settings. Researchers should find this study significant providing direction for testing of interventions through such agencies as hospice and home care programs. The way services are offered such as routinely offering respite care to all palliative patients and their families is one example of an intervention. Another example could be the establishment of bereavement support groups in local communities and then evaluating the perceived value of such groups. In

addition the results of this study could be compared to previous findings and will add to the pool of information on this aggregate. Findings of this study, when combined with future studies, will be important for health planning to meet the needs of the terminally ill and their families both within the region and other rural regions of Canada. Palliative care, community health and home care programs could all be impacted. This study is unique in that little Canadian research has been done in this area and even less from a rural perspective.

Summary

This study used a qualitative ethnographic approach to understand the experiences of unpaid informal caregivers of terminally ill persons in the Central Regional Health Authority of Manitoba. There was a need for a study such as this as little research has been done in rural Manitoba portraying the experiences of caregivers of the terminally ill. This study will have relevance to health care providers as well as to policy and program developers in the Central Region. No formal study has been done in this regard in the Central Region of Manitoba. Main assumptions have been presented as well as research questions that were used to address the problem. To provide clarity, key terms and concepts were defined.

CHAPTER TWO

REVIEW OF THE LITERATURE

A literature review was done to provide a foundation for this study. "Good research does not exist in a vacuum. For research findings to be useful, they should be an extension of previous knowledge and theory as well as a guide for future research activity" (Polit & Hungler, 1995, p. 32). The literature review assisted in identifying aspects of the caregiving experience as well as areas where more research was needed. Manual as well as computer-generated literature searches (CINHAL, MEDLINE) were conducted. Databases from Health Canada, Statistics Canada, as well as the Central RHA and the Manitoba Centre for Health Policy and Evaluation were accessed. Books, periodicals, smaller publications from agencies, as well as information from web sites of government and health agencies were all used. In addition some information was obtained through personal interviews with key informants from specific agencies. Those approached were from the Central Region Palliative Care and the Winnipeg Regional Health Authority (WRHA) Palliative Care sub-program. The director and several palliative care coordinators from local palliative care programs from the Central RHA were contacted to gain an understanding of what services were offered and what challenges rural palliative care programs face. Two clinical nurse specialists and three palliative care nurses from the WRHA were interviewed to gain a perspective on palliative care in Manitoba generally and to gain a broader perspective on the needs of caregivers.

The literature review provides a profile of the caregiver. Facets of the caregiving experience detailed in the literature will be presented. In order to understand the uniqueness of dealing with a rural population, this review includes aspects of rural health and rural communities. The literature review will conclude with an overview of the Central Regional Health Authority. A brief summary will then point out the gaps in the literature.

Profile of the Caregiver

A synthesis of the literature provides a profile of the caregiver. This group consists of the informal unpaid caregivers of the terminally ill. Between 60 and 80 percent of caregivers are female (Hileman & Lackey, 1990; Meyers & Gray, 2001; Weitzner & McMillan, 1999). The average age of caregivers is 59 to 65 years (Meyers & Grey, 2001; Stajduhar, 2003; Steele & Fitch, 1996; Weitzner & McMillan, 1999). Sixty percent are retired. Informal caregivers are usually a spouse or a daughter. This is significant in that the majority of caregivers are either elderly females or daughters who may find themselves in the "sandwich generation" juggling family and work responsibilities as well as caregiving (Davis, Cowley, & Ryland, 1996; Meyers & Gray, 2001). Usually one person is primarily responsible for direct care and coordination of care even though multiple members of a household may provide care (Given, 1995). In terms of the relationship between the caregiver and the patient, wives are the most common caregivers followed by daughters. Husbands of the patient are the next most prevalent group of caregivers followed by sons or mothers of the patient. Non-family caregivers are not common (Weitzner & McMillan, 1999).

To understand the aggregate of caregivers it is also necessary to portray the patients or the terminally ill receiving care. The literature reviewed primarily referred to persons dying from cancer but did also include illnesses of Multiple Sclerosis, Alzheimer's, and Acquired Immune Deficiency Syndrome (AIDS). Those most likely to die at home have cancer or AIDS (Christakis & Esarce, 1996; Vachon, 1998). Age ranges of those dying at home are conflicting. Gilbar and Steiner (1996) found younger persons were more likely to die at home, while Rhymes (1991) found that those over the age of 65 were more likely to die at home. These studies did not differentiate the type of terminal illness such as AIDS or cancer. This author suggests that the type of illness the person has and the particular illness trajectory may account for discrepancies in ages of those dying at home. Persons with Alzheimer's tend to be seniors, while those with AIDS tend to be in the young adult to middle age range.

Studies that looked at the socio-economic status of palliative patients and their families found by and large that those choosing to die at home were of higher socio-economic class or had more financial resources (Gilbar & Steiner, 1996; Seale, Addington-Hall, & McCarthy, 1997; Vachon, 1998). These study results were produced in the United States and Great Britain. At the time of the literature search, Canadian results on socio-economic status were not available. The extent to which these results can be applied in the Canadian setting may be somewhat limited. The American private-market health care system would create more financial hardship for families than the National Health Service (NHS) of Great Britain and certainly more hardship than the Canadian publicly funded system.

Another factor affecting whether terminal patients will die at home is whether they have accepted the fact that they are going to die (Vachon, 1998). Several studies from Great Britain showed that acceptance of death both by the patient and the family / caregiver was seen to increase the likelihood of dying at home (Gilbar & Steiner, 1996; Hinton 1994; Seale et al., 1997). Patients as well as their caregivers were studied. The Gilbar and Steiner (1966) and Seale et al. (1997) studies were conducted in health districts with hospice services and the Hinton (1994) study was conducted on persons with terminal illnesses using home care services. Acceptance of death was seen as a prerequisite for a planned home death especially where resources needed to be mobilized to accommodate this (Hinton). *Hospice* has been defined as an institution that provides palliative and supportive interdisciplinary services to dying persons and their families who are at home or in specialized in-patient settings (Dirckx, 1997). In the Central Region, hospice refers to the palliative care services provided in the local hospitals and at-home support provided through the local regional palliative care programs.

Those persons who live alone, do not have a primary caregiver or have a caregiver in poor health are less likely to die at home (Cleary & Carbonne, 1997; Hinton, 1994; Livadiotakis, 2002; Vachon, 1998). Those with brain or prostate cancer are less likely to die at home as are those where the burden of care is heavy or prolonged (Gilbar & Steiner, 1996; Vachon, 1998). Patients with chronic diseases such as COPD (chronic obstructive pulmonary disease) and congestive heart failure are less likely to die at home (Lynn & Wilkinson, 1998). Several American studies found that persons of colour were less likely to die at home (Cleary & Carbonne, 1997; Miller & Mike, 1995). No Canadian studies were found on race or ethnicity and death at home. However in conversation with

palliative care coordinators in the WRHA, they echoed a similar observation. Few Aboriginals or persons living alone received palliative home care services (M. Brownlee & M. Ternowski, personal conversation, October, 2001). The Manitoba Centre for Health Policy and Research (Martens et al., 2002) completed a study on the health of Aboriginals, both on and off reserve, which sheds some light on hospice care in the Aboriginal population. Although statistics on deaths at home are not provided, information can be extrapolated that provides some guidance. Cancer related deaths are somewhat lower in the Aboriginal population than the general population. However circulatory diseases do account for the majority of deaths. Included in this would be circulatory conditions related to diabetes. HIV and AIDS are emerging as causes for concern as well. The literature shows that patients with conditions requiring complicated care (such as diabetes and its devastating consequences) are seldom able to die at home. Also the home environment needs to be adequately equipped to support the needs of the patient. This study by Martens et al. (2002) shows that great numbers of Aboriginals live in sub-standard housing. It might be assumed that many Aboriginals would not be able to provide home hospice care. Liviadiotakis (2002) notes that, in Canada, palliative home care services are being challenged with increasing numbers of persons requesting care be delivered in their single room hotels where no telephone or bathroom is present or those who do not have a home to go to. An article by Kinsella, Cooper, Picton, and Murtagh (2000) reviewing American caregivers of palliative patients concludes that cultural minorities were more likely to report lower levels of caregiver stress and are more likely to use religion as a coping strategy. They conclude that it is important for health care

providers to be knowledgeable about cultural practices and beliefs of patients and their families.

Palliative is defined in the literature according to life expectancy. The length of time in palliative care can range from one day to several years with an average of 36 days (Vachon, 1998). The WRHA uses a life expectancy of six months or less as a criterion for admission to the program (Winnipeg Regional Health Authority, 2002). The Central RHA has just begun tracking data of the clients in their program. Admission criteria relating to life expectancy is not as strict as in the WRHA. Central Region had 297 palliative clients in their program from April 1, 2003 to March 31, 2004 with 242 patients being cared for in hospital and 55 receiving at-home care. A Canadian study by Livadiotakis (2002) reveals that 80 to 90% of the terminally ill in Canada are dying in hospitals or other institutions. However she goes on to note that in a recent Angus Reid Report, 84% of all Canadians surveyed indicated a preference to spend their final days at home with the available Home Care services. In Manitoba, a Palliative Care Program Coordinator voiced concerns that undetermined numbers of palliative patients are being missed and not receiving the benefits of palliative care. A possible reason for this is that there are inconsistencies in declaring when a patient is palliative (J.M. Graham, personal communication, March, 2002). In addition, the illness trajectory of some patients is very uncertain with referrals to the palliative care programs as late as several hours or days of death. Another reason is the public as well as some health care providers may not be aware of the services that are offered by the palliative care program (J.M. Graham, personal communication, April, 2002). Patients do receive palliative care however even

though not connected to formal programs from local physicians, nurses and family members.

Needs of the Caregiver

Caregiving is a multidimensional and complex concept. It has been described as a task, a transition, a role and a process (Swanson, Jenson, Specht, Johnson, & Maas, 1997). Taking on the role of caregiver may require the spouse caregiver to take on the vacated role of the patient (Buehler & Lee, 1992). Often other roles such as parent and grandparent are set-aside with provider of nursing care becoming the major role (Buehler & Lee). Caregiving requires knowledge and skills. There are skills required to manage the patient's care such as managing pain and symptoms and meeting the patient's nutritional needs. There is a need to be able to problem-solve, make decisions, and manage time. Social skills are important to be able to communicate with health care providers and to mobilize resources (Given, 1995, 1997; Jensen & Given, 1991).

Generally as the health status of the patient declines the needs of the caregiver increase (Hileman et al., 1992; Hinds, 1985; Weitzner, Jacobson, Wagner, Friedland, & Cox, 1999).

Caregiver burden was the term found in numerous articles to describe the strain experienced by caregivers. Caregiver burden takes into account the stress created by direct patient care tasks, the amount of support from the family, disruption of personal routines and schedules, and the sense of overload in role expectations (Given, 1995). The literature shows the development and utilization of instruments to measure caregiver burden. Some of the more utilized instruments measuring these variables are: Needs Assessment Interview (Decker & Young, 1991), Caregiver Strain Index (Meyers & Gray,

2001), Caregiver Load Scale (Oberst, Thomas, Gass, & Ward, 1989), Home Caregiver Need Survey (Harrington, Lackey, & Gates, 1996; Hileman et al., 1992; Steele & Fitch, 1996), and Caregiver Burden Inventory (Emlet, 1996).

The literature shows that the interpersonal relationships with the dying persons often create psycho-social needs which can be the greatest and most perplexing needs (Nolan, Grant, & Ellis, 1990; Pasacrete & McCorkle, 2000; Vachon, 1998). The caregiver is attempting to provide physical and emotional support to the dying person while dealing with his/her feelings of loss. There are affective psychological needs relating to a loss of emotional closeness to the dying person and loss of a social companion and confidante (Hinds, 1985). There is a loss of privacy from numerous direct service workers entering the home (Schachter, 1992). Uncertainty caused by the trajectory of the illness causes psychological distress as does watching the suffering of the patient (Hinds, 1985; Weitzner & McMillan, 1999). One research article pointed to symptom control as an important therapeutic strategy for both patients and caregivers (Given, 1995).

There is the need for time for self, time to manage the tasks of caregiving, time for others, and time to be with the dying loved one (Brown & Stetz, 1999; Hull, 1992). The time required for caring for their loved one leaves little time to connect with their community. The lack of time for self-care places caregivers at increased risk for poor health (Jepson et al., 1999; Nugent, 1988; Vachon, 1998). Stress and fatigue "predispose caregivers to physical health problems, emotional distress and feelings of burden, isolation and frustration" (Oberst et al., 1989, p. 210). This risk may be even more magnified with rural caregivers, as they tend to be more self-reliant and seek professional

help as a last resort at the best of times than their urban counterparts. Long and Weinert (1989) identified the concept of self-reliance of rural residents, as one of six concepts, based on a decade of research in rural areas (primarily Montana).

The incredible exhaustion experienced by caregivers creates a real need for respite (Bramwell, Mackenzie, Laschinger, & Cameron, 1995). The literature identifies the availability of a palliative or respite bed in a facility as one of the strongest predictors of whether palliative patients are able to be cared for at home until death (Vachon, 1998). While palliative care programs exist, caregivers feel they cannot leave the bedside of the dying person (M. Brownlee & M. Ternowski, WRHA palliative care nurses, personal conversation, October, 2001). In rural regions they may also have to travel to the next town or community for services, which would add to the time away (Conley & Burman, 1997). Time spent caregiving has an impact on the employment of the caregiver necessitating adaptations and changes. Given (1995) reports that caregivers may find they leave work early, arrive late, miss work without pay, take personal or sick days, or alter work hours. In addition caregivers employed outside the home report decreased productivity at work.

One Canadian article (Health Canada, 1999b) presents a typical scenario of the work and the burden of the informal caregiver in a rural area.

Faced with the responsibility of caring for a terminally ill family member in addition to the demanding work of running a farm, what do most families do? They work harder. They can't neglect the farm work, and they can't neglect the patient. This can lead to stress, exhaustion, burnout and physical illness in the caregivers. (p. 4)

Caregivers are at risk for psychological morbidity and are in need of professional support and intervention. (Hull, 1992, Jepson et al., 1999; Pasacreta & McCorkle, 2000).

Caregivers may not access palliative services such as respite care or home care in their region. They may be unaware of the services, the services may not be conveniently accessible or there may not be coverage 24 hours a day. This corroborates information shared by the regional director of palliative care in the Central region (J.M. Graham, personal conversation, March, 2002). There is a need for visiting palliative care nurses or a clinical team as well as an emergency response team.

The amount of stress perceived by caregivers may relate to their ability to cope with stress in general. A study by Bass and Bowman (1990) links "inherent traits of hardiness and optimism" in the caregiver as predictors of ability to cope with the situation. They define hardiness as "feelings of mastery or control over life, a strong commitment to self, high self esteem, and a positive attitude toward changes and challenges" (p. 36).

The needs relating to direct patient care include a need for information, the need to know what to expect and what resources are available and how to access them (Conley & Burman, 1997; Harrington et al., 1996; Swanson et al., 1997; Vachon, 1998). In addition to the need for skills to manage the physical aspects of the care, which can increase as the patient deteriorates, there is a need for speedy professional support such as a 24-hour emergency team to attend to crises.

Another general category of needs could be described as needs relating to instrumental tasks. These include managing and maintaining a household, organizing the care such as appointments and arranging transportation. A study by Silveira and Winstead-Fry (1997) examining the needs of 30 terminal cancer patients and 30 caregivers in rural settings showed that nurses in the community often underestimate

these practical and household needs. This study utilized instruments measuring patient needs and caregiver needs and asked the respondents to rate the importance of these needs on a scale of 1 to 10.

Lower socio-economic status has been linked to increased needs and burden for caregivers. In one study of 47 family caregivers, low socio-economic status was linked to fewer years of education and increased caregiver burden (Kinsella et al., 2000). Kinsella et al. conclude that “people with a lower SES (socio-economic status) may be less likely to be aware and take advantage of available support services that might help lighten caregiving demands” (p. 48).

Positive Aspects of the Caregiving Experience

Although most of the literature focuses on the needs created by the caregiving experience some literature and research reflects snippets of positive aspects of the caregiving experience. An exploratory descriptive study of 14 informal family caregivers was done to elicit information about the caregiver’s understanding of the illness trajectory (Holing, 1986). Interviews were conducted with 14 participants, twelve months following the death of the patient. Positive aspects were reflected in statements such as “the joy of togetherness” (caregiver and the patient in the final days), “we came to a beautiful understanding”, “It was a party – her party – a swan song” (referring to a family Thanksgiving) (p. 34). In addition caregivers identified the satisfaction of caring for their loved one. “I knew how he liked things done – I could do it best”. “Being at home meant everything to him” (p. 35). In Holing’s study, 22% of caregivers actually described the time of death as positive – “as a relief for the end” and “a time of quiet peacefulness and acceptance”. This study is of value as it revealed that even illnesses with uncertain or

difficult trajectories could offer rewarding and joyful events. Hunt (2003) conducted a meta-analysis on the literature available on the effects of the caregiving experience on family caregivers. She validated the notion that even burdensome or stressful activities can be associated with feelings of satisfaction for the caregivers.

In addition, nurses and other health care providers can play a pivotal role in helping family caregivers see positively what they have been able to do and assuage feelings of guilt for what they have not been able to do (Holing, 1986).

Schott-Bauer (1993) in a study of 113 spouse caregivers found that elderly caregivers experienced less caregiver burden (and possibly experienced more positive events) than younger caregivers. She attributes this more positive outcome on the flexibility that retirees build into their lives allowing caregivers to reschedule the rest of their lives around care.

A positive side effect of the caregiving experience revealed in several studies was the caregivers' perceptions that they themselves had become stronger people. They had gained strength, knowledge and unexpected competencies they did not know they were capable of from the experience (Brown & Stetz 1999; Stajduhar, 2003).

Rural Versus Urban Communities

In the past decade literature has emerged presenting differences that exist between rural and urban populations in values, culture and ultimately approaches to program development. There is no universally accepted definition of rural. Instead rural is best defined on a continuum from living in a small city to living out in the isolated frontier (Bigbee, 1993a).

Rural populations tend to define their health based on a functional model versus a clinical model. Ability (or inability) to function defines health or illness as opposed to a medical diagnosis of illness or wellness. Researchers of rural populations have described this as a health definition based on their ability to work as opposed to the absence of disease (Long, 1993; Wainwright, 2000). There is less importance placed on comfort, cosmetic, or life-prolonging aspects of health. Work needs rank above health needs and illness is viewed as the interference with the ability to work (Bigbee, 1993a; Bushy, 1991; Weinert & Long, 1991). In addition, rural communities do not view emotional health as part of overall health and well being (Bushy, 1991). A study of rural caregivers by Conley and Burman (1997) showed that rural families are less likely to utilize home care services than their urban counterparts. They used a qualitative approach and interviewed 14 families in rural Wyoming looking for informational needs of home caregivers and how those needs were being met. Conley and Burman account for the results that less home care services are used because information about existing programs and services is not as available to caregivers in rural areas not because there are fewer services.

Local organizations can be trusted and programs run solely by outsiders are held under suspicion (Bushy, 1991; Weinert & Long, 1987). Health Canada (1999b) mentions that although rural palliative care resources are scarcer, it is more common for other community agencies and service clubs to get involved as needed. Volunteerism is high in rural communities and can be a good resource to augment any program. Volunteers also ensure the grassroots participation and ownership in a program.

It takes about 10 years to become an insider or trusted in a rural community (Bushy, 1991). Lines of communication in rural areas are less formal. For example women's community groups and coffee shops are the best places to get information. Conley and Burman's study (1997) showed that rural caregivers were more likely to use informal communication or the "underground" to seek out information and satisfy their informational needs.

Rural communities tend to be morally and politically conservative (Bigbee, 1993a). Families are larger and reflect the more traditional nuclear family structure. The gender roles are traditional and women are viewed as primary caregivers. Bigbee beautifully describes the role of women as caregivers in rural communities. "A tradition of self-care within the family is present with older women typically serving as carriers of the collective healing experience" (p. 133). Women's groups play prominently in the social scene in rural communities acting in volunteer support and fund raising capacities as well as support by women for women (Bushy, 1991). Male caregivers, therefore, can be at greater risk for burnout as they are not afforded the same support offered to women. (Weinert & Burnam, 1994).

Living in a rural community has been described as "living in a fishbowl" (Wainwright, 2000). The informal lines of communication as well as the social relatedness of the community contribute to lack of anonymity. Interactions are based on long-term complex relationships with family and friends although there are fewer social networks. Family activities are central to rural communities. These communities have a high degree of perceived social support in comparison to urban communities.

Geographical distance creates isolation that impacts the availability and accessibility of services. In combination with the knowledge that many caregivers are elderly females who perhaps no longer drive, creative and innovative planning is necessary to deliver programs and services. Isolation and distance impact communication, transportation, economics and formal and informal service delivery. Rural populations however are accustomed to traveling distances to obtain or receive goods and services. McRae, Caty, Nelder, and Picard (2000) in a study of 13 family caregivers in remote rural Ontario found that accessing services especially from tertiary centres proved challenging. Participants in this study experienced a high degree satisfaction with care delivered at the local level however.

Traits of self-reliance, independence and hardiness in rural populations can result in delays for treatment. Professional resources will be used when self-resources fail. Cancer rates are the same but the cancers are detected at more advanced stages than in urban populations (Bushy, 1991; Weinert & Burman, 1994). The author was not able to verify this data with data from the Central region, as data was only available on incidence and mortality from cancer. No data was available on stage of disease. In addition to independence and self-reliance creating delays for treatment, Wainwright (2000) also argues that as health is viewed as the ability to work, rural residents tend to wait longer to seek treatment if seeing a doctor will interfere with their ability to be at work. In addition people in rural communities often need to travel distances to get to the doctor. This acts as a hindrance in seeking prompt medical attention and diagnosis.

In rural populations and small communities it is important to remember that small numbers attending does not mean small numbers are benefiting. Informal social networks

predominate and benefits will ripple through the community from those attending (Long, 1993).

Nurses are viewed as knowledge brokers in the community and are expected to go beyond normal expectations for a nurse (Bushy, 1991). Nurses are seen as always on duty in rural communities and are called upon for advice and assistance by acquaintances.

The Central Regional Health Authority – Manitoba

The Central RHA is located in the south central region of Manitoba. Its boundaries are the Red River on the east, Winnipeg to the northeast, Lake Manitoba and Gladstone in the north, as far west as St Claude and Crystal City, and south to the American border. This covers an area of 17,443 square kilometres. This region is primarily a prairie ecozone with agriculture and agricultural support services sustaining the economy.

The population of the Central RHA is around 100,000 people thereby making it the largest health authority in the province next to the WRHA. Fifty-one percent of the population lives in villages, towns or small cities. The remaining 49% live in rural municipalities. There are 37 incorporated communities (which include Hutterite colonies) and 6 First Nation communities. There is diversity of culture and ethnicity in the region. German and Dutch ethnic groups, many claiming Mennonite roots, make up the largest portion followed by French, British, Aboriginal and others. One-half of all persons over the age of 15 are legally married and not separated. There is a low rate of single parent families in comparison to the rest of the province. This might be accounted for by the strong traditional and religious values held by this rural community. Income levels in the Central region are lower than the rest of the province but the region boasts low

unemployment rates. High numbers of the population are employed in agriculture or related industries and services (RHA Central Manitoba, 1998).

The people of the Central Region see their region as diverse and thriving, with warmth, small-town friendliness, and rich traditions (RHA Central Manitoba, 1998). There is a large well-developed volunteer base and there has always been strong community leadership and participation. The community believes there are many health resources with competent caring health care providers to meet their needs. The Manitoba Centre for Health Policy and Evaluation (2002) ranks the Central RHA as the fourth highest region for overall health. The centre uses premature death rates as the best indicator of overall health because they are also the best predictors of illness.

Challenges in the Central RHA include many that are prevalent in the rest of the province such as severe climate creating difficulty with transportation in the winter. Physician recruitment, death rates in first nation communities, substance abuse, teen pregnancies, and farm safety and farm chemical use are all echoed throughout many of the rural communities in the province. Unique challenges include the risk of flooding from the Red River, environmental concerns, as well as air and water pollution from aerial spraying (RHA Central Manitoba, 1998). There is a fear of loss of health care facilities and loss of health care employees from the region. The population distribution makes health care challenging. There are not enough resources, financial and human, to run comprehensive programs in rural communities. Transportation is also an issue. Rural populations must often travel great distances to receive services. The Manitoba Centre for Health Policy and Evaluation (2002) did a study involving rural regional health authorities to see where people travel to receive specialized services. In the Central

region, about 75% of specialized health care services were provided in Winnipeg with the remainder provided in the Central region or in neighbouring regions. As many of the terminally ill are cancer patients, in the past they have often needed to travel to Winnipeg to see specialists such as oncologists or for palliative treatments such as radiation. There now are however two community cancer programs located in the Boundary Trails Hospital and the Portage District Hospital where increasing numbers of patients are being seen.

Gaps in the Literature and Limitations

The literature review does present a good profile of the caregiver. The majority of caregivers are elderly females usually caring for a spouse. Quantitative studies have begun to measure variables such as caregiver burden and stress yet little has been documented on the experiences and stories of the caregiver. Since the early 1990's there has been literature emerging on the concept of rural health. The literature search revealed that there were only a handful of contributing authors to the concept of rural health. These authors were all from the states of North Dakota, Montana, and Wyoming. Due to the limited geographic regions studied by the rural health authors (all non-Canadian) and the few numbers of authors, this was perceived as a gap in the literature. The effect of living in a rural location on the caregiving experience as well as characteristics of persons living in rural areas could not be presumed to be valid when approaching this study for these reasons. In Canada there is a paucity of literature documenting studies on rural health with palliative patients and their families in the context of the Canadian health care system. This study has been an attempt to address these gaps.

Summary

The literature review provided a profile of informal caregivers of terminally ill patients as well as the patients themselves. They are most often family members, usually the spouse or the daughter of the patient. Most often the caregivers are elderly women. Persons choosing to die at home usually are in a mid to upper socio-economic class without serious financial concerns. The most common causes of death of those who die at home are cancer and AIDS. Patients with certain diseases such as brain or prostate cancer or where the care becomes complicated usually return to the hospital to die. It has been noted in the US that persons of colour are less likely to die at home. In Manitoba a similar observation has been made with the Aboriginal population although scientific studies are yet to be done.

The needs of the caregiver are complex. The caregiver often is required to take on the role previously occupied by the patient. Intellectually the caregiver has needs to handle the complex care of the patient as well as attend to other household matters. The caregiver is often attempting to provide emotional support to the dying person while at the same time deal with his/her own feelings of impending loss. Lack of time was a common identified need. This was not only lack of time to care for the dying person and attend to other household chores but to have time for self-care. Fatigue is a common complaint of caregivers. Caregivers are at increased risks for physical illnesses.

There are some positive aspects of the caregiving experience. Caregivers report they became stronger as persons, acquiring skills and knowledge. There was joy in being together as a family and with the dying person and there was satisfaction in being able to provide the care and support to the patient.

The review of the literature presents a portrait of rural cultures. Persons in rural communities tend to gauge “health” by their ability to work. Rural populations tend to be more self-reliant and hardier. Resources are scarcer in rural areas however community and service clubs can fill in the gaps. Gender roles are traditional where women are viewed as primary caregivers. There is a lack of anonymity in rural communities and lines of communication tend to be informal. There were limitations however to the portrayal of rural cultures and caution was used not to extrapolate these findings to the research participants.

Finally, a description of the Central Region Health Authority was presented. The region is primarily agricultural. If not directly involved in agriculture, many of the jobs in the region support this agricultural base. The Central Region is seen as having rich resources. One of these resources is seen to be the health care system. Challenges in the region relate to geographical distances between services and transportation.

CHAPTER THREE

CONCEPTUAL FRAMEWORK

The conceptual framework chosen to inform this study is the Framework for Understanding the Primary Caregiver Experience (Meyers & Gray, 2001). This conceptual framework concisely summarizes and organizes the accumulated knowledge from the literature about the caregiving experience into an orderly scheme (Appendix A). Characteristics of the caregiver are listed as the *background* or *context*. Aspects of the caregiving experience, echoed in the literature, such as fatigue, lack of time for self, lack of privacy and changes in roles are presented in this framework as *stressors*.

Meyers and Gray (2001) further extend the purpose of this framework beyond description of the phenomena of caregiving. Their framework provides a basis for the prediction of the occurrence of the phenomena as well as outcomes. This framework, however, was not used in this study to predict outcomes in the caregivers who were interviewed, but rather as a guide for the discussion of the findings. This study was not bound by the framework but rather the data itself was allowed to direct the researcher in an open-minded exploratory fashion. The voices of the caregivers provided the most accurate reflection of the experience.

Although not directly stated, it is evident that this framework is based upon a holistic view of the person. Many variables affect the outcome of the caregiving experience. Physical, psychological, emotional, mental, and spiritual aspects are considered. This framework fits well with a health promotion and population health approach as has been adopted by Health Canada. There is evidence of consideration of

the factors that enable people to be healthy or, conversely, hinder wellness. In Canada, these have been listed as the Determinants of Health and include such items as gender, education, income, social support networks and culture (Health Canada, 1999a). For this reason, although this conceptual framework was not developed in a Canadian context, it is a good fit for use in a Canadian study.

Several other frameworks were considered but not selected. Stetz (1989) presents a framework for understanding the perceived health of caregivers. She uses five background characteristics and demographics that are known to be predictors of caregiver burden or strain and relates them to the caregiver's overall health. While this could be a useful tool in some settings, this research project is investigating the overall caregiving experience not only the caregiver's health or outcome of the experience. The researcher is not entering the process with a preconceived idea that the whole experience is a negative one with the background of the caregiver contributing to that experience. Rather it is hoped that what will emerge is a true representation of the caregiving experience with both positive and negative aspects.

A second framework by Given (1995) was considered. Her model is directed at improving outcomes in cancer care. She considers the background characteristics of the caregivers, the nature of the cancer, the formal and informal supports as well as the needs of the family. The outcomes she identifies are social, psychological, and functional both for the patient and the caregiver. While some of the concepts of the caregiving experience as presented in the literature were expressed, the researcher considered this model inappropriate as it is directed at interventions to improve care. This research is an

exploratory study to gain understanding into an experience in a particular rural context and it is too premature to look at interventions.

A final model, which was considered, was the Newman systems model (Beckman et al., 2000). This model might be valuable and applicable in future research as it can be applied to an individual situation or a whole community, i.e., all caregivers in the Central Region. This model looks at stressors in the individual's (caregiver's) life and seeks out the most appropriate intervention level – primary, secondary, or tertiary. Again, the Neuman Systems model is directed at improving interventions. This study is a preliminary exploratory study looking at the experiences of caregiving. Subsequent study in this area may find any one of the above three models appropriate however.

Summary

The Framework for Understanding the Primary Caregiver Experience (Meyers & Gray, 2001) was selected to organize the accumulated knowledge from the literature about the caregivers, the patients and the caregiving experience. The framework was not selected for its ability to predict outcomes and was not be used to do so in this study. Rather the framework was used to guide the discussion of the findings.

CHAPTER FOUR

THE RESEARCH DESIGN

This chapter presents the research design as well as the methodology for the study. Ethical considerations are presented, as are the processes of recruitment, interviewing, managing the data and data analysis. In addition attention to the processes to ensure confirmation of the findings or rigor in the research are included.

Design

Ethnography

This study was designed to examine and describe the experience of providing care for a dying person in the home from the perspective of a family care provider. It was designed to provide insight into the lived experience of the informal unpaid caregiver. A qualitative approach was the best fit for this study as it can capture the breadth, complexity, and elusiveness of human responses to health and illness. Qualitative methods are well suited for documenting and analyzing these responses and are flexible enough to accommodate this complexity. An ethnographic research design was used. This qualitative approach has a philosophy where multiple “truths” rather than one constructed reality can exist to include the complexity and uniqueness of each individual’s experience.

According to Steeves and Kahn (1995), people interpret their life experiences through the filters of their culture. Ethnography demands that the researcher become immersed in the culture of the subjects and prolonged observation of the group is necessary. Culture, in this reference, implies more than ethnicity. Culture is not an

individual trait but is a group of patterns and beliefs that are shared by a particular community over a period of time (LeCompte & Schensul, 1999). The product of ethnographic research is the “interpretive story, reconstruction, or narrative about a group of people (a community). It includes some historical material and paints a picture of people going about their daily lives as it happened over a relatively representative period of time” (p. 4). According to Sandelowski (1991), the narratives or stories of the participants will be their understanding or representation of life at a period in time or a given moment rather than the life itself.

Historically ethnography involved intense immersion with a group of people over an extended period of time, often years. Today briefer periods of engagement are seen with a more narrow focus or “lens” through which the community is being viewed. Streubert and Carpenter (1999) refer to this shorter more focused study as “mini-ethnography”. This study looked at an aggregate in the Central Regional Health Authority who shared a similar experience. They have all cared for a dying family member or friend in a home setting. Only this one experience in their lives over a specific period of time was focused upon as opposed to all their culture and experiences.

Other methods employing a qualitative approach to research such as phenomenology can explore the meaning of the lived experience. In this study however, ethnography was chosen over phenomenology, as it was able to speak to the research question more comprehensively. Crotty (1998) addresses the conundrum of choosing a methodology in a very pragmatic way. Researchers are to decide what it is they want to know and then pick the best method to answer that question. The question being asked is “What was it like to be a caregiver in a rural location?” The literature review presents

persons living in a rural area as persons with rural cultural traits. The caregivers in the Central Regional Health Authority share a culture - the *culture of rurality*. Ethnography seeks to understand the meanings and perceptions of the participants against the backdrop of their culture or worldview (Crotty). This study sought to understand the meaning of the caregiving experience in the context of the rural culture. Ethnography then can situate the individual's experience within the broader context.

Ethnographic research has some additional characteristics or principles. This type of research needs to be conducted in a naturalistic setting. It requires the building of trust or rapport between the participant / community and the researcher. Building trust requires "levelling the playing field" or creating a reciprocal equal relationship between the researcher and participant. Ethnography has a commitment to accurately reflect the views and perspectives of the participants. The researcher and the participant together create the "data". Through exploring areas together, and seeking clarification and validation of the data, a picture of the experience is created. Attempts were made to consider these data collection principles and will be addressed.

This research involved semi-structured interviews with open-ended questions with the caregiver in the home of the caregiver or a location of their choice. The interviews were tape-recorded and transcribed to written text by an experienced transcriptionist.

The researcher was open to including other forms of expression other than verbal narrative portraying the experience such as art forms.

Narratives assume many forms. They are heard, seen, and read; they are told, performed, painted, sculpted and written.... Narration captures a narrator's interpretation of a link among the elements of the past, present and future in a liminal place and fleeting moment in time. (Sandelowski, 1991, p. 162)

One poem was presented during the interviews but it was not used for analysis. The reasons were that it was not written by the participant and was about the deceased and not the caregiving experience itself. No other art forms were identified.

The Research Plan / Methodology

The Sample

The sample was purposefully recruited by the palliative care coordinators from the region. Purposive or judgemental sampling implies that in this study the subjects are selected on the basis of some predetermined criteria (Polit & Hungler, 1995). The criteria in this study was the knowledge and experience of being a caregiver for a friend or family member in the home setting.

The sample consisted of nine persons who had acted as the primary caregiver for a dying person in the Central RHA of Manitoba. The regional director of palliative care provided the researcher with the names of eight palliative care coordinators in the region who might have participants that would meet the criteria. From those eight recruiters, nine persons met the criteria and were agreeable to an interview. No caregivers approached by coordinators declined and all persons recruited were interviewed. All caregivers either resided in a rural region of the Central Region during the caregiving experience or returned to this region to care for the dying family member. The criteria in this study were based on their knowledge and experience of being a caregiver for a friend or family member in the home setting. This meant they must have provided care in a home setting for a dying friend or family member in the days, weeks, or months preceding death. It was not imperative that the patient actually died in the home. Therefore even if the last days were spent in hospital, these caregivers were included in

the study. The interviews focused on what transpired in the home setting as opposed to the experience of being with a dying person in the hospital. This was handled by directing questions in the interview back to the time at home.

Another criterion for inclusion in the interview was that at least six months had to have passed since the patient died. This was done as an ethical consideration to protect the participants, as they are a vulnerable population. All participants were interviewed following the death of the patient. Interviewing was not done during the actual experience, as a prominent stress for caregivers is a lack of time. Interviews would have taken time away from the bedside of the loved one or robbed the caregivers of their own respite and rest. The caregivers were also considered vulnerable, as they are grieving. There was variability in the literature as to the length of time of the acute grieving period (Cowles & Rogers, 1991; Gass & Chang, 1989; Jacob, 1996; Martocchio, 1985). Bereavement varies from individual to individual. The perception of the bereavement event is dynamic and changes with the passing of time (Bass & Bowman, 1990). There was some agreement in the literature, however that the early period (up until approximately four months) is the most emotionally distressing (Demi & Miles, 1986; Jacob, 1996). The bereaved are physically and emotionally exhausted from providing care and may have neglected self-care. If the bereaved is a spouse, they are just "beginning to reorganize their lives, confronting their own mortality and have a desire to plan for the future" (Jacob, 1996, p. 284). According to Jacob, in the period following six months (7 to 16 months), loneliness and wanting to remember the deceased predominate. "More time was being spent on caring for themselves, seeing physicians, exercising, eating nutritiously, and getting proper rest" (p. 284). Therefore in order not to interview

participants during the most vulnerable period, the participants were not interviewed sooner than six months following the death. The time intervals ranged from 7 to 24 months. In addition the palliative care coordinators selected individuals who they judged would be emotionally ready to discuss their experiences. All the palliative care coordinators in the region have training in bereavement. Understanding grief and bereavement assisted them in selecting participants who would be past the acute phase of grieving and might be ready to discuss their experiences.

Other selection criteria included: the caregivers must be at least 18 years of age, able to speak, read and write English, be willing to discuss their caregiving experiences and be available for a one to two hour interview.

The nine participants provide a good geographical representation from locations spanning the Central RHA. This was seen to be important, as the rural nature of the experience was being explored in the context of the Central RHA.

Thematic Saturation

The plan was to interview until saturation of the data became apparent. It was anticipated that approximately eight interviews would be done. *Saturation* of data implies that new data that is being collected though interviews fits into the categories or themes already devised and no new information from the interviews is forthcoming (Denzin & Lincoln, 2000; Morse, 1995). In fact saturation was becoming apparent after the sixth or seventh interview. However until that point all the participants had been females. The last two interviewed were males. This order occurred by chance. The researcher was waiting for these two interviews before concluding that saturation had occurred. The male interviews did provide some new insights on the caregiving experience that were not

there from the female perspective. This was an important piece in understanding the cultural aspects of rural caregivers.

The Setting

Interviews were all conducted by one primary researcher. A naturalistic setting was preferred in the home of the primary caregiver at a pre-arranged time convenient to the participant. A naturalistic setting for the collection of research data implies that the setting is natural to those being studied. This ideally would have been the home setting of the caregivers. "The setting can influence the way people behave or feel and how they respond to questions....In-depth qualitative studies are best done in naturalistic settings to study the full context within research subjects live and work" (Polit & Hungler, 1995, p. 142). One participant chose not to be interviewed in her home and a private office in a community clinic was chosen as an alternative. Ethnographic research demands that the researcher go to the participant and attempt to become part of their experience and culture. The interviews were all conducted with only the researcher and the participant without others present, as it was thought they might not express their true experiences if others were listening.

Ethical Considerations

Approval for study was obtained at three levels. The researcher's thesis committee reviewed the proposal for the study to help assure the ethical issues were addressed. The Education Nursing Research Ethics Board (ENREB) at the University of Manitoba then granted approval for this study to proceed. Finally the Palliative Care Director in the Central Region and her team provided support, access to the population under study and approval to continue with this study.

Informed consent of the participants / caregivers was obtained after the study was explained and the potential participant had time to ask questions. The participants were made aware that participation in the study was voluntary and they could withdraw at any time. Participants were informed that confidentiality would be maintained and that interview data would be identified only by coded information with no names. Assurance was given that consent forms would be stored separately from the interview data.

Considerations were taken to acknowledge the caregivers as a vulnerable population. The interviews did not take place during the caregiving experience or in the early bereavement period.

No known risks to the participants were apparent in this study. However on several occasions when the participant seemed distressed, the interviewer turned off the tape recorder, stopped the interview and provided emotional support. The interview proceeded when the participant felt ready. Longer-term follow-up plans for support were in place but were not needed. Had it been necessary, a referral could have been made through the local palliative care programs for bereavement support via mental health counselling or pastoral care services.

Interview Schedule

After obtaining approval from the thesis committee and permission from the Ethics Review Board at the University of Manitoba, the Central Region Palliative Care Program team was approached to determine if they would like to participate. The researcher negotiated terms of access to the community through the Central Region Palliative Care Coordinator. The researcher presented information highlighting the area of proposed study and its implementation. This included the study design, the criteria for

selection of participants, and the recruitment process. Informal discussion via email followed with the region's thirteen palliative care coordinators and the regional coordinator. Formal approval for access to caregivers of the terminally ill in the community who are known to the palliative care program was obtained as well as cooperation from the palliative team for the recruitment of study participants.

Verbal and written instructions were given to the local palliative care coordinators for recruitment of participants. Initial contact with the subjects was made by the palliative care coordinators who acted as recruiters. An honorarium, \$250.00, was given to the Central Region Palliative Care Program for professional development (for example for purchase of audiovisual materials for training, books, or enrolment in conferences or courses).

The recruiters made initial contact with the potential subjects by phone. The recruiters used the initial contact statement when phoning participants (Appendix B). If the caregiver agreed to participate, consent was then obtained to provide their name and phone number to the researcher. The recruiters forwarded this information to the researcher. The caregivers were informed that the researcher would contact them by phone. The researcher contacted the participants by phone and explained the study to them. All caregivers recruited agreed to meet with the researcher at a convenient place and time for the caregiver. At that meeting a written description of the study was given to the participant / caregiver (Appendix C). After the caregivers agreed to participate the consent (Appendix C) was signed and a demographic survey was completed (Appendix D). The demographic survey provided a profile of the population of caregivers.

Table 1

Interview Schedule For All Participants

Person conducting task	Palliative coordinators	Primary researcher	Primary researcher
	Initial Contact/ recruitment	Description of study and information, consent, and demographic survey	Qualitative Interview

The Interview

Each interview lasted approximately one and one-half hours. The interviews were face-to-face interviews and the researcher attempted to create a relaxed setting for the participants to voice their experiences. The participants selected where in the home they would like the interview to take place. Most interviews took place sitting at a kitchen or dining room table with the tape recorder off to one side of the table. All the interviews were tape-recorded. Five of the nine tape recordings were interrupted at some point, either to deal with interruptions such as a dog barking to be let out, the participant going for a glass of water or for the participant to regain composure. The interviews were semi-structured, following the standard interview questions although the questions were not necessarily asked in the same order but allowed to flow with the general direction of the conversation. The research questions were broad questions to stimulate discussion (Appendix E). Depending upon the response, questions followed to probe a little deeper. The interview opened with a question that asked how it came about that this person became the care provider for the patient in the home setting. The questions then moved toward gaining an understanding of what a typical day was like for the patient and the caregiver. A question was asked about what lightened the load or what sustained them as caregivers throughout the experience. Resources that the caregivers and patients used

were discussed. Negative aspects of the experience and barriers and obstacles were explored. Caregivers were asked to share what they had learned from the experience and what advice they would have for others going through this experience as well as what they would like to see in their community to support caregivers of the terminally ill.

These questions were developed to guide the interview and were based upon the information from the preliminary literature review. From the literature it was known that there were positive as well as negative aspects to the experience. These questions invited the participant to share that information. As this study was designed to explore this experience from a rural perspective it was important to look at the resources that were utilized in the rural setting as well.

All participants were given the phone number of the researcher should they want to call to clarify or revise something they had said. Only one participant called the researcher within hours of the interview to add some information to one of the questions. This response was logged in the field notes of the interview.

All the interviews were concluded by the researcher thanking the caregiver for their contribution and by presenting the participant with a Thank-you card, a candleholder and candle as a token of appreciation.

Data Analysis

In ethnography analysis occurs continuously, from the selection of the problem to the final stages of writing (Fetterman, 1989). Margarete Sandelowski's (1995) plan for qualitative data analysis was adapted for use in an ethnographic study. Sandelowski's process involves preparation of the data or having the interviews transcribed to written text. The transcriptions, according to Sandelowski, should include other cues such as

pauses and periods of silence, laughter, crying etc. Detailed field notes were kept throughout the data collection and analysis process to record the data that did not appear in the transcribed interviews. This included data such as visual observations that were not part of the audiotape. Examples would include the participant's body language, behaviours interpreted as nervousness such as requesting to smoke during the interview. Other field notes included parts of conversations that occurred after the tape recorder had been shut off and the caregiver was seeing me out. In addition detailed journal notes were made immediately following the interview. These journal notes logged the thoughts and feelings and personal reflections and emotions that were invoked for me, the researcher, with that particular interview. An example would be the caregiver who pointed to the chair where I was sitting, and said that was her husband's favourite chair. She went on to say that is where he was sitting when he decided to be transferred to the hospital (where he died a few hours later). In addition notes were made as the researcher listened to the tape-recorded interview again prior to handing the tape to the transcriptionist.

To gain an appreciation for the pauses, tone of voice etc. the researcher listened to the tapes several times in addition to reviewing the transcribed interviews. The process involved the researcher's immersion in the data or reading and re-reading the transcripts to get a sense of the whole. Extracting the facts or elements of data that are least subject to the researcher's interpretation followed. This was achieved by looking at the interview questions and looking for the responses to the questions. This was a starting point for developing categories.

Throughout the analysis as overarching or major themes or story lines emerged they were coded. In ethnography, the search for themes is referred to as *componential*

analysis. Componential analysis is the systematic search for attributes associated with cultural categories. This is a systematic way of breaking down the data to units of meaning. Each unit of meaning is considered an attribute of a culture (Streubert & Carpenter, 1999). The researcher was immersed in the data for extended periods over five months. The researcher was prepared to live with some ambiguity for a while, as some themes were not immediately apparent and to avoid premature closure on the data analysis.

Data analysis began during the interview period. Journal entries were made to include information that was not recorded in the tapes of the interviews immediately following the interview. This included visual observations during the interview and pieces of conversations that did not make it onto the tape. Several months were spent reading, re-reading and analysing the data. Journal notes were kept as themes and concepts started to emerge. A poster-type of board was constructed with removable "Sticky notes". Themes, sub-themes and concepts were placed on these notes and grouped and then re-grouped by categories on the poster board. Examining the components of the data searching for themes or componential analysis has two objectives: to specify the conditions under which participants name something and to understand under what conditions the participants give something a specific name. "Componential analysis is language driven" (Streubert & Carpenter, 1999, p. 164). The transcripts were studied line by line. Concepts were flagged and eventually placed with similar concepts under a category or theme. Attributes or components of those themes were examined. Relationships between those attributes as well as relationships to the

whole were considered. Differences as well as similarities between themes and their attributes were closely studied.

Ethnography requires the observation of social situations and the behaviour (activities) carried out by people in a particular location over a period of time (Streubert & Carpenter, 1999). This observation of a social scene of rural caregivers led to the discovery of cultural themes. Culture, in this sense, is defined by the commonality shared by all the caregivers. They were all providing care for a dying relative in a rural location, affected by the ways of thinking and acting of rural populations. Two themes (each with sub-themes) were identified by sorting the data pieces according to similarities. The findings are an attempt to portray not only the very common patterns (and meanings associated with them) from the caregivers' experiences, but also are an attempt to include the unusual and situation specific events.

Common themes were identified from the narratives. The researcher moved back and forth from the whole or overarching themes to parts or sub-themes and then back to the whole. From the common themes of the narratives, common patterns of meaning were developed. Exemplars from the texts highlight and validate the themes and offer something useful to practitioners to direct practice in the area of caring for the dying and their families. Aims of ethnographic research are to understand sociocultural problems in communities in an attempt to bring about positive change (LeCompte & Schensul, 1999).

Following the selection of the main themes, earlier field notes were reviewed to ensure that all concepts that had been flagged earlier in the analysis process were incorporated into the final selection either as a theme or an attribute.

The thesis committee chairperson reviewed the coding and themes obtained from the semi-structured interviews and the internal member of the committee reviewed the findings. To maintain confidentiality, the external member of the committee, Dr. Cornelius Woelk, did not have access to the raw data due to his role in Palliative Care in the Central Region.

Rigor

In quantitative research, methods of reliability and validity let the reader of the research know how dependable and how “true” the findings of the study are. Similarly in qualitative research it is necessary to build in methods that will produce results that truly represent the experiences of the participants. Attention to confirmation of the findings in qualitative research is known as rigor. Struebert and Carpenter (1999) have identified four areas of rigor for qualitative research – credibility, dependability, confirmability, and transferability.

“*Credibility* includes activities that increase the probability that credible findings will be produced” (Streubert & Carpenter, 1999, p. 29). Ways of ensuring credibility are through prolonged engagement with the participants and through “member checks”. Every effort was made to accurately represent the experiences of the nine caregivers interviewed. Throughout the interview process the researcher attempted to seek clarification and validation from the participant to decrease the likelihood of misunderstandings or misinterpretations of experiences. Participants were also provided with the researcher’s phone number to add or clarify anything following the interview.

Dependability is similar to validity in qualitative research in that the question asked is, “How dependable are the results?” (Streubert & Carpenter, 1999). Ethnography

provides a context-bound view of a phenomenon. According to Streubert and Carpenter, in an ethnographic study the phenomenon is the culture. Culture is dynamic or ever-changing, therefore this study of caregivers will provide one view or one snapshot of the caregiving experience in a rural context. The themes were compared as to how they fit into the whole and how the findings contributed to the research questions. The findings do respond to the research questions and provide a glimpse into the experience of a rural caregiver.

Confirmability is the audit trail that shows the thought processes leading to the conclusions (Steubert & Carpenter, 1995). In ethnography, field notes are an integral part of the data collection process. Field notes and journal notes were developed that contained both the researcher's observations as well as thoughts on emerging themes and interpretation of the data. These notes were saved and complete the audit trail showing the development of thoughts about the phenomenon.

Transferability is the probability that the study findings will have meaning to others in similar situations. The written account of the study in Chapter Five is rich in detail of the experience and the meaning of the experience as the caregivers perceived it. According to Lincoln and Guba (1985) "it is not the naturalist's task to provide an index of transferability; it is his or her responsibility to provide a data base that makes transferability judgement possible on the part of potential appliers" (p. 316). Attempts have been made to provide exemplars and descriptions that are rich enough to allow the readers to be able to identify with the experience or transfer it into their context.

Reimbursement

Although financial reimbursement was not given to the participants they received, in appreciation for their participation, a small commemorative gift made by an artist from within the Central Region at the time of the interview (candle holders and candles). The gifts were not given as incentives as the participants were not aware of them until the close of the interview. No travel costs were ensued by the participants.

Summary

An ethnographic design was chosen to capture the complexity of the research topic. Ethnography can capture a representation of what life as a caregiver was like for these participants at that period in time. The aggregate will have all shared a similar experience –caring for a dying friend or family member in a home setting. Another point of similarity is that all the caregivers reside in a rural location.

The sample was recruited by the area palliative care coordinators and the researcher obtained informed signed consent. None of the caregivers approached declined the interview. Nine caregivers from the Central RHA were interviewed. Data was collected through semi-structured interviews in the home setting for eight of the caregivers and one interview was held at an office in the Central RHA for the convenience of the participant. Interviews were tape-recorded and transcribed. The issue of saturation was addressed. Ethical considerations were attended to. Approval was obtained from Ethics Review Board at the University of Manitoba prior to starting the study. Care was taken not to interview during the caregiving experience or in the early bereavement period. On several occasions when the participant seemed emotional or

distressed the interview was interrupted and emotional support was given to the individual. Participants were given a gift as reimbursement.

The interview schedule presents the process followed in this study and rationale for the research questions is presented as well.

Attention to the confirmation of the findings or methods of rigor has been built into the research. The researcher spent protracted amount of time with the data and allowed themes to emerge in the data analysis. Two of the researcher's thesis committee members reviewed the themes from the analysis. The feedback that was provided from the committee assisted the researcher in providing more clarity to the concepts and themes and provided support for the themes with evidence from the data. The thematic analysis section was re-worked and re-submitted several times before proceeding to the discussion and recommendations.

CHAPTER FIVE

THE FINDINGS

This chapter presents the findings from the study, which includes a discussion of the sampling and interview process, a demographic profile of the sample of caregivers and an exposition of the caregivers' experience. Two general themes (each with sub-themes) were identified: *The Work of Caregiving* and *Coping and Coming Through the Experience*.

The Sample

The sample consisted of nine persons who had acted as the primary caregiver for a dying person in the Central Regional Health Authority of Manitoba. As explained in Chapter Four, nine persons were interviewed before thematic saturation was evident. All caregivers either resided in a rural region of the Central Region during the caregiving experience or returned to this region to care for the dying family member. The criteria in this study were based on their knowledge and experience of being a caregiver for a friend or family member in the home setting. This meant they must have provided care in a home setting for a dying friend or family member in the days, weeks, or months preceding death. It was not imperative that the patient actually died in the home. Therefore even if the last days were spent in hospital, these caregivers were included in the study. The interviews focused on what transpired in the home setting as opposed to the experience of being with a dying person in the hospital. Another criterion for inclusion in the interview was that at least six months had to have passed since the patient died. Chapter Four presents the rationale to avoid interviewing vulnerable persons during

acute bereavement. In addition the palliative care coordinators used their judgement to select individuals who they believed would be ready to discuss their experiences. Other selection criteria included: the caregivers must be at least 18 years of age, able to speak, read and write English, be willing to discuss their caregiving experiences and be available for a one to two hour interview.

As the palliative care coordinators were located in small communities across a wide geographic region spanning the entire Central RHA, the participants they recruited for the study are also representative of the various rural communities in the region.

Demographics

Caregivers ranged in age from 38 to 80 years of age. Three were under 50 years of age, two were between 50 and 60 years of age, one between 60 and 70 and three between 70 and 80 years. The average age was 58 years. Seven female and two male caregivers were interviewed.

A cross-section of ethnic groups was represented. This occurred by chance as ethnic background was not considered part of the criteria for recruitment by the palliative care coordinators. There were three claiming French-Canadian roots and one with a French / Polish background. There was one of Dutch descent, two of German ancestry, and three with roots to the United Kingdom i.e. Irish, Scottish, and English.

Two caregivers had attended or completed university. Three had attended a college or trade school after high school. Three had attended or completed high school and one had an elementary school education.

Four of the caregivers were retired, two were working part-time, and one was working full-time. Two caregivers were unable to carry on in their employment with the

heavy demands of caregiving. One quit her job and one took a leave-of-absence to provide care.

There were four spouses caring for their partners – three wives and one husband. Two daughters were caring for their mothers and one granddaughter cared for her grandmother. One caregiver was a sister to the patient and one son cared for his father.

Living arrangements did not change for the four married caregiver / patient couples. The other arrangements resulted in the more dramatic changes to lifestyles and changes of addresses. Two caregivers moved the patient into their own homes and made physical accommodations for this. One caregiver moved her family into the patient's home to provide continuous care. Two caregivers continued to maintain their own place of residence caring for their own family as well as commuting to the home of the dying patient to be the primary caregiver. For both of the latter their stays at the home of the dying were often extended overnight or for several days at a time.

Medical records or health care professionals were not consulted to determine the patient's type of illness. The participant's description was used exclusively for cause of death. Five patients died from cancers – ovarian, kidney, cervical, lung, and bone. Other conditions were: bipolar disorder with a co-morbidity of emphysema, congestive heart failure, muscular dystrophy with a co-morbidity of emphysema, and one without a diagnosis or simply of "uncontrolled pain".

The time spent caregiving varied from 6 weeks to 48 months. The average length of time caring for the patient was four and one half months (excluding the one caregiver with a 48 month time span). The time since the experience of caregiving varied from 7 months to 24 months.

The demographic survey did not include the location of the patient when he / she died but this did come out in the interviews. Four patients died at home and five died in a local community hospital. Of the hospital deaths, two caregivers reported that the death in hospital felt unexpected or they were expecting the patient to come home at least one more time and possibly die at home.

A summary of the ages, gender, ethnic origin, education, size of the rural community, length of time of the caregiving experience, and time lapsed (at interview time) since the patient has died can be found in Appendix F. Pseudonyms were used to protect the identity of the participants.

The Themes

The information shared by the caregivers provided the researcher with a view into their world both as they remember it during the caregiving experience and now as they reflect back on this time and what it meant to them. Every effort was made to accurately represent the experiences of the caregivers. This was addressed in Chapter Four under the four methods of obtaining rigor – credibility, dependability, confirmability and transferability. In summary the researcher attempted to have the participants verify that what the researcher understood to be the experience of the participants was in fact correct. This was done by “member checks” or utilizing communication techniques such as asking “Did I hear you right, you said ...”. An interview question guide was used to focus the discussion. This facilitated ensuring that responses were being compared to similar experiences between the participants. The researcher’s thought processes were logged in journal notes and field notes. The field notes logged information that was not evident on audiotapes such as body language and demeanour of the caregivers during the

interview and bits of significant conversation that occurred after the tape recorder was shut off. The journal notes recorded the researcher's thought processes as to emerging themes throughout the interview and analysis process. Included in these notes were index cards and posters mapping concepts and themes as they emerged as well as relationships between concepts.

The two themes are: *The Work of Caregiving, and Coping and Coming Through the Experience.*

The Work of Caregiving

The first theme is *The Work of Caregiving*. This theme covers the effort and the labour involved in the experience both physical and psychological. What was involved in the tasks of providing care for a dying person in the home? What were the challenges of the task at hand? Included in this theme is also a look at what incited the person to take on this task of becoming a caregiver. The theme, *The Work of Caregiving*, can be divided into five sub-themes, *The Sense of Mission, The Problem of Fatigue, Uncertainty, The Challenges of Pain and Other Symptoms, and Role Overload and Effects on Lifestyle*. For all the caregivers this experience was all encompassing. Most everything in their lives changed or was put on hold while they were the primary caregivers. Jobs, children, spouses, places of residence and even financial situations were affected during this time. Days and nights revolved around the organization for, and provision of care, advocating for the patient and taking on new roles. Seeking information to understand the disease process, how to access supplies and services and learning how to carry out the physical part of providing care were foremost mental and physical activities. Much mental energy went into making sense of the caregiving experience both while the caregivers were

intensely involved in it and upon reflection of what transpired. Their stories reflect what the *work* part of the experience was like for them.

The Sense of Mission

What is it that allows people to set aside their entire lives for days, weeks, months or even years and become focused on caring for a dying person? This sense of mission pervades all aspects of the caregiver's life and provides justification for the role even after several years have passed. "Mission" in this label means the calling to the task at hand. It examines the sense of duty and other factors that motivated the caregiver to take on the caregiver role as well as to persist when things became difficult. Examination of this sense of mission also provides insights into the joys of the experience as well as the hardships.

The mission was driven, in part, by the caregiver's desire to honour the patient's wish to be cared for at home by a family member. All the caregivers were a close line relative of the patient. They were a spouse, a daughter, a son, a sibling or a granddaughter. Foremost for all the caregivers, it was the understanding that to be cared for at home by a family member was the patient's wish. The caregivers had a real sense that they knew what that patient wanted, wished for, dreaded most, and needed more than anyone else. This feeling that they as caregivers, and only they, knew the patient well enough to provide this personalized care, created burden for the caregivers. Tied in with a sense of knowing the patient's needs better than anyone else, was also a feeling of guilt when they were not able to ensure the delivery of care for the patient. Several spoke of incredible guilt resulting when something happened to the patient and they were not there. Grace spoke of leaving the house to attend the funeral of a friend leaving her sick

husband unattended. She felt guilty shortly after arriving at the funeral and turned around and came home. In the short time she was away her husband had fallen and was unable to get up.

Phyllis related how her husband's greatest fear was choking. On the day he died she had to take him to the hospital but was planning to take him home again. She had gone home to eat and rest and had just drifted off to sleep when she received a call from the hospital informing her that her husband had had a pulmonary embolus.

I felt really bad because his one fear was choking. He had had this once before and he had described to me afterwards the dreadful feeling of not being able to breathe. That time he was grateful that he was able to push the buzzer and the nurse was right there and they intervened. But this time, when this happened, I wasn't there.

Undertaking the mission of caregiving created burden for the caregivers. The sense that they as caregivers knew what was best for the patient created added responsibilities and a sense that they as caregivers were always "on call" and in charge. They had now been placed in charge of affairs of tending to the patient's needs as well as running the household.

Knowing what the patient feared and what they wanted motivated the caregivers to become the caregiver and motivated them to go on. For some patients and caregivers the thought of personal care being provided by a stranger, they believed, would be an insult to their dignity and an invasion of their sense of privacy. One lady said while she was providing care she didn't really notice the fatigue because to her at the time "it was her mission". The extreme fatigue caught up with her after her husband died. This sense of mission as well as sense of duty pervades the interviews.

The benefits of the caregiving experience justified the mission. Looking back on the experience caregivers spoke of a sense of incredible satisfaction. Paula related that the caregiving experience was “one of her best experiences and one of the best things she ever did”. Phyllis and Gloria told very similar stories of how their care and their being there calmed the patient or helped them through a critical time. “John was very restless in the bed and his pulse was so rapid we could hardly count it and when he knew I was on the way his pulse went right down and he quieted down”. Gloria was certain that her presence allowed her grandmother to relax and know that things were being taken care of. Her grandmother slipped away peacefully when she returned home after being out for a day. The loving actions of caregiving such as holding a hand or giving sips of water and backrubs provided a sense of satisfaction and being able to help. Being able to do something that was constructive or comforting for the patient was described as very important and necessary in a situation that seemed hopeless.

For some of the caregivers, providing care was viewed as an act of reciprocity. “When I was ill my husband stood by me. How could I not stand by him?” and “I just had to go, make her environment stable and predictable like she’s always done for us through our childhood”. For others providing care at home seemed like the right thing to do. This is what the patient would have done for them. One gentleman took his aging dying father into his home as the home had belonged to the patient in earlier times. Closely related to the sense of duty for some of the caregivers, guilt was a motivating factor – or rather, avoidance of guilt. Some of the patients had expressed that to be cared for at home by a family member was their fondest wish and the caregivers could not refuse.

In addition to the sense of duty motivating the caregivers to provide care, there was one caregiver who felt that in part the caregiving role was thrust upon her. She described herself as being the "most available" in the family. Helen was married but had no children and so was delegated in an informal way by the patient and her siblings. She may have taken on the role as primary caregiver regardless of her family's assumptions, but felt somewhat that this had been imposed on her. This added another dimension to the mission in terms of freedom of choice to take on this task.

Another facet to the concept of mission is the concept of internal and external motivational factors. The definition of mission so far has encompassed internal motivational factors. There were other external motivators. One caregiver, who happened to be a nurse, moved this sense of mission to a more altruistic level by expressing this should be the right of all patients to choose where to die.

It should not make the patient feel beholding. It should be a given. It's part of being taken care of till you die; it's not that we're doing them a favour. It's something that everyone should be expected to be able to have at the end of their days.

Sometimes events that transpired undermined the caregiver's satisfaction with the sense of mission. This strong sense of mission to "be there" and "be with" the patient created a sense of regret and confusion for those who were not present when the patient died. There was bewilderment, regret, and a sense of being cheated out of having missed the time of death even though the caregivers were close at hand. "Why did I leave the room to get the nurse? Why didn't we pray instead?" Paula's wish was to be there when her sister took her last breath in case her sister needed her. She had been sitting at the bedside for weeks and found it hard to take when her sister died when she left the room for a few minutes.

The Problem of Fatigue

Being the primary caregiver in most of the families meant unending work, being unable to get away and incredible physical mental and emotional fatigue. Some of the caregivers were unaware of the effects of fatigue and exhaustion on their own health while they were in the experience. Several described a "breaking point" or fatigue to the point of exhaustion. Contributing to the problem of fatigue were the problems of always being on-call, lack of uninterrupted time for sleep, being geographically distant from the patient or place of caregiving, and extenuating factors of the nature of the patient's condition. The impact of fatigue and exhaustion on the grieving process also came through in the interviews.

The role of caregiver often meant being on call 24 hours a day seven days a week. The burden of being on-call was greater for those not residing with the patient or being geographically farther apart. For Mary, a participant who was also a trained nurse, that meant trekking across town to give her mother a shot of Demerol. Being a caregiver, for Mary, meant never being too far from the phone in case a call would come through saying she was needed. The burden lifted somewhat when Mary moved her mother in with her. Helen, another participant in the study, received many a call as she was travelling back to her home an hour away, only to have to return once again to her mother's bedside. Being on call meant interrupted rest for the caregivers. "And we had a bell for him, and you know, you'd just be drifting off and the bell would ring". Several caregivers compared the fatigue to being a new mother or having a baby in the house or somewhat like sleeping with only one eye shut.

Several of the patients experienced mental confusion and needed close monitoring even at night interrupting or preventing sleep for the caregivers. One lady tied her and husband's arms together so she would be aware if he tried to get up at night.

Despite the fatigue they experienced, the caregivers spoke of an internal force that gave them the strength to go on right when they thought they couldn't go on any more. Al who experienced significant fatigue in providing long-term care for his wife characterized this internal force as "courage".

Some days you would think you wouldn't make it to the end of the day... but then you would get a little more courage, and you knew you had to, so you did it all over again. Some days and nights seemed endless. We did a lot of sleeping in the daytime. Sometimes I didn't get up to answer the doorbell because we were so tired and we needed all the sleep we could get.

Phyllis spoke of a resilience and determination that she attributed to her sense of mission that persisted over and above the fatigue.

But I kept on going because that was my mission. But I know I was tired because afterwards is when it hit.... You have the strength to just keep on doing it. And that's why I say if I was tired I didn't know it because this is what I did.

Fatigue, to the point of exhaustion, left some of the caregivers feeling that they were functioning in a daze, no longer aware of just how tired they were. Paula's story describes some of this.

I didn't cry. There were no tears. It was a haze – no, it was more like being a robot. Every day was like the day before and you just knew where you had to be. And all of a sudden you're at the end of the week and we'd start all over again.... There's something in you that just kicks up the next notch that takes you day by day.

Many of the caregivers had pre-existing factors that contributed to the fatigue. Several had health problems of their own and for others, especially the elderly, providing

the physical care was a challenge. What came through in the stories was the self-sacrificing nature of the caregivers even amid physical, mental and emotional fatigue.

I was exhausted. I was stressed, feeling inadequate. I was pulled in so many directions and I have my own health problems. And because I didn't know how long she was going to live, I told myself, that's OK, you can overextend, because once she's gone all these additional responsibilities will be gone and it will be time to care for yourself.

Four of the caregivers were seniors (over 65 years) and providing physical care was often difficult for them. Phyllis and Grace both described incidents where the patient fell, or almost fell, pulling them down with them during transferring from a bed to a chair. Grace herself is very arthritic and found providing the physical care difficult to manage. Al felt the effects on his health as well as he is a diabetic.

The effects of fatigue and exhaustion carried over into the bereavement period. One caregiver described effects on her own health. After her mother died she had several blackouts or fainting spells that were attributed to fatigue and stress. She required sedatives for a while to catch up on some rest. Others described feeling so emotionally and physically drained that they were unable to cry or grieve for a while following the death. Sally described it this way. "After he died I was so tired I could not even grieve for him. I was sad he was gone but my body seemed to think it was a blessing". It was almost a year later that she felt she was now able to grieve. Grace had a similar experience.

At first I think people thought I was hard. Then after a year passed I became a basket case. I thought it would get easier but it got worse. I don't think I did much shedding of tears then. Not in public. Not for a long time. Now I can't stop.

Some caregivers made an effort to create time for self-care during this distressing time. Some mentioned taking time out for physical exercise like going for walks or just going out.

Several of the caregivers mentioned that fatigue was just as much an issue when the patient was in the hospital as when they were at home. There were different stressors in the hospital setting. Gloria described the best part of the caregiving experience as the time she decided to move into the patient's home to care for her. Moving into the patient's home meant contending with the patient's normal routine as opposed to the routine of the hospital.

I got more tired when she was in the hospital that I did at home. At home I could sit and relax and sit and do nothing instead of going back and forth to the hospital and sitting in chairs that were uncomfortable and contending with beepers and buzzers and call bells and intrusive noises that you don't have when you're dying at home.

Uncertainty

The third sub-theme under the *Work of Caregiving* is that of *Uncertainty*. The caregivers did not know exactly how long the patient would live, what dying would look like and what would be expected of them as caregivers at the time of death. Conflicting information from health care personnel compounded the uncertainty. In addition some caregivers had experienced receiving an incorrect diagnosis or missed diagnosis earlier leaving them distrustful of the medical system.

There was uncertainty about the disease trajectory and how long the patient had to live. For the purposes of this study the illness trajectory is defined as path or course of the physical illness. For these patients and families that course ended with death. Corbin and Strauss (1988) have identified that not only is *trajectory* referent to the physical unfolding of the disease but also carries with it the *impact* or consequences on the patient and family caregivers. Corbin and Strauss characterize disease trajectories as having a

“fateful” dimension to them. It is as though the end is determined but neither patient nor doctor knows exactly what this will look like. This adds to the uncertainty.

There was uncertainty about what the dying process looked like and what they could expect. There was also uncertainty as to whether they as caregivers were doing a good job and whether they were making the right decisions. The uncertainty drove the caregivers to seek out information. The informational needs of the caregivers were tremendous.

The concept of time recurred in the interviews in relation to understanding the illness trajectory. The amount of time the caregivers thought the patient had left to live and the actual amount of time the patients actually did live usually differed. “Not knowing” when death would come was perplexing and unsettling for the caregivers.

In our mind we had the quantity of years and then the family doctor thought it was now months. It worked out to be under two months till she did pass away. It was like years and then it's months and then whoa, two months not even!

Periods of crisis occasionally necessitated short periods of hospitalization. There was always the uncertainty of whether the patient would come home again from those hospitalizations – some did, some did not.

The uncertain illness trajectory created a fear of the unknown as to how the disease would progress and what they could expect in terms of the patient's condition and symptoms as well as what would be expected of them. One participant stated:

There was a constant not knowing of how the disease would develop and affect her and what kinds of needs I would have to be meeting and would I be qualified or adequate to provide that and who should I call if not.

It was not always clear what the diagnosis or primary site of the disease were. This added to the feelings of uncertainty. If the medical system did not even know what

was going on, where could the caregivers go to get the information they needed?

Uncertainty then resulted from a lack of timely information or from receiving conflicting pieces of information. Sometimes however, when caregivers were given information they found that information too upsetting to deal with. Helen had been told her mother could die from haemorrhaging. The family did not want to take the patient home to die because the images they were left with were frightening. Gloria spoke of how the rest of the family were reluctant to care for the patient because they were afraid of the patient choking or having a pain episode that they would be unable to know how to handle.

Some uncertainty resulted from communication difficulties with health care providers. While most caregivers spoke of receiving honest and straightforward information and answers from health care professionals, some had a different experience. Receiving vague or incomplete information caused suffering for the patients and the families. However, as mentioned earlier, sometimes receiving straightforward and factual information also caused distress for the caregivers. One patient and her caregiver were told by a doctor at the cancer clinic in Winnipeg, when the patient's chemotherapy had been discontinued, that they would

Let her (the patient) fly on her own from here. And then he told the nurse to make another appointment time and he really didn't say what that appointment time was for. And he didn't clarify that more. And we didn't ask more.

The patient and her family were left wondering what the prognosis and course of treatment, if any, was left for them. Palliative care nurses, volunteers and physicians did much toward providing information for patients and families and facilitating their roles as caregivers thereby helping to alleviate uncertainty. This will be addressed under a later theme *Coping and Coming Through the Experience*.

Holding on and letting go. Uncertainty created a dynamic for the caregivers that the researcher has described as *Holding on and letting go*. The caregivers spoke of an emotional state that vacillated between trying to hold on to the patient and letting them go – between waiting for death as a release and giving the patient permission to die and hoping for more time left with the person. The caregivers spoke of a pull between holding on to the dying and letting go. Al spoke of the uncertainty of when death could come and the need to keep on planning for his wife as though she were to keep on living. “We would talk about it that it could happen or that it might happen, but we had to keep on planning for her”. Another caregiver spoke about the concept of hope in relation to holding on to the patient and letting go.

You still always have the hope that something is going to happen. Something’s going to come up. God’s not going to do this to me. You hope, but you know the outcome. You want to keep her comfortable. So what you hope for changes.

The stories of the participants included narratives of what the patient needed to let go. For some it was permission from the family. For others it was seeing a relative one last time or saying good-bye to a home and yard. And for others it was resolving family business and relationship affairs.

Factors that mitigated uncertainty. The caregivers spoke of some factors that helped mitigate uncertainty. Anticipatory guidance as to what to expect during the dying process and the steps to take when the patient died were invaluable in reducing uncertainty. One caregiver received this information and guidance from a palliative care worker, another from the palliative care physician. Paula and Gloria both related how valuable it was to have practical information available that prepared them for what to do

and not to panic at the time of death. The implications of the importance of receiving accurate and timely information will be discussed in Chapter Six.

A health care background was seen as invaluable in allaying uncertainty. Understanding the medical system as well as having some experience in witnessing patients with similar conditions was an asset. Three of the caregivers were nurses and relied on their nursing knowledge to understand the disease and the dying process yet each of the three expressed surprises or things and events that they had not witnessed before in their nursing experience. Several of the nurse-caregivers marvelled at how caregivers without an "inside" to the health care system would be able to organize care, obtain supplies and have enough knowledge to know when to advocate for the patient or seek outside help.

The Challenges of Pain and Other Symptoms

Pain and its management created challenges for the caregivers. Psychological distress that arose from watching the pain of their loved ones was a huge issue. Decision-making issues around pain control and when to seek hospital admission were also challenges. In addition the consequences of the side effects of pain medication as well as the consequences of uncontrolled pain eroded confidence in the medical system. Other symptoms such as lack of appetite or inability to eat and weight loss were psychologically distressing to the caregivers but to a lesser extent than observing patients in pain.

The first challenge seems to be caregivers having to bear vicarious witness to the pain experience. Watching their loved ones in pain was a very distressing experience for the family caregivers. Many judged how bad the pain was by the frequency with which

they had to administer the pain medication. When the pain medication became ineffective or the times between doses became closer, the caregivers became distressed. They were left with the feeling that pain management was no longer achievable. None of the caregivers mentioned difficulties with making decisions about when to give medications for break-through pain. However two of the caregivers who happened to be trained nurses questioned the choice of pain medication that was chosen. In both cases the medication needed to be changed due to causing the undesirable side effect of hallucinations.

Helen spoke of how the pain her mother went through was enough to make the patient and the family wish for death.

She had this pain episode and that's when I knew I could say goodbye. Her whole body shuddered, like a spasm. I heard her say "God hurry up, I just want to be dead already". She never had talked about death one way or another. And for her to say it plainly. If she was ready to go, I was ready to let her go and it is time.

In addition to pain the patients experienced related to the disease there was pain that was in fact brought on or made worse by the caregiver. Gloria tried to do dressing changes on her family member. This was very painful for the patient. This caregiver described this as the most negative aspect of the caregiving experience and being worse than pain from the disease process. She did not want to be responsible for inflicting pain even if the end result (having a dressing changed) was necessary.

Another challenge seems to be related to decision making around the issue of pain control. Three of the patients were hospitalized for pain control. Caregivers of patients who died in hospital used uncontrolled or escalating pain as the "benchmark" for bringing the patient to the hospital.

Erosion of confidence in the medical system resulted for the caregivers when pain was not well controlled or when there were intolerable side effects. Two of the patients experienced hallucinations and confusion from pain medication to the point where a different medication needed to be tried. "The suffering, when she wasn't pain controlled that was the hardest thing to bear. We can fly a man to the moon but we can't control pain. That made no sense". A second caregiver's response reflects the frustration with what she viewed as inconsistencies in medical management of pain and symptom control:

So much of this is a shot in the dark because it depends who your oncologist is. There's someone else who has exactly the same diagnosis and they're taking them down a different path and you think, so which one is right and who decides? Are these doctors playing God or are they going with their best information? There's no consistency here. There's millions of dollars going into cancer research but they're still taking shots in the dark.

In addition to the distress caused by witnessing their loved ones in pain, the caregivers, friends and family found the physical changes like weight loss, apparent wasting away and the patient's inability to care for themselves hard to watch. Paula suggested that few friends of her sister came by as she neared death because of her skeletal like appearance.

Attempting normal activities such as eating a meal together were also painful reminders that the person was dying. Many of the patients were unable to eat and this was difficult for the caregivers to watch. Not being able to feed and nourish a patient left the caregivers feeling helpless. Grace, who had spent much of her adult life as a cook found it unbearable to witness her husband, once a large robust man, unable to eat her cooking and fade away. This seemed especially poignant as caregivers discussed what their days

and family times centred around. These times usually revolved around sharing a meal and visiting.

Role Overload and Effects on Lifestyle

Most of the caregivers expressed how their lives and lifestyles were altered during the caregiving experience. There were structural changes to homes and changes of residence for either the patient or caregiver. Lifestyles were altered sometimes drastically. Caregivers found themselves taking on new roles – either to get the job of caregiving done or to fill roles being vacated by the dying person.

Environmental / structural changes. Adjustments were made to homes to accommodate the patient. All the homes needed some type of structural change or at the very least some new equipment such as a hospital bed brought into the home. Equipment, such as hospital beds, was arranged through loans from local home care programs although one gentleman caregiver purchased a hospital bed with electric controls himself from someone in the community. The reason he bore this cost was it was important that the patient be able to raise and lower his bed by himself during periods when the son (the primary caregiver) was working on the farm. Home care was in place but the attendants were only there for periods throughout the day. The patients who received home care services had medical supplies such as home oxygen, dressing supplies, gloves and syringes provided through the Manitoba Home Care Program. However there seemed to be inconsistencies as to who paid for medical supplies. Several of the caregivers mentioned covering the costs of syringes and medical equipment for the patient. Mary specifically mentioned the high cost of syringes and alcohol swabs but stated it did not

cause hardship for the family to pay for it. Mary was administering the medications herself, as she was a nurse.

Other alterations to homes included installing a hand-held shower for bathing and setting up privacy screens and curtains when patients' beds were moved into the living room or elsewhere in the home. Other expenses included equipment to devise means of "patient call systems". Several families purchased cell phones for the patient to access the caregiver. Two purchased "walkie-talkies" so the patient could contact the caregiver when they were out in the yard.

Living arrangements. For some of the families the lifestyle changes during the patient's terminal illness were drastic. Living arrangements were adjusted, and for some, normal family life was disrupted. Some caregivers moved away from children and spouses to care for a dying family member. Some caregivers moved in with the patient or moved the patient into their homes. In four of the homes the patient's bedroom was moved into the living room or family room of the house. This also made that patient and their care the focal point of the family life.

Family life and careers. Families and careers were affected. For some who were working outside of the home, careers and jobs were put on hold. Some quit their jobs or changed jobs to accommodate being away from work. Others felt that their quality of work suffered while they were juggling responsibilities. Several caregivers who had been working felt the effects financially of not being able to go to work. Families and children suffered while parents and spouses were consumed providing care to a dying relative. Grace spoke of how her normal routine was interrupted.

My life changed to the point of where I stopped attending functions and doing things that I would normally do, like going to the seniors centre. When I did errands or went out to do anything, I did it in a hurry.

A positive outcome of moving closer to the patient to care for him / her was the family closeness and strengthening of family ties in the patient's last days of life.

Taking on new roles. The caregivers found themselves taking on new roles during the experience. These were roles they often felt unprepared to take on. They assumed roles that the patient had vacated because of their illness. They became the nurse, a patient care manager, household manager and organizer, and sometimes, the business manager of a family business. Taking on these roles also included advocating for the patient and making decisions for the patient. Making decisions for the patient often left the caregiver feeling guilty for justifying those decisions. Often the caregiver resisted taking on a new role as a strategy to preserve normalcy in the home.

Role as nurse. The caregivers spoke of their role as a nurse. By this they meant that by caring for the patient in the home setting, they were required to provide physical and medical care for the patient. Three of the caregivers were nurses or were retired from nursing. They all spoke of how valuable their nursing knowledge was. Not only did they have the knowledge and skills to provide the physical care for the patient, but they knew how the health care system worked and were able to access supplies, information, and individuals who could assist them with their care. Sometimes, however, the knowledge the nurse-caregivers brought to the experience created more stress rather than alleviate it. One caregiver did not want to be thought of as a "difficult" family member and create a fuss when her patient was given a painkiller she thought would have untoward side

effects. In order to appear compliant and trusting of the medical system she remained silent. "You just listen. They tell you what to do and you do anything you can".

Taking on the role of nurse had an impact psychologically on the caregiver and the patient by changing the relationship between marriage partners. The patient sometimes became dependent on the care provider where there had previously existed a co-existence. Phyllis described it this way:

I think the role changes a bit psychologically when you become a caregiver, a nurse. Because he was always very much a man and he would never let me rub his feet or things like that. Maybe if he had a sore shoulder (he'd say) "I'll just have to work it out. I'm OK." And then to start taking on that role – it's almost a mothering role. He didn't want me fussing over him.

Another caregiver linked the nursing role to a mothering role. She reflected on feeling as though she was becoming a mother to her husband as he became more dependant and how she tried to preserve the patient's dignity. She consciously resisted taking on that role.

I started taking on a mothering role and I was very conscious not to treat him as though he was my child. I'd just be kind of casual and flippant about it.... He never let me fuss over him before and I didn't want that to change.

For one caregiver who was a trained nurse, caring for the patient in the home setting assisted in freeing her from feeling she was "on duty". This nurse worked in the hospital where her grandmother had been a patient until she decided to take her home to die.

Having her at home took the pressure off. I didn't feel like I had another schedule or agenda to meet. And in the hospital you are juggling these different roles. In the hospital I am a nurse. I'm a grandchild, a granddaughter and this allowed me to be in that role. I couldn't be in that role in the hospital because that's not the job I do there. When I could be at home with her, then I could be her granddaughter.

For caregivers without a background in health care, being put in a nurse's role, a role for which they were not formally prepared, necessitated a search for information to learn how to provide the care. The role of nurse was more foreign to the two male caregivers as compared to the female caregivers in the sample. One gentleman took his elderly father into his home to care for him and provided personal care such as assistance toileting and bathing. The other gentleman, who prior to retirement was a truck driver, felt he was on call 24 hours a day as a nurse caring for his wife. Most of the day was spent managing her physical care. She was a diabetic in addition to having a terminal illness and needed to have her blood sugar monitored closely and insulin given accordingly. She also required gastrostomy tube feedings and suctioning and medications given through the gastrostomy tube. By the time one set of treatments was done, it was time to start over. There were huge learning needs for this man to take on the nursing role. This same gentleman expressed frustration for feeling clumsy at not having delicate hands and the manual dexterity needed to change the ties on his wife's tracheotomy. Informational needs for other caregivers also included where and how to access supplies.

All the caregivers who lived with the patient, either in their own home or the patient's home described the importance of establishing routines and creating a normal as possible home life for the patient. This made it easier emotionally and physically to provide care. Gloria described the best part of the caregiving experience as the time she decided to move into the patient's home to care for her. Moving into the patient's home meant contending with the patient's normal routine as opposed to the routine of the hospital.

I got more tired when she was in the hospital that I did at home. At home I could sit and relax and sit and do nothing instead of going back and forth

to the hospital and sitting in chairs that were uncomfortable and contending with beepers and buzzers and call bells and intrusive noises that you don't have when you're dying at home.

Household organizer role. This role refers to all the day-to-day management activities required of the caregiver during the experience. Some activities were new, such as those organizing patient care and appointments. Other activities were not new to the caregivers. These were activities such as cooking and cleaning, tending the yard, paying bills and running the household. Some of those household activities or chores were ones formerly done by the patient. This aspect will be enlarged upon later under the heading *Taking on vacated roles*. Energy and time was spent organizing the care of the patient, obtaining care supplies and equipment, transporting the patient to appointments and treatments and managing household affairs. Several of the caregivers' families lived on operating farms with large yards that needed tending. Two of the caregivers were mothers with school age children. Much time was spent juggling the many roles and responsibilities.

Included in the role of managing the household was a role of managing information for friends and family. As the caregivers obtained information about the patient's illness and prognosis, they in turn, became information brokers for the rest of the family. For some this responsibility became overwhelming adding to the caregiver's sense of burden. This was especially true when they were unsure of the information they had received and when the patient's condition changed rapidly. "And I felt like people were calling me from everywhere. I got a call from (a relative) because my sister-in-law had told him some information and he wanted to make sure it was accurate".

Taking on vacated roles. The stories of the caregivers reflect how they had to take on roles that the patient had previously assumed. This was often foreign and difficult for them. One caregiver recounted:

I was taking care of things I had never touched before. I had to learn how to use the range and dishwasher, the washer and dryer and all that. But she was still here to give me instructions so I did learn that before she couldn't do it any more.

There was a sense of not taking away from the patient the things they could still do or wanted to do. One caregiver saw her role, as being "the hands" for her mother to do whatever it was her mother wanted to have done.

Sometimes the patient had been the main caregiver and caretaker in the family. The patient's vacated role now had to be filled by another family member. "Annie (the patient) was the oldest in the family. She was the caregiver. She was the one that kept everything in order. Christmas was always set up this way and things were just so." It seems the role of caregiver, when vacated by the patient, is a large role to fill. This could have been more fully discussed during the interview but was not realized until later.

The narratives of the caregivers reveal their attempts at transitioning into their new roles as the patients deteriorated. Attempts were made to value and respect the patients' opinions and still allow them to be part of the family life and decisions as long as possible. An elderly gentleman was allowed to be part of the farming operation his son had taken over from him right up until the day he died. The patient phoned from the hospital three days before he died to check up on what was going on. One wife enabled her husband to carry on his farming business by making the times of transactions as easy as possible without taking over what had been his job. "If someone came to meet him about this field or that field, I always made sure I didn't take over. I would make sure he

was ready in his wheelchair, I would make coffee and whatever". She remained in the background but was making a conscious effort to learn the intricacies of the farming operation that she was going to need to fulfill the position her husband was leaving. Several other caregivers assisted the patients to take care of business and get their affairs in order. This included dividing up possessions among family members, settling property ownership, assisting with legal affairs, making funeral arrangements and settling issues within the family relationships.

Role of patient advocate. Advocacy in this study refers to campaigning for the best interests of the patient when the patient became unable to do so for him or herself. Several of the caregivers needed to step in and advocate for the patient when they felt the patient's needs were not being met adequately both while the patient was at home or in the hospital. This included asking to have treatments discontinued, refusing certain medications for pain, requesting different pain medication and making the decision to transport the patient to the hospital. One caregiver who was a nurse advocated to have her grandmother declared palliative and requested a referral to the palliative care physician in the community. Sometimes the caregiver needed to act as a gatekeeper and step in between strangers or friends and visitors to provide privacy for the patient.

In addition to advocating for the patient, sometimes the caregiver needed to advocate to have his or her own needs met. One caregiver struggled with home care for several weeks trying to convince them that they really needed respite care.

As an advocate for the patient the caregiver was often making decisions for the patient. There were several dimensions to the decision-making role. First there was the issue of making the right decision. It was not always easy for the caregivers to make

decisions for the patient. Some of the caregivers were left with feelings of guilt as to whether they had made the correct decisions. One lady who felt her husband needed rest turned away visitors from the door. Now she wonders if she made the right decision.

Another dimension to the decision-making role is that of proxy decision making and overriding the patient's wishes. Several of the caregivers made decisions when the patient was too ill to do so for themselves. Gloria made the decision to have her grandmother transported by ambulance to the hospital for a period for pain control even when her grandmother did not wish to go. Phyllis needed to make a decision about the extensiveness of the intervention for her husband when he was hospitalized near the end. This involved consenting to a catheter to drain his bladder.

The Issue of Transportation

The families also felt that urban health care providers did not understand the difficulties facing ill persons needing to travel. One gentleman was required to go to Winnipeg to receive radiation treatments as a palliative measure. The clinic kept booking him in at 8:00 a.m. This meant leaving home at 6:00 a.m. to get there on time. One caregiver spoke of the burden and stress caused by the need to travel to Winnipeg for care.

And it was such a chore to get her to Winnipeg. And it was such a chore for her to get dressed and it took a lot out of her. We decided there was no reason to go to Winnipeg. We could do everything we needed to do here.

In addition to the hardship created by transporting patients, driving distances posed a problem for some of the caregivers. Sally, an elderly caregiver, needed to travel about 50 kilometres each way to visit her husband during the time he was hospitalized. She felt she needed to do her visiting during the day as night time driving posed a

problem for her on winding roads that were often ice covered. Some communities had volunteer drivers to provide assistance to these patients and families. This also allowed the caregiver a period of respite while someone else transported the patient to the appointment.

Coping and Coming Through the Experience

The theme of *Coping and Coming Through the Experience* refers to the caregivers' perceptions of factors that aided them through the experience. There were internal and external factors that enabled them to be the care provider for a dying person. Internal factors refer to qualities of personality and character that they, the caregiver, possessed such as hardiness and a sense of humour. External factors were those things that they could draw on from the community and institutions in their society.

The second part of this theme reveals how the caregivers perceive they are doing now and how this experience changed them and their perspectives on life.

There are eight sub-themes within this major thematic stream. They include: *Inner strength, Hardiness and innovation, Use of routines as a way of coping, Use of humour, Women as caregivers, Rural health care resources: home care, palliative care physicians and hospitals and local health care providers, Rural communities as caring communities, Faith and spirituality, and Bereavement: reconciling the experience and new priorities. Inner Strength, Hardiness and Innovation*

Several of the caregivers spoke of becoming aware of inner characteristics they possessed that they were not aware of previously. They spoke of an inner strength and an inner reserve, of hardiness and of possessing the capabilities to be innovative in caring

for their loved ones. It was these characteristics that they believed helped them cope during their time of caregiving.

It's amazing the strength you can find. If somebody would have told me a year or a month before that this is what I would do, I would say "There's no way!" And you know you did it. We all did it. You find strength where you just don't visualize there would ever be enough. There is something within you that just kicks up the next notch to take you day by day.

One lady described herself as being hardy or becoming hardy during the caregiving experience. She jokingly referred to herself as being hardy like a perennial plant being able to survive the winter and still bloom again.

In order to cope and meet the demands of providing physical care, the caregivers needed to be innovative in overcoming difficulties. Grace, who has severe arthritis, found an innovative way of transferring her husband from the bed to the chair by breaking up the movement into little steps and letting the patient rest in between. Phyllis found a similar method of moving her husband unassisted in her home.

Use of Routines as a Way of Coping

Providing care for a dying family member was a chaotic, confusing and disorganizing experience for most of the participants. Their lives had been disrupted. Jobs and careers were put on hold and social activities and outings were curtailed. Establishing new routines and reverting back to familiar family-centred routines were an attempt at creating stability and organization.

In addition to helping the caregivers cope the caregivers believed the maintenance of normalcy in the household was beneficial for the patient. Routines enabled the patients to remain part of life even though they were dying. When asked what a typical day was like for them during the caregiving experience many stated they tried to maintain as

normal a day as possible. Most caregivers' stories about routine were centred on having coffee, reading the newspaper, eating meals together, and enjoying socialization with family. For some, maintaining this normal environment was very important. Gloria's story describes some of this.

When I was there I did exactly as she would have probably done. I would make breakfast and I would wash the dishes and I did the laundry and I pulled out her little washing machine. And I did it just the way she used to do it. I put the fireplace on if it was chilly or opened the blinds in the daytime and had the sunshine on her and the little things that I knew she liked. I had the TV on and I had her right in the heart of the home. She was surrounded by her regular noises. The TV noises like *Truth or Consequences* and *Alex Trebeck*, cartoons and the baseball game. Her bed was in the living room and we cooked our meals and we gave her drinks and *Ensure* and water and stuff. We had birthday parties. We had anniversary parties. We had people come in and have a drink with us. Her friends came over and we would sit at the dinner table she would entertain at and the kids would come and play cards while she was over in the bed. Her house was built with an open concept. She always said "When I'm in the kitchen I don't want to miss anything that's going on in the living room when people are visiting". She was always part of it. So that's the way we continued.

Routines became a way of conveying to the patient that they were still a part of the family, the household, and very much a part of the living. Routines or going about the normal business of living was seen as not giving up or losing hope for the dying person.

Routines did more than create structure for the caregivers and demonstrate respect for the patient. The routines were comforting reminders of good times spent with the dying person. These details were important as the caregivers told their stories to me. Minute details of the last days and weeks were related as cherished memories.

Use of Humour

When asked what lightened the load for them during the time of caregiving several of the participants responded that a sense of humour eased the stress and acted as

a release. Interestingly it was often the patient that instigated the humour. Mary's mother was at the point of not being able to eat. The one meal that the patient would attempt however was chicken soup. Upon bringing her mother the soup one day, her mother quipped, "What, is that all you can cook?" Humour, coming from the patient, in this situation eased the distress for the caregiver. As mentioned earlier, many caregivers found it distressing to watch the resulting weight loss from the inability to eat.

For one son and his father, humour allowed them to demonstrate love and caring for each other in an acceptable masculine way. The bachelor son gently teased his father (the patient) that he (the son) should have had him (the father) move in with him long ago because now the women in the community were bringing over baking. This eased the transition for the patient's move into the home of his son. This father and son had always related to each other in this fashion.

Other participants also attributed their (and the patient's) sense of humour as important in "lightening their load" during a difficult experience. Some exemplars are:

We (caregiver and patient) discussed what she (the patient) wanted for her funeral. And I mean we had fun with it, deciding how and what she wanted this to be and who she wanted to give the eulogy and so I think that was important....Nobody was allowed to wear a tie to the funeral. And she (the patient) would have somebody there to cut the bloody tie off him if he wore it to the church....Our family is crazy; it's off the wall. Very close brothers and sisters. We joked up until the time she died.

Another comment was: "One of the things that was very special was seeing my daughters interact with their dad. They could still make jokes with him and tease him about things".

Women as Caregivers

Some of the participants articulated that they felt being female made the job of caregiving easier. One reason cited was that women were conditioned to becoming nurturing care providers in their communities. The participants also identified the camaraderie enjoyed by women in general as enabling a supportive network for the caregiver.

Women in the study believed that females were seen as naturally being more nurturing and mothering and more natural as nurses. Caregiving was seen as an innately feminine virtue. One female participant expressed it this way: "As a woman, you think about everyone else first; making sure that their mentality and their well being is taken care of". The role of caretaker / caregiver is an expected role of the female gender. It was seen as a "given". This may have made it easier for the women in the study to become caregivers, as it was a comfortable fit into their view of the world. Grace, an elderly woman, described caregiving as "part of our (women's) history" and that not taking on the caregiving role would be seen by other women in their communities as a failure or disgraceful. It was seen as an unspoken expectation for the woman to assume the caregiving role. "Family always came first to my mother and we were raised that way. She would have done this for us". Women, mothering, nursing and caring are all concepts that were connected for these families.

In addition to the peer pressure or expectations of society one woman did feel pressured by her family to take over as primary caregiver. Helen, a married daughter without children, was assumed to be the one to take over the caregiving role for her

mother because she did not have children. The family assumed her role and responsibilities to be lighter than theirs as she did not have the mothering responsibilities.

One participant in the study addressed the area of the suitability of women as caregivers somewhat differently. Phyllis spoke of a special understanding among women and women supporting each other. Not only did she feel women are more suited to being caregivers, but the nature of women's relationships provides a valuable emotional support system. She called a female friend to come to assist her in caring for her husband. "She's always available and of course she brought her toothbrush and pajamas and stayed over". There was an unspoken understanding that what was needed was more than physical help and included emotional support or "standing by" and "being with" her friend for the longer term.

Rural Health Care Resources

This sub-theme addresses the issue of resources to support the dying patients and their families in the rural setting. The rural health care resources were generally viewed positively by the participants and associated with making the work of caregiving easier. All the families expressed satisfaction with the care received in their rural communities at the local delivery level. The resources or health care institutions addressed were: home care, palliative care, the physicians, the hospitals and nurses and other local care providers. Identified as a concern, was the issue of transportation in rural areas to access health care services.

Home care. Use of home care services varied among the patients. Several utilized home care for medications and nurse visits as well as personal care. Other families felt they were able to cope without home care. Two caregivers expressed frustration with

home care services. Both felt the services offered were not flexible enough to meet the needs of the patient. One lady was unable to get respite care for a sitter to stay with her husband so she could get out. There was also some confusion as to what services were provided by home care. One caregiver personally hired and paid for a sitter through the services offered to seniors in the community. This sitter was essential so the caregiver could go to work.

Several patients did not receive home care services because personal care was deemed too private to be provided by an outsider. For others however it seemed a better choice to have personal care provided by someone who did not know the patient. Occasionally by not allowing home care to come in, the cost was borne by the caregiver. To protect the privacy of the patient the caregiver sacrificed respite care and took on a burden that sometimes was substantial. One gentleman had heavy medical care for his wife and two elderly women struggled providing physical care for their husbands.

Palliative care. All caregivers in this study utilized the services of palliative care to some degree or another. Palliative care was seen as instrumental in enabling the caregivers to provide at-home care until death.

The palliative care volunteer visitor fit in perfectly. She didn't feel like an intruder in our house....She made it simple. She took care of us. She made it easy for us to do what we had to do. She took over all the rest of it, from making tea to just listening. She helped us more than she helped my sister (the patient). And therefore we could help my sister. She provided so much information on what was going to happen and what we could expect (both with the course of the illness and at the time of death). The support she brought was phenomenal. Just to have somebody's phone number to call day or night. How much more reassuring can it be than that?

Palliative care was seen as instrumental in assisting the rest of the family in addition to the primary caregiver to carry on. "They (family members) felt as though they

had their jobs to do and it made them feel they could do something. She (the palliative care volunteer) encouraged the family and kept them coming back day after day.”

The physicians. Five of the nine caregivers mentioned receiving care from the rural palliative care physician. Several mentioned that the patient had received a home visit from the doctor. They were both surprised and appreciative of the visits. They appreciated the openness and honesty from this physician as well as the compassion and caring from the regional oncology department.

Frustrations were evident, however, regarding the experiences the care providers had with the physicians in Winnipeg. They felt that neither they nor the patient were treated as persons but rather as a number or a particular “disease” in the larger centres.

The oncologist was not personable. And I can see where they turn themselves off. I know they can only reach a certain point and then they can't handle it any more. But this was the first time for us and this was my Mom.

Another caregiver related the distress she felt when she had to call the physician at the cancer clinic in Winnipeg when her mother took a turn for the worse. She was referred to a doctor she had never met. Her memories of the telephone conversation with this doctor reveal her frustration.

There was one time when she had a really high fever. And I was concerned. And I called in to the cancer clinic, and it was a doctor we had never met. And he kind of brushed me off and said, ‘Well if you're really worried you can bring her in to the Emergency (in Winnipeg).’ And I didn't want to bring her all the way (to Winnipeg) to the Emergency because she was so unwell. And then he said “Well if it really isn't an emergency...” That doctor made me feel like I shouldn't be calling.

The hospitals and local care providers. All the participants in the study received and were appreciative of the personable care received in the rural hospitals. Even though many of the patients started receiving care in Winnipeg, eventually the health care shifted

to the rural hospitals and doctors for all the patients. None of the patients were hospitalized in Winnipeg during the palliative phase of the illness. Patients and families appreciated being cared for by persons who knew who they were and had the information at their fingertips to respond to any crises.

A good thing was, I was able to call the hospital and they told me her chart was right there – just call. They'll know who you are and what she's on (painkillers) and what you can give her and not give her. In addition to making sure she's on her breakthrough medication.

Six of the caregivers mentioned how reassuring it was to know that their local hospital had a palliative care bed waiting for this patient should they need to be hospitalized. "They were very open to take him, day or night... There was always a bed and that made it easier to care for him. Because I knew they're there."

The caregivers also felt the hospital staff in the rural health care communities went out of their way to accommodate the dying patient and the family. During a blizzard one patient developed a very high fever. The wife called the hospital but they were unable to send an ambulance due to the weather. The nurse at the hospital knew another nurse that lived in the same village as this family. This nurse was contacted and she bundled up and walked over to the patient's house and spent the night. She stabilized the patient and brought the fever under control. Before leaving for her shift at the local hospital in the morning she made arrangements for the patient to be transferred to the hospital. In another community a patient needed to routinely go to the hospital for blood tests. This patient was dying of lung cancer and was very short of breath. A trip like that took most of his physical strength reserve and left both him and his wife exhausted. A friend who happened to be a lab technician at the local hospital passed through this remote community on her way to work. She volunteered to stop by the house in the

mornings and collect the blood specimen and take it in to the hospital. This saved the patient and the caregiver a lot of time and effort. Several caregivers mentioned that staff at the hospital or pharmacy would personally deliver supplies or medications to the patient's home.

In rural communities the patients knew most of the health care providers at the local hospital and it is not unusual for people to work in more than one facility. One man felt reassured when he recognized the ambulance driver who came to transport him to the hospital as the kindly orderly at the hospital who had cared for him on other admissions. There was a real sense of being treated with dignity and respect. This made a tough situation easier for the patient and the family.

Rural Communities as Caring Communities

This sub-theme refers to the support received from the rural social community and how this support assisted the caregivers in their task. Living in close rural communities for the most part helped the caregivers cope during their experiences. Many of the caregivers received offers of assistance. Neighbours could be called upon to assist and were very willing to help out in any way possible. Grace had a neighbour who was a nurse come over to provide respite care at night occasionally. She also called another neighbour to assist when her husband had fallen. "I just picked up the phone and called somebody that had never been in this house. And he said, 'Anytime. Anytime you need us you call us'. And others too. And they would have been here on the double". Most of the caregivers mentioned an outpouring of food coming into the home. There were also offers to care for the children of caregivers.

There was a real sense of social connectedness to the community. The literature review also expressed that rural communities are socially connected. If families are not bloodline relatives there usually is a long history of acquaintance at some level. Most of the caregivers knew the health care providers in the community and could call on them for information or assistance. This social connectedness was at the expense of loss of privacy for some families however. One lady refused home care because she did not want others coming into her home and knowing her affairs. Another lady did not want visitors to know how sick she was.

My Mom was a very private person. She didn't want to show people her illness. It surprised me when on the last Sunday she was home, the day before she went into palliative care, an aunt and uncle who rarely visit my Mom at her home, came to visit her. And my Mom had gone into the washroom and she stored everything that looked like it was connected to an illness in the bathtub and she pulled the shower curtain closed. It's like; "you're not seeing that part of me". So if there were community services out there, my Mom was sending the message that I'm dealing with it on my own.

Conversely, one lady did not experience the same compassion and caring from her community. She believes this was because her husband had an illness that had a stigma in the community. Her husband had suffered from mental illness for many years. She noticed that it was difficult for people in the community to speak with her about it.

I remember going to the grocery store and the person beside me would be asked, "How's your husband doing and how are the kids doing?" But never would anyone ask me "How is your husband doing?" And they knew he was in the hospital. They knew.

Two caregivers mentioned the fact that much of the community stayed away once the patient became gravely ill. One attributed it to them not wanting to see the patient wasting away and the other person attributed it to the community being afraid of death. One's own mortality seems real and looming when friends are dying.

Faith and Spirituality

This sub-theme concerns the role that the caregivers perceived of faith and spirituality in helping them through the difficult experience of caring for and then losing a loved one. Faith in a higher being and support from the church community sustained many of the caregivers. Several mentioned visits from clergy for both the patients and the families as being comforting before and around the time of death and helpful during the bereavement period. In addition, witnessing experiences that the caregivers interpreted as spiritual sustained the caregivers and comforted them. These were not so much experiences of the caregiver but what they perceived was happening to the patient.

An example of an experience the caregiver referred to as spiritual as the patient neared death was:

But she just hung on. And finally we called in a minister. And we just stood around the bed and said the Lord's Prayer...and my son, he was six, was sitting on the bed with her. He was brushing her hair. He wanted Auntie to look beautiful for the angels. Within an hour she took her last breath.

Here they believed their faith and prayer facilitated a peaceful death.

Some families drew upon traditions of their faith near the time of death even though they had not been actively practicing them recently. Several mentioned saying the Lord's Prayer or reciting portions of scripture around the bedside of the patient. Some of the caregivers believed these traditions were important and should be brought to the patient. When Helen's mother became confused near the end of her life she brought a tape of the Rosary and played it for her mother. She stated she believed it would help her mother "link back to some routine of her spiritual self".

Stories that the caregivers shared during the interviews had spiritual overtones and images in them. Several of these centred around a real sense that the dying person had passed on to a better life or passed into heaven or to meet those gone before.

Her eyes were still open and she didn't say much. And out of the blue her eyes opened and she was looking out of the window. And their farm is beautiful. And she has this most peaceful beautiful look on her face. And she started to smile. I asked her "What are you smiling at?" You know she said, "the people". I said, "what people?" And she said "the people in the hallway", and she's looking out the window. I say, "What are the people doing?". She said, "They're just waiting, waiting to go home". It gave me a chill up my spine. I said, "Are you waiting?" And she said, "No it's not my turn yet". And she saw Mom. She talked to Mom....And even if you don't believe, even if it wasn't real, it helps you through. It's comforting.

Bereavement: Reconciling the Experience, New Priorities

This sub-theme of *Coping and Coming Through the Experience* refers to the "coming through" part of the experience. This sub-theme examines the overall "taste" left in the mouths of those who embarked on the experience. It explores the positive as well as the negative aspects and includes the caregivers' reflections on grief and grieving and how they think the experience affected their priorities.

The positive aspects of the caregiving experience. The caregivers' stories reveal many positive aspects of caring for the patient in the home setting. At home there were opportunities for the tying up of loose ends or unfinished business in the family, precious conversations and healing of rifts in families and time for intimacy and just being together. Caring for the patient in the privacy of one's home afforded the patient some dignity which most of the caregivers felt would be lost in a hospital setting. Some also believed that allowing the patient to remain interested in the affairs of the family was respectful and did not exclude the patient from being part of the living. Other positive aspects of the experience included: the satisfaction of being able to "do" something for

the patient, the satisfaction of fulfilling the patient's wishes and for some, the experience of being with the patient as they died. One caregiver described going through this experience as completion of the cycle of life. "Death is a part of life and this just kind of finishes the cycle for you". In addition death at home normalized the dying experience for family members.

The closeness and the intimacy shared between the patient, the caregivers, and the family during the palliative phase were seen as positive. Some of the comments were: "We talked about things that would have probably never been talked about. The closeness we had helped a lot with the ending". Traditions were handed off from one generation to another and there was much time for reminiscing.

Reflecting on their experiences, the caregivers felt that much of the positive nature of the experience could be attributed to caring for the patient in the home as opposed to the hospital. There was the belief that this type of experience would be difficult to come by in the hospital setting. One caregiver viewed it this way,

We need to give them so much dignity. We need to provide them with time to reflect. Like to talk about all the good and the bad times. And that can sometimes only happen in the household because that's where your memories are often made. You sit around the card table and you start shooting the breeze and you start talking about those good old days. It's kind of hard to do that when you're in the hospital and you're not playing cards and you're looking to see whether or not that person's chest is rising and falling all the time. And there are people interrupting, coming to turn them and stuff.

It was important to all the caregivers that they had been able to assist in fulfilling the wishes of the patient by caring for them at home. "When we got her pain under control, she woke up and she knew where she was. And that just made her dying so much

easier because this is what she wanted right from day one". The gratitude expressed verbally or in spirit by the patient made all the work worthwhile.

For some families it was important to include the children in the experience. This was seen as a positive experience and normalized death and dying for the family. Paula's children were with their aunt when she died, as were Gloria's children with their grandmother. Gloria stated,

Dying is a part of living. And it's terribly important that the kids see not only the beginning of life but also the end of life. Because it doesn't have to be scary and it doesn't have to be horrendous.

The caregiving experience had a profound effect on all individuals interviewed for the study. With the passing of time the positive aspects of the caregiving experiences seem to prevail over the negative ones. Several participants described this as the best experience of their life.

The negative aspects of the caregiving experience. The negative experiences are reflected under the first theme, *the Work of Caregiving*. They include: the psychological distress in watching their loved one suffer, feeling overwhelmed with both the physical care of the patient and the information needed to carry out that care, the uncertainty associated with a terminal illness and death, incredible fatigue, feeling overwhelmed with taking on new roles, and guilt and feelings of insecurity as to whether the correct proxy decisions were made for the patient by the caregiver.

Grief and mourning. This study would not have been complete without some discussion of grief and the grieving experience. For these caregivers this was a very memorable and for some a life altering experience. A brief discussion of grief and the work of mourning is included in Chapter Six's discussion of the findings. Several aspects

of the bereavement period will be presented here. One aspect of grief is anticipatory grieving. Anticipatory grief in this study is defined as grieving before the person has died. The family starts to anticipate what life will be like without this person. Anticipatory grieving was significant for some of the caregivers. Paula described anticipatory grief as she witnessed it in her family: "You start to grieve before she's dead. Because you're watching her die. You know she's not going to be here. They (the patient and spouse) grieved together early on, both of them for the things they weren't going to do together."

There was a sense for most of the caregivers that the bereavement was easier because they had been there for the dying person and had provided the care. Knowing that the death had been peaceful was reassuring for all the caregivers. The knowledge that they had been able to ease the transition from life to death lessened the grief. "It was the perfect situation. It was peaceful for her. I know it was. I knew we had done all we could do and it was the right thing for her".

All the caregivers shared some of their memories about the day and time of death. Several caregivers spoke of the abrupt ending that death brought. When the patient died there was a real sense of death's finality. This person who was part of the family life, even though they were dying at one moment, is gone the next. Sally, seven months following the death of her husband, expressed that reality of the death has not yet settled in.

I don't know if I still realize it. The last year of his life he was close to death several times. I could not comprehend that he was really going. We saw him dying, we were there but it is still as if the realization had not yet set in to say our good-byes because this was it.

Phyllis as well knew death was imminent but didn't really expect her husband to die on the day he did. Gloria cannot remember what they did with the hospital bed that was in

their home or any other details in cleaning up after the death. All those details were no longer important.

The fatigue and exhaustion from the experience delayed the grieving for some as mentioned earlier. There was a tension between relief that the suffering was over for the patient and the busyness was gone for the caregiver, with feelings of loss and sadness. For some of the caregivers adjusting to a life without the patient has been difficult. Al cared for his wife for an extended period of time where the patient required heavy physical and complicated medical care. Even a year after the death he finds it difficult to go out even on errands without feeling the need to rush back. "Even when I walk out into the garden I take the cell phone with me because when she was here I always had a phone with me...in case she needed me". He also spoke about continuing on without his partner.

You get used to things. You're not happy but you get used to things. When I get up in the morning I miss her, but I'm used to it now that she won't be here any more. So some things do change.

Effect on priorities. Most of the caregivers shared that this experience had altered their view on life and changed their priorities. Family and relationships have become more important. Mending relationships and spending time with family and friends is important. Careers and possessions have taken on less importance. Sally believes her children have become more aware of each other and are more supportive. Helen now asks herself if there is meaning in the work she does. Is it important to other people? Does it make a difference? Al, after caring for his dying wife, has become more aware and sensitive to others in his community who are going through a similar experience. He stated, "You see the world in a whole different light. You're not the same any more".

Summary

Chapter Five presented the findings from the data. The sampling process was discussed, as was the data analysis process. The sample size was adequate for this approach to the research question. The participants were able to share their impressions and memories of the experience. Componential analysis was done to extract themes from the data. A prolonged period of time was spent with the interview data after which two themes emerged. A demographic profile of the caregivers was presented and summarized in a table.

This chapter introduced the two themes and expanded on their attributes and sub-themes. The theme of the *Work of Caregiving* was divided into five sub-themes describing the caregiver's *Sense of Mission, the Problem of Fatigue, Uncertainty, the Challenges of Pain and Other Symptoms and Role overload and Effects on Lifestyle*. The second theme *Coping and Coming Through the Experience* describes the resources both in the rural community as well as internal resources the caregivers needed to come through the experience. This theme portrays the reflective part of the experience as the caregivers look back on it. It also gives the readers a sense of how the caregivers view grief and bereavement and how this experience changed their perspectives on life.

CHAPTER SIX

DISCUSSION, RECOMMENDATIONS, AND CONCLUSION

This final chapter will present a discussion of the research study. The discussion is based on findings from Chapter Five. A short discussion of the approach and methodology employed in this study will be presented. The findings will be reviewed against the backdrop of the review of the literature (Chapter 2) and conceptual framework – *The Framework for Understanding the Primary Caregiver Experience* (Chapter Three). Limitations of this study will be presented followed by a discussion of the salient points derived from the themes. The caregivers' stories provided not only insights into the challenges and frustrations facing caregivers in the community but also provided a sense of what was working well and suggestions as to how to improve the situation. Therefore included in this part of the discussion, will be recommendations for policy, practice, education and research.

Discussion and Recommendations

The Approach

The qualitative approach of ethnography was appropriate for this study. Ethnography seeks to understand the human experience within the context of a culture or a world-view. The stories of the participants are reflective of their world-view in the personal context of their caregiving experience. The narratives are representative of their experiences at a specific period of time. The time they spent caregiving is examined in the social context of rural Manitoba. While many aspects of the experience – both positive and negative, evident in the findings, might be voiced by urban caregivers, there

are aspects of the caregiving experience that are unique to the rural setting. These aspects will be incorporated into discussion section *Salient Points for Discussion*.

The Conceptual Framework

The Framework for Understanding the Primary Caregiver Experience (Meyers & Gray, 2001) was selected to inform this research study prior to the collection of data (Appendix A). This framework was selected as it best represented the review of the literature from Chapter Two. This framework seemed to sum up and organize the information from the preliminary literature review.

The theme identified as the *Work of Caregiving* echoes some of the factors labelled in the conceptual framework as stressors. Fatigue and physical exhaustion, role changes and the distress produced by an uncertain illness trajectory are all reflected as “stressors” in this framework. What are missing in the framework however are the positive aspects of the caregiving experience. Throughout the findings in both themes *The Work of Caregiving* and *Coping and Coming Through the Experience*, are stories of joy, rewards of the experience, peace and resolution. Caregivers described this as “the best experience of their lives”, and in reflecting on their experiences voiced this “as a privilege and not wanting it any other way”. The participants reported, for example, that they did not even realize how tired they were during the time they were providing care because of a sense of “mission”. They believed they were doing what was in the best interests of the patient. There was healing of rifts in some families and a sense of cohesiveness and intimacy for most of the families. By allowing the death to take place at home and close to all generations of the family there was a sense of “completing the circle of life”. The participants believed they had become stronger and had a fresh

perspective on life with new priorities. This corroborates with the literature on palliative family member caregiving experiences (Brown & Stetz, 1999; Holing, 1986; Hunt, 2003; Schachter, 1992; Stajduhar, 2003).

The conceptual framework does reflect some of the mediating factors in dealing with stress, identified in the study's findings, such as the caregivers' coping strategies and external supports such as hospice care. The findings however do present some additional mitigating factors or present some enhanced descriptions of those factors under the theme *Coping and Coming Through the Experience*. For example, caregiver qualities such as maintaining a sense of humour, and being innovative were seen as mitigating factors for the caregivers. Also the neighbourliness of rural communities was viewed as a factor in assisting the caregivers.

Humour as a way of coping can allow the individual to view the stressful situation from a different perspective and view it as less threatening and more of a challenge (Honing, 1986; Martin, 1989).

Internal factors or qualities of personality such as hardiness and courage also sustained these care providers in the study. This will be further elaborated on under the *Profile of the Caregiver*

Most of the caregivers believed that the caregiving role was easier for women. For example one gentleman felt his masculine "trucker's" hands were too large and lacking in the dexterity needed to draw up his wife's medications in a syringe. Other caregivers believed that women were better suited to the caregiver role, as they had been doing this throughout their whole lives as nurturers and mothers. Caregivers also learned to cope by being innovative and developing new routines. Several elderly women related

how they had discovered innovative ways of performing physically difficult tasks such as transferring their husbands from bed to chair. Developing new routines was another factor that aided the caregivers. One example was taking rests at times when the patient might be sleeping. For some this meant taking the phone off the hook and drawing the drapes during the day to get rest. Hull (1992) identifies this method of coping as “changing the environment”. When it is difficult to cope, developing routines and restructuring the order of affairs in the home gives the caregiver a sense of control.

A stress for the caregivers was coping with uncertainty. Responses to coping with uncertainty such as that of an uncertain illness trajectory are individualized. The literature has identified a coping strategy such as “taking one day at a time” or reframing the experience. The caregiver when faced with uncertainty takes the negative aspects or possibilities of poor outcomes and cognitively reformulates the experience to derive meaning (Hull, 1992). Several of the caregivers expressed that they just “took one day at a time” and felt “blessed for having some time to spend with the (patient)”. The literature identifies that coping strategies aimed to “alter or manage the stressful environment or the meaning of the stressors are linked to lower levels of depression and anxiety” (Kinsella et al., 2000, p. 46).

A mitigating factor in reducing uncertainty is providing education and information (Stajduar, 2003). A dilemma arises when the doctors don’t have the information either. Lamont and Christakis (2003) write that with the de-emphasis of prognosis in favor of diagnosis and therapeutics in the medical literature, physicians may have difficulty finding the survival information they need to make appropriate estimates of survival for patients who develop cancer. It can also be difficult for doctors to disclose

prognostic information to clients. What does that do to hope the patient might have and what happens when the “patient does not die on time”?

Faith and spirituality are not identified in the model of conceptual framework as mediating factors. However Meyers and Gray (2001) do include faith and spirituality as being positively associated with the ability to cope (p. 22). Faith and spirituality assist the family to make sense of the experience and find comfort. An integrated review of the literature on faith and health by Lin and Bauer-Wu (2003) suggests that psycho-spiritual well-being assists not only the dying patient to cope more effectively with a terminal illness and find meaning in the experience but has the same benefits to family members.

External mediating factors included health care agencies and resources as well as supportive rural communities. Hospitals were seen as accommodating for palliative patients. Many family members mentioned how important it was to them to know they could call the hospital at any time of day or night and receive information and support from persons who knew the patient's condition. In addition most of the caregivers mentioned how vital it was to know there was a bed available for the patient if care could not be managed at home. Hospital staff was seen as being very accommodating and ready to go out of their way to provide service. For example in these rural communities supplies and services were often delivered by off duty staff on their way to or from work. The staff did this out of concern for the families and patients without reimbursement. Rural communities were viewed as supportive with neighbours offering practical assistance for the families. One lady stated that neighbours came over and managed the farming operations without being asked. This component of social connectedness, anticipating the needs of others and responding generously, I believe, is unique to rural communities.

This fits with the literature that supports the claim that volunteerism is predominant in rural communities (Bushy, 1991; Weinert & Long, 1987). In the researcher's opinion this is reflective of the pioneer roots of Canadians. People living in remote areas have always needed to be innovative and pull together to survive. The Central RHA community assessment profile identifies the existence of a large volunteer base as a strength of this region (RHA Central - Manitoba, 1998).

Role changes for the caregiver necessitated by caring for a dying person are identified as significant factors in this model. Role changes and taking on new roles did in fact have a significant impact on the caregiving experience. The findings from this study, as well as from the literature review, support the notion of stress placed on the caregivers and their families as they attempted to take on new roles as well as juggle all other responsibilities (Davis et al., 1996; Meyers & Gray, 2001). The role of advocate for the patient and for the caregiver's own needs can leave the caregiver exhausted. In addition the role of advocate may necessitate the caregiver to make decisions as a proxy for the patient. This can leave the caregiver with unresolved guilt. He / she may have had to make decisions in opposition to what the patient may have wanted leaving them with feelings of guilt (Hull, 1992; Stajduhar, 2003).

A shortcoming of utilizing the Meyers and Gray (2001) framework for this study is that the rural culture component is not present. The significance is that this is an ethnographical study looking at the caregiving experience in the context of the rural culture. Perhaps an adaptation of this model could include the rural culture component as encompassing the context, the stressors and the mediating factors. For example some elements of "rurality" such as caring and socially connected communities would have

been mitigating factors. Having to drive long distances to access services would have been a stressor. This shows the need for adaptations to the framework used, based on use and development of other frameworks addressing palliative care, the work of caregiving, and the rural family caregiver.

Limitations of the Study

While the data derived from the stories of the nine participants was rich and insightful, aspects of the caregiving experience may have been missed. The Central RHA is culturally and geographically diverse and this sample may not have reflected that diversity. The sample was recruited by palliative care coordinators from across the region. The sample is representative of the diverse geography but it may possibly not present a true picture of the culture. The more densely populated areas may be underrepresented. Further study would be recommended with recruitment of participants on a per capita basis in these communities. In addition Aboriginal groups are not represented at all.

As discussed in Chapter Four another limitation of the study might be that the participants were all recruited by the palliative care coordinators. This would eliminate families who were not formally connected with the palliative care program. In addition the question must be raised about the recruitment process. Those who did not have a positive experience and were not willing to speak about it may have been missed. The instruction to the palliative care coordinators was to recruit persons who “were willing to speak about this experience”.

Future research should include recruitment strategies to include Aboriginals, those with negative experiences as caregivers, those not connected to formal palliative

care programs as well as recruiting more participants from heavier populated towns. In addition focus groups of caregivers from rural areas could provide a variety of views and should be considered for future research. This study must be considered within these limitations and may not provide a complete representation across all settings or jurisdictions.

Salient Points Derived from the Themes

Salient points from the identified themes will be discussed and compared to the literature review. Recommendations for policy, practice, education and research are incorporated into this discussion.

Points for discussion include the following: the participants' perceptions about the quality of end-of-life care in their communities; socio-economic status and the costs of dying at home; who are the patients and the caregivers; delayed grieving as a result of the caregivers' exhaustion; the refusal of respite and home care services; primary care and the problem of transportation; coordination of hospice services; the challenges of complicated and heavy physical care; preventing undue stress and burnout of caregivers; pain control; flexibility in services; and practical support / volunteers.

Perceived Quality of End-of-Life Care in Rural Manitoba

Despite barriers and individual challenges to providing hospice care, overall the caregivers held in high regard the end-of-life care provided in their rural communities. There were many stories of health care providers going out of their way to facilitate the hospice process for families. Many nurses, physicians, and other health care providers made house calls and provided after hours care that was not expected in their job. For the most part, hospitals were seen as being accommodating toward palliative patients and

many caregivers expressed that just knowing this support was there had a large influence in their ability to carry out caring for a patient at home. This is supported by the literature on dying at home. Having a "life-line" or 24-hour support available can give families the confidence to provide at-home-care (Graham, 2002; Vachon, 1998). Most of the caregivers had called the hospital at some point for guidance and advice. All the caregivers expressed how important it was to feel that the health care staff knew them and treated them personably. This fits with the literature review exposition of rural communities. Persons to be trusted are from within the community and there is a real feeling of social connectedness (Bushy, 1991; Wainwright, 2000; Weinert & Long, 1987).

Socio-economic Status and the Costs of Dying at Home

The literature points to the fact that most persons who are able to receive end-of-life care at home are of a higher socio-economic status (Gilbar & Steiner, 1996; Seale et al., 1997; Vachon, 1998). While specifics about the family's socio-economic status were not fully explored, the findings are supported in the literature. Even in the Canadian health care system where there is universal health care there were costs that were borne by the patient and the family. Some families covered the costs of supplies such as syringes and alcohol swabs when they themselves were administering the medications. Those not receiving the services of home care seemed to bear more costs. For example, had home care been providing the service such as injections for pain control, the syringes and alcohol swabs would have been provided. Home care also provides dressings and items such as disposable gloves if they are providing the service.

There seemed to be inconsistencies in whether or not the cost of pain medication was covered by the provincial medical insurance. One elderly gentleman's pain medication was covered but some others were not. One lady mentioned the cost of pain patch medications and wondered how some other families could manage the cost even though they themselves did not experience hardship. Since the time these participants provided care there have been policy changes directed at ensuring coverage for medications for palliative patients. There were, however, inconsistencies in this study that did not become apparent to the researcher until near the end of the data collection process. This too could have been more fully explored and would be a recommendation for future research. It may have been that some caregivers were not aware that supplies like dressings and syringes could be covered. It is important that policy makers understand and continue to ensure complete coverage of medications and supplies for palliative patients whether they chose to die at home or in a facility. It is also recommended that information be made available about what services and supplies can be obtained for free to palliative patients and their families.

Families covered the costs of modifications made to the home and in some instances purchased equipment as well. These modifications included adding secondary handrails to stairways and installing handheld showers for ease in bathing. One family installed privacy curtains to partition off a living room to facilitate caring for the patient on the main floor. Wheelchairs and commodes for toileting could be loaned through home care services but smaller items such as bedpans needed to be purchased. Several caregivers expressed concern that providing care at home might be prohibitive for some families because of these costs.

Several caregivers quit their jobs or took extended leaves to care for the patient.

One nurse caregiver did not feel she had the option to take a leave to care for her mother and therefore quit her job. This was in part due to the uncertainty created by this illness trajectory. She did not know how long she would be caring for her mother. She had returned to work around the time of the interview but had lost some of her benefits and seniority. During the time she was off work the family did have to make some accommodations to live on a reduced income. Ceasing employment may not be an option for some family members and may have prohibited them from providing care. Since the time of the study the Canadian government has instated compassionate leave with pay to care for gravely ill family members for federal employees. It will be important for health care providers to make family caregivers aware of this allowance so they can avail themselves of this benefit.

Another participant reduced her workload by about one half to juggle a job, a family and care for her mother. Several caregivers who continued working felt that they were not doing an adequate job in the workplace during this time. One caregiver expressed gratitude to her employer and co-workers for understanding her situation.

In addition eight of the nine patients at some point required an ambulance to transfer them to a hospital. Some had insurance coverage and some did not. None of the participants stated that this cost had created hardship for their family however several were quick to state that they recognized that others might not have the resources. It would be recommended that policy makers look at the costs of ambulance coverage for palliative patients.

A Profile of the Caregivers

The literature states it is less likely for patients to die at home if they require complicated care or where the burden of care is heavy or prolonged (Gilbar & Steiner, 1996; Vachon, 1998). This did not prove to be entirely true in the findings. One gentleman cared for his wife with very heavy and complicated care for a period of four years. This participant also did not fit into the expected profile of a caregiver as presented in the literature as he was a male. Sixty to eighty percent of caregivers in the literature are female.

The demographic profile of the caregivers fits with the profile of the caregiver from the literature review. The average age of the caregiver in this study was 58 years. The literature presented a similar age range of 59 to 65 years (Meyers & Gray, 2001; Stajduhar, 2003; Steele & Fitch, 1996; Weitzner & McMillan, 1999). The literature states the majority of caregivers (60 to 80%) tend to be wives caring for their husbands followed by daughters caring for a parent (Davis et al, 1996; Meyers & Gray, 2001). The subjects in this study showed slight differences with about 33% of the caregivers being wives. There were three wives, two daughters, one husband, one son, one sister, and one granddaughter who were caregivers. The literature states that it is usually one person that assumes the role of primary caregiver even though other family members may provide care (Given, 1995). This was the case in all families of the participants in the study. They assumed the role of primary caregiver with varying involvement from other family members and friends.

A discussion is warranted on the role of women as caregivers. The participants did view the caregiving role as a "women's role". Several attributed this to gender role

expectations in the rural community and others saw it as innate and “natural” for women to take on this role. One participant also articulated that this role of caregiver is easier for women to handle because women tend to draw on other women for emotional support and men tend not to. Psychologists have long held to the notion that the traditional female gender role is characterized by dependency and is relationship based while the male gender role is independent and less relationship based (Martin, 1991). For males to discuss difficulties with other males might be perceived as a weakness. Rural communities tend to adhere to traditional gender roles (Bigbee, 1993a; Conley & Burman, 1997; Weinart & Burman, 1994). Rural nursing researchers support the notion of women as assumed caregivers in rural communities (Bigbee, 1993b; Bushy 1991).

Traits of self-perceived hardiness and resiliency in the rural caregivers were visible in the data. This is consistent with the literature in determining who will be able to be a caregiver. The caregiver needs to be able to have a feeling of control over life and generally have a positive attitude when tackling life’s challenges. Bass and Bowman (1990) used these traits as indicators of the caregiver being actually able to fulfill the role. Hardiness has been defined as “a constellation of personality characteristics that function as a resistance source in encounter with stressful life events” (Kobasa, Maddi, & Kahn, 1982). The literature on hardiness identifies three components of hardiness – control, commitment and challenge (Bigbee 1993b, p. 41). Hardy persons find their experiences interesting and seek meaning from them. They expect change to be the norm and despite their stress maintain a perspective. They believe they will have the power to exert influence over the stress (Bigbee, 1993b, Ford-Gilboe & Cohen, 2000). This fits well

with the understanding of rural culture, which emphasizes independence, self-reliance and self-care.

Deciding to Provide Care at Home

For most of these caregivers the decision to care for the patient at home was based on a promise made to the patient, a sense that they (the caregiver) knew better than anyone else what the patient wanted as well as a sense of duty or obligation. These same motivators can be identified in the literature (Holing, 1986; Stajduhar, 2003; Weitzner & McMillan, 1999). For some of the caregivers this translated into their “mission” for caregiving.

In addition, the literature supports the concept that caring for a patient at home is a means of preserving the patient’s dignity (Chochinov, Hack, Hassard, Kristjansson, McClement, & Harlos, 2002). This study attempted to identify the extent to which dying patients are able to maintain a sense of dignity. Palliative patients who were cared for at home were more likely to have a sense of intact dignity and were less likely to feel anxious depressed or hopeless. This corroborates with the caregivers’ perceptions that caring for the patient at home was “best”.

There were comments made in the interviews that suggested the caregiving role was thrust upon several of the caregivers. Stajduhar (2003) noted in her study of family members who provided palliative care at home, that sometimes the caregivers felt “stuck” and “tied down” in their role. She noted significant variability in how the caregivers made their decisions to provide home care – all the way from making a “snap decision” without a lot of thought to “indifferent decisions” where they felt they had little choice, to “negotiated decisions” where a lot of thought and negotiation with the patient occurred.

Stajduhar (2003) found that sometimes caregivers felt that their "sacrifices were minimized" by persons who commented on "how wonderful it was" (p. 30) that they were providing this for their loved one. The notion of being "stuck" in the role once the decision was made to provide at-home care was not fully explored in the interviews. Further exploration may reveal if "feeling stuck" is in fact an issue for caregivers. Health care providers should be sensitive to caregivers and reassure them that there is "a way out" and that transferring the patient to the hospital for palliation is not a failure.

Delayed Grieving as a Result of Exhaustion

Fatigue to the point of physical exhaustion was evident in the data. Two of the participants expressed that the emotional and physical exhaustion prevented them from grieving. It took a year before several of these caregivers felt they were able to grieve.

Minimal literature was found specifically on the effects of delayed grief. However the literature on unresolved grief is useful. Grief has been defined in the literature as the "process of experiencing the psychological, behavioural, social, and physical reactions to the loss" (Marrone, 1998, p. 108). But Marrone goes on to state that grief is a passive reaction and is only the beginning of mourning. Mourning differs from grief or is an extension in the bereavement process. It is the active process of the bereaved "moving to re-orientate himself / herself in relation to the deceased, the self, the outside world" (p. 108). The positive outcome of uncomplicated mourning is an individual who knows the reality that their loved one is gone but yet can identify positive aspects of the mourning experience and can integrate the loss into their lives. Anticipatory grief or grieving before the patient dies may facilitate the process of mourning as the individual has begun to visualize what the world will be like without the deceased (Marrone). When

grieving is delayed however, complicated mourning may result. The literature describes the delayed or absent grief reaction as being unhealthy, likely to cause psychosomatic complaints such as headaches, insomnia and body pains. Absent grief reactions can be associated with life-threatening diseases such as heart disease and cancer (Marrone). Stroebe and Stroebe (1987) describe the *broken heart syndrome*, which refers to the findings that widows or widowers are more likely to die within the first two years of the death of a spouse.

In addition, several of the participants noted that immediately following the death of the family member there was strong and continuous support from friends, family and the community. These participants noted however that within several months the visits, the phone calls and other means of support dropped off. This is important in the context of delayed grieving, as these individuals would be less likely to have the needed support when they are finally able to grieve.

During each interview that I conducted, I noted how appreciative the participants were to talk about their experiences. To share what they had been through with a new person wanting to hear their story I believe is therapeutic. Some of these caregivers were well past the death event (up to two years). I believe families should receive bereavement support from palliative care programs either through a volunteer or a support group, if they want support, for at least one year and maybe beyond that. One palliative care coordinator suggested that it might also be beneficial to allow caregivers to share their story with someone who does not know them or know how the events in their situation unfolded. Caregivers and family members may be reluctant to share the negative aspects

of the experience with health care providers from their own rural communities. They might not want to offend anyone who they might need to call upon again in the future.

Refusal of Respite and Home Care

Fatigue was a significant factor for these caregivers yet only a few received respite care. Reasons for this were; the caregivers felt guilty leaving the patient, the caregivers felt it was their “mission” and did not want to leave, and sometimes the patient did not want persons other than family members caring for them. These findings echo what was presented in the literature and add the rural mindset dimension of a “work ethic”.

Faced with the responsibility of caring for a terminally ill family member in addition to the demanding work of running a farm, what do most families do? They work harder. They can't neglect the farm work, and they can't neglect the patient. This can lead to stress, exhaustion, burnout and physical illness in the caregivers. (Health Canada, 1999b, p. 4)

One caregiver also reported that they were unable to get home care services until it was too late (the day the patient died).

Health care providers need to take charge and strongly encourage respite even for short periods. It might be only long enough to take a nap or go for a walk outside in the yard. Care providers need to have someone assist them to care for themselves.

Refusal of home care services by the patient is not surprising when one considers what is known about rural communities. Everybody knows everybody else's business in a small community. The literature refers to this as “living in a fishbowl” (Wainright, 2000). The possibility that the patient would know the direct service provider in a small community is considerable. Home care and respite services need to be offered in a professional manner with assurances of maintaining the strictest confidentiality. In

addition, when a home becomes the central hub for patient care with equipment and health care providers coming into the home the “sense of comfort and privacy associated with home, a place where we are at liberty to be ourselves” (Stajduhar, 2003, p. 33) is lost. Those coordinating home care and palliative care can be instrumental in working with families and other health care providers to make the delivery of services the least intrusive as possible with the minimal number of health care providers coming into the home and assist families when setting up the ‘sick room’ for the patient in the home.

Primary Care and the Problem of Transportation

Frustrations with health care tended to revolve around visits to doctors in Winnipeg who were not seen as caring. Patients found travel difficult and tiring and they believed the physicians did not really know them. This translated into feelings of physicians not caring about them. Perhaps the expectations the caregivers held were based on their experiences at the local rural level. All the participants spoke highly of rural physicians who took the time to listen to their concerns and went out of their way for them. Therefore it is recommended that as soon as possible after a patient has been declared palliative, the primary care would be shifted from Winnipeg to the patient’s community health care facility and local physician. Oncology care and palliative care can be directed from the health care facilities in the Central RHA. In addition it is important to promote and support any local initiatives where volunteer drivers transport patients and their families to appointments both within and outside the region.

Coordination of Hospice Service

Provision of hospice care requires a coordinated team effort between home care services, the palliative care volunteer visitation program, pastoral care, the local hospital,

dietary, physiotherapy, occupational therapy and the physician. In some of the communities cohesive care was evident. Several caregivers mentioned how instrumental the palliative care coordinator was in facilitating and coordinating the care of the patient, providing emotional support to the family, and generally guiding them through the experience. For some of the caregivers, however, there were frustrations getting respite care and knowing where and how to access supplies and services. It is recommended that with the patient's permission and input, there be team efforts in the planning and delivery of palliative care in the region. This may mean a client / family conference with the various disciplines to coordinate care and services.

It is important that patients and their families be able to access information and services in their communities. Caregivers were often left on their own to find information and resources. It is recommended to have a booklet of all possible resources for the terminally ill patient and the family listing resources and a contact person. This list should be inclusive offering information on not only health care resources but also legal, spiritual, social, mental health and financial. The palliative care organizations at the local community level are in an ideal location to coordinate this "one-stop-shopping" type of approach to care.

The Challenge of Complicated and Heavy Physical Care

Three out of nine of the caregivers were nurses. A background and training in nursing made it easier for these caregivers to take on this role. The literature review suggests that the information needs of caregivers are great. There are demands not only to provide the physical nursing care but also to know where and how to access supplies and services (Conley & Burman, 1997; Harrington et al., 1996; Swanson et al., 1997;

Vachon, 1998). Social skills to access services and advocate for the patient as well as the ability to problem solve are also essential (Given, 1995; 1997; Jenson & Given, 1991).

Several of the nurse caregivers expressed that they could not comprehend how someone could physically care for a patient at home without this valuable training. It is recommended that health care providers encourage the accessing and utilization of home care nursing services. This would address the challenges of caring for patients with heavy or complicated care and also avoid overwhelming the caregiver. The literature does point out that patients where the physical care is complicated or where there is prolonged caregiving are least likely to die at home (Gilbar & Steiner, 1996; Vachon, 1998). In addition when nurses are caring for family members they need to be treated as any non-professional caregiver without assuming they know everything.

Preventing Undue Stress and Burnout of Caregivers

One caregiver in the study described performing a painful dressing change on her loved one as the hardest part of the caregiving experience. Therefore even if caregivers have health care training they should not be expected to perform unpleasant or painful procedures on their family members. It is one thing to care for a patient but it is very different caring for a loved one. Home care and palliative nurses need to explore this gently with family members who are prepared and trained to take on these tasks. The health care professional needs to be truthful about the pain or discomfort the patient might experience and be ready to send in replacements if needed. In rural areas it is commonplace for people to assume multiple roles in the community and nurses may wind up caring for friends and relatives at work. When a caregiver becomes the nurse inflicting treatments on the patient she / he loses the opportunity to simply be the daughter, spouse,

granddaughter etc. Health care providers need to lift this responsibility of being “the nurse” from the caregivers or relieve them from their professional role.

Pain Control

Pain management for the patient was a major concern of these caregivers. Several expressed frustration and loss of confidence in the medical system when trial and error was used to find the most appropriate medication.

It is important that all patients can benefit from the latest evidence based practice in pain management. It would be important that family physicians avail themselves of this information and collaborate with the regional palliative care physician. Another recommendation would be for health care professionals to involve family caregivers and patients in the decision-making processes of choosing analgesics to control pain. Side effects of pain medication such as hallucinations were often distressing for patients and their families in four of the interviews and they should be aware of this.

Bearing witness to pain and suffering in their loved ones has been documented in the literature. Kristjansson and Ashcroft (1994), in a study with families of cancer patients, noted that adverse symptoms and pain are not only phenomena experienced by the dying individual but are experienced by the entire family. Pain and suffering prompt a search for meaning and meaningfulness is strongly correlated to global quality of life for both the patient and the family (Mehta & Ezer, 2003). In pain associated with cancer, that pain is a reminder of inevitable death. In addition witnessing their loved ones in pain left caregivers with feelings of helplessness, fear and unfairness (Ferrell & Dean, 1995).

Watching their loved ones in pain can have lasting effects on the caregiver. They may be haunted by the memories of watching their loved one suffer. They may have had

feelings of helplessness or guilt or may feel anger and blame the health care system for the suffering of the patient (Marrone, 1998). Pain control must be paramount in palliative care following best practice guidelines. Health care providers need to understand that pain affects the whole family, not only the individual. Support and counselling for family members may be needed during the palliative phase and during bereavement.

Emotional Pain

The literature did reflect the psychological or emotional pain experienced by the caregiver as being the most distressing. Interpersonal relationships with the dying person (Nolan et al., 1990; Pasacreta & McCorkle, 2000; Vachon, 1998), uncertainty caused by the illness trajectory (Hinds, 1985; Weitzner & McMillan, 1999) and bearing witness to uncontrolled pain in the patient (Given, 1995) were the major causes for psychological distress reported in the literature. The stress resulting from interpersonal relationships refers to the barrage of emotions experienced by the caregiver as he/ she is dealing with his / her own senses of loss and grief as and are trying to support the dying person emotionally.

The findings from this study also reveal another cause for emotional pain. This is psychological pain inflicted by health care providers and sometimes institutions. Dr. David Kuhl (2003) coined the term *iatrogenic suffering* to describe this type of pain. While he uses this description primarily to describe the emotional pain of patients it can be easily extended to include the pain inflicted on family members and caregivers. Health care providers do not intentionally inflict pain on patients and their families but the health care provider's own psychological issues and time pressures may portray an attitude of uncaring. Responding to the "disease" as opposed to responding to the "person" can

cause this type of suffering. Inflicting emotional pain results from poor communication techniques. The health care provider may use vague descriptions or medical jargon to portray bad news. He / she may be silent at the wrong time or fill an important silence with nervous chatter.

Helen's story revealed an experience like this. When the treatments had failed, the doctor told the family they "would let the patient fly on her own from here and then they booked another appointment". This added to the uncertainty and fear for the patient and family. They felt on one hand that they were being abandoned because the treatments were not working and yet were being asked to return for another appointment. Dr. Kuhl (2003), himself a physician, provides an understanding of what happens between a patient / family member and a doctor that adds to emotional distress. The doctor did not explain what had happened with the course of the disease but more importantly did not stop to check on how the patient and her daughter were taking this or what the implications were for them. Kuhl would explain this doctor's response as a coping mechanism. The doctor is dealing with a sense of failure – the disease has not responded to treatment.

The timing is such that most often bad news is delivered at a time when the emotional needs of the patient and family are greatest and the doctor's training to address those needs is minimal. The patient longs for a message from the heart, whereas the doctor is trained to communicate the facts. An emotional need is met with a cognitive response. (Kuhl, 2003, p. 53)

The tone and manner of the health care provider portray an unspoken message. The fears and unresolved psychological issues of the care provider can be portrayed as uncaring. Mary also experienced this response from a physician in caring for her mother as she was dying.

The oncologist was not personable. And I can see where they turn themselves off. I know they can only reach a certain point and then they can't handle it any more. But this was the first time for us and this was my Mom.

Kuhl's (2003) response to removing iatrogenic suffering is through improving communication techniques for doctors, nurses and other health care providers. We as health care providers must be willing to face our own fears of terminal illness and death and treat patients as persons rather than diseases. Relieving emotional suffering comes through active listening to the patient and family and treating them with the utmost respect.

Communicating (bad news) is best if it is given in the context of a close relationship between the physician and the patient, one characterized by mutual respect, trust, and honesty. Such a relationship is not created overnight but is built up over time... The clinical objectivity that should enter into our decisions must come from a doctor familiar with our values and the lives we have led, and not just the virtual stranger whose super specialized biomedical skills we have called upon. (Kuhl, 2003, p. 293)

This quotation again reinforces the idea to have patients cared for in their rural communities where they are known and are more likely to be treated personably. The patients, caregivers and health care providers in a community have a history, a cultural understanding and a social connectedness apart from the illness and disease process.

Flexibility in Services

There is a need for more flexibility and imagination in the delivery of health care services when we are dealing with the dying. It could mean ordering new equipment that had never been used before, or sending in caregivers at unusual times. It will take courage for health care providers to move beyond the routine services. It has been said, "Sometimes you just need to jump and grow wings on the way down" (author unknown). Coordinators of home care palliative care and hospice care programs need to be flexible

and willing to take risks and allow the direct service providers some flexibility in delivering services to accommodate the wishes of the dying. If home care and palliative care programs adopted this attitude we might see patients and their families getting their needs met and wishes fulfilled, even the unusual. One lady told me after the tape recorder was turned off, that one thing her husband wanted was to go outside during a gentle snowfall in December. As he was very frail they could not think of a way of doing this. When she mentioned this to the home care coordinator she was told home care did not provide services like that and this was not possible without any further discussion or consideration. Maybe we, as health care providers, need to imagine and scheme for what might seem ridiculous. Even the knowledge that someone had tried to accommodate a patient's wishes would go a long way.

Practical Support / Volunteers

One must never underestimate the care provided by well-intentioned caring neighbours in rural communities. Offers of childcare, assistance with meals and housekeeping, or even the compassionate ear of a neighbour sustained these caregivers through a rough time. The literature review showed that volunteerism is high in the Central RHA and generally in rural communities. This is a tremendous resource to families of dying patients. Sustained efforts placed into harnessing these wonderful individuals who give of themselves for others are a necessity. Local palliative care organizations should be on the lookout to recruit volunteers and to then provide training to maximize this resource.

Recommendations and Implications for Policy, Practice, Education and Research

These findings can have implications for policy, practice, education and research. Embedded in this discussion are recommendations that arose from the findings. A summary of these recommendations follows and includes a Table of the Summary of Recommendations. These recommendations however needed to be considered in a balance of the many things that were wonderful representations of excellence in health care in the Central RHA and are not intended to degrade the quality of health care, as it existed at the time of the interviews, in this region.

Future Research

There is a need for development of conceptual frameworks addressing palliative care, the work of caregiving and the rural family caregiver. There has been little research in this area especially from the rural perspective. A framework would be useful to understand the experience and direct future studies.

A limitation of this study was the under-representation of some groups. It is recommended that further studies recruit participant groups who were not represented in this study. These include those who might not necessarily be connected to a formal palliative care program, those with negative experiences and Aboriginals. In addition areas with larger populations may need a greater number of participants recruited to provide a fairer representation.

Recommendations to Ease the Financial Burden of Caregiving

Several recommendations arose related to easing the financial stress on caregivers. Families and patients need to be aware that medications are now covered for

palliative patients. This was not the case during the time some of these participants were caregivers.

Education of health care providers as to the benefits is essential so patients and families receive the information. In addition, health care providers need to be able to assist clients and their families to avail themselves of covered services such as rental of hospital and medical equipment and supplies through the provincial home care programs. In this study several caregivers bought equipment that could have been rented but the caregivers were not always aware of this.

Nurses and doctors need to have the knowledge or know where to refer families about the new caregiver paid leave available to federal employees. This might enable more people to become care providers for family members if they knew they would be partially reimbursed and return to a job.

A recommendation for change to policy would be to have ambulance transfers to the hospital covered for palliative patients without additional insurance. Eight out of nine patients in this study were transferred to the hospital at least once for treatment. The cost would be prohibitive for some families in the region and may affect whether patients are able to be cared for at home.

Families did not always know what services were available and how to access them. A recommendation would be to develop a resource booklet listing all services and service providers available for palliative patients and their families in the region. This booklet could be made available to patients and their families once they had been declared palliative.

Better Integration of Palliative Health Care Services

There is a need for better integration of health services for the terminally ill. The findings demonstrated that some caregivers had difficulty accessing services and there was little evidence of programs such as home care and palliative care working together. Networking between programs would create awareness as to what other programs were offering and would reduce overlaps and also help fill in the gaps. For example, getting respite care was a problem for several of the caregivers. It was difficult at times for the home care programs to find staff for respite at times that were beneficial for the families. Home care provides respite workers and palliative care programs in the region have volunteer respite workers. Cooperation and knowledge of each other's services can assist in coordinating services and reduce the gaps in the system.

There is also a need for flexible policies in home care that can accommodate the wishes of the dying patient. This may mean additional funding for palliative home care to accommodate additional staff if needed.

Ongoing Bereavement Support and Funding for Local Palliative Programs

Ongoing bereavement support was identified in the findings as a need. There is a need for individual support such as that which is already being offered through the local palliative care programs. In addition it would be recommended that there be grief and bereavement support groups offered consistently throughout the region as an additional place for caregivers to share their experiences if they so wish. These groups have been offered but on an inconsistent basis in several communities.

Policies in turn need to reflect the commitment to ongoing support for the bereaved as well as the dying. Currently local palliative care programs in the Central

RHA operate at the local level by raising their own funds. Hence energies of the volunteers are often used for fundraising rather than providing hospice care. More monies need to trickle down to the local palliative care organizations from the regional, provincial and federal levels.

Provision of Services Close to Home

The findings identified the difficulties encountered for patients and families when they had to travel to Winnipeg for care. Travel was difficult and uncomfortable for patients and many of the caregivers found driving difficult for a variety of reasons. The findings also reflected the high degree of perceived satisfaction with care provided in local rural hospitals and health care communities. This agrees with the literature (McRae et al., 2000). Therefore it is recommended that, as soon as possible after a patient has been declared palliative, the responsibility for care be shifted to a local physician and local health care community, if the patient so wishes. Physicians in the region can also be encouraged to access the regional palliative care physician as situations arise.

Reducing the Stress for Caregivers

Health care providers need to encourage the accessing and utilization of home care services. Respite care is important to address the fatigue of caregivers and nursing expertise is needed whenever there is complicated medical care or heavy physical care involved in caring for the patient.

Health care providers can assist families with the psychological distress, which can ensue if family members need to perform uncomfortable or painful procedures on a patient. Here again nurses and doctors can strongly encourage the utilization of

visiting nurses for this care. The family caregivers need to be given permission to excuse themselves from these tasks.

We, as health care providers, need to be aware of the effect our communication with families has on them and their perceptions about whether we care. Active listening is vital to demonstrate respect and understanding. Ongoing education and awareness of how we as health care providers listen and communicate is important.

The caregivers face uncertainty – uncertainty about the prognosis, uncertainty about how long the patient has to live and uncertainty as to whether they are doing a good job. The best mitigation for uncertainty is intervention (Barron, 2000). Education and providing timely information to families would alleviate the uncertainty. Completing a family assessment identifying needs and concerns of the family should be done initially when the patient is declared palliative. In addition the palliative care nurse should check in with the family to address needs and concerns as they arise.

Pain Management

Pain and its management was a sub-theme from the findings. Physicians need to avail themselves of the latest evidence and information about controlling pain to effectively manage these patients. Health care facilities need to have resources in pain management for palliative patients and ongoing education in pain management. Physicians can also consult the regional palliative care physician. In addition patients and families need to be made aware of the side effects of pain medications, such as hallucinations, and be involved in the decision-making processes when analgesics are selected.

Building a Volunteer Base

All findings, both from the literature and the data, show that rural folks offer their services freely. Many of the social and health programs rely heavily on volunteers in rural communities. Therefore it is recommended to work at sustaining and building the volunteer base. Policy makers need to consider the value of volunteers in the health care system and to recognize this through volunteer appreciation events as well as providing the finances to train these volunteers.

Table 2

Table of the Summary of Recommendations

Recommendations	Implications for Policy	Implications for Practice	Implications for Education	Implications for Research
1. Future research: Need for conceptual frameworks for rural palliative populations				To guide research and practice
2. Future research: Need for more studies (either new or replicated) in this population with recruitment strategies to reflect missed groups		Lead to a better understanding of informal caregivers in rural areas		Will either strengthen existing knowledge or open new areas needing exploration
3. Financial: Those medications, medical supplies and ambulance transfers to hospital be consistently covered for palliative patients. Development of a resource guide booklet for palliative patients and families.	Policy makers will need to ensure the continued implementation of existing policies and look at additional coverage such as ambulance transportation	Better teaching of clients as to what services are covered and assist clients to access them.	Education of health care providers as well as consumers of health care that coverage exists	
4. Need for better integration of home care and palliative care services	Policies developed to integrate services avoiding overlaps and discovering gaps in hospice care. Home care policies that are flexible enough to accommodate the wishes of the dying.	Client case conferences with families to involve all appropriate disciplines. Palliative care coordinators assess needs and continue to facilitate the delivery of services	Education of health care providers as to what services are available and who the providers are	Further studies needed to identify gaps in the system
5. Bereavement support and Funding for palliative care programs: need for bereavement support groups	Policies need to include the allocation of funds to run these groups and programs at the local level.	Implications: more energy on delivering services as opposed to fund raising.		
6. Provision of care close to home		Rural physicians assume the management of the patient's care utilizing expertise of regional p.c. physician. Care coordinators (nurses, palliative care and home care) can assist families in identifying a local physician		

Table of recommendations continued

Recommendations	Implications for Policy	Implications for Practice	Implications for Education	Implications for Research
7. Reducing caregiver stress		Doctors and nurses need to encourage home care and assist family members to pass on medical treatments that are difficult for them as family to perform on their loved one.	Ongoing awareness and education of health care providers in communication	
8. Pain management	Health care facilities need better resources in pain management for palliative patients	Physicians need to seek out the latest evidence based pain management. Health care providers need to understand "pain" affects the whole family.	Families need to be involved in the decision-making process, educated about medication side effects.	
9. Building a volunteer base	Policy makers need to allow money for training volunteers	Volunteer appreciation events are important	Education and training for volunteers in hospice programs	

Personal Reflections

This study has provided me with new insights, a time of reflection and personal growth. When I began this study there were biases and assumptions held by me, of which I was unaware. I now understand that I believed medical care to be superior in urban centres such as Winnipeg when compared to rural health care. This bias may have existed, as I believed specialized equipment and diagnostics were an important part of the outcome of health care. I learned that this is not the case. Rural health centres and communities provide excellence in palliative care. Care is delivered competently, sensitively and compassionately in rural communities.

Another belief I held was that there was not much difference for the patient and family if the patient died at home or in the hospital. With many years of experience as a hospital nurse I believed hospital palliative care was superior. I could not really understand why families would opt for the inconvenience and work of caring for a patient at home. I now understand that being able to "do" something for the dying person is an important part of reconciling the experience. Opportunities for family closeness that happened in the home setting would be difficult if not impossible to reconstruct in a

hospital setting. I also believed that a death in the home would be a haunting and unsettling experience. Not one of the participants whose patient had died at home felt the least bit uncomfortable with a home death. Rather the death in the home setting was viewed as something beautiful.

One assumption I held was that differences exist between rural and urban communities. Through the readings in the literature review and listening to the storytellers in this study, this assumption was confirmed. Rural populations are unique, have unique challenges and also unique strengths.

My wish is that I will be able to carry what I have learned into my rural practice and make conditions better for families assisting their loved ones to be at home.

Dissemination of the Findings

To be worthwhile, the findings of a research study need to be shared, so the important question remains of how to distribute the knowledge or make it available.

The findings of this research and recommendations will be shared with the community of those who participated – the caregivers. The caregivers were all asked if they would like to see a summary of the findings and recommendations from the study. All nine participants expressed interest and provided a mailing address.

From the onset there has been the expectation that these results will be presented to the Central RHA Palliative Care and Home Care programs. The Manitoba Hospice and Palliative Care organization has expressed interest as well. The Public Information and Awareness Group, which is a sub-committee of the Secretariat for Palliative and End-of-Life Care of Health Canada, has expressed interest and were welcoming the rural perspective. The information could also be shared with other health care providers in

other regions through conferences or scientific meetings. Several small community palliative care programs as well as several local church groups have requested a presentation of the findings as well. In addition the findings will be submitted for publication in a palliative care or oncology-nursing journal.

Conclusion

These nine caregivers shared so freely of themselves and their experiences through their stories. I respect the voices of these caregivers and believe that what they told me was *their* truth about how they viewed their experience. These findings are a compilation of those truths. The important aspects of what was told in their stories are reflected in the themes and sub-themes, which at points, overlap with each other.

I will be forever grateful to these nine individuals for what I learned from them. I was left with the feeling after each interview that despite the challenges this had been a positive experience for each and every caregiver. They were all grateful for having the opportunity to care for their loved one in the warm familiar environment of the home and experience the full circle of life and death. Choosing to die at home is a right of all persons and must be respected.

It is my hope and wish that what was learned from these stories will lead to a better understanding of the caregiving experience and ultimately improve palliative and hospice care in the Central Region of Manitoba and beyond.

References

- Barron, C. R. (2000). Stress, uncertainty and health. In V. Hill (Ed.), *Handbook of stress coping and health: Implications for nursing research, theory, and practice*. Thousand Oakes: Sage.
- Bass, D., & Bowman, K. (1990). The transition from caregiving to bereavement: The relationship of caregiver strain and adjustment to death. *The Gerontologist*, 30(1), 35-42.
- Beckman, S. J., Boxley-Harges, S., Bruick-Sorge C., Mathews Harris, S., Hermiz, M. E., Meininger, M. et al. (2000). Betty Neuman Systems Model. In E. T. Anderson & J. M. McFarlane (Eds.). *Community as partner: Theory and practice in nursing* (pp. 269-304). Philadelphia: Lippincott.
- Bigbee, J. L. (1993a) The uniqueness of rural nursing. *Rural Nursing* 28(1), 131-144.
- Bigbee, J. L. (1993b) The concept of hardiness as applied to rural nursing. *Rural Nursing* 28(1), 39-58.
- Bramwell, L., MacKenzie, J., Laschinger, H., & Cameron, N. (1995). Need for overnight respite for primary caregivers of hospice clients. *Cancer Nursing*, 18(5), 337-343.
- Brown, M. A., & Stetz, K. (1999). The labour of caregiving: A theoretical model of caregiving during potentially fatal illness. *Qualitative Health Research*, 9(2), 182-197.
- Buehler, J. A., & Lee, H. J. (1992). Exploration of home resources for rural families with cancer. *Cancer Nursing*, 15(4), 299-308.
- Bushy, A. (1991). Rural determinants in family health: Considerations for community nurses. In A. Bushy, *Rural nursing*, Vol. I (pp. 133-145). Newbury Park: Sage.

- Chochinov, H. M., Hack, T., Hassard, T., Kristjansson, L. J., McClement, S., Harlos, M. (2002). Dignity in the terminally ill: A cross-sectional, cohort study. *The Lancet*, 360, 2026. Retrieved June 26, 2004 from <http://www.sciencedirect.com>
- Christakis, N. A., & Esarce, J. J. (1996). Survival of Medicare patients after enrolment in hospice care programs. *JAMA*, 335, 172-178.
- Cleary, J. F., & Carbone, P. P. (1997). Palliative medicine in the elderly. *Cancer*, 80, 1335-1347.
- Conley, V. M., & Burman, M. E. (1997). Informational needs of caregivers of terminal patients in a rural state. *Home Healthcare Nurse*, 15(11), 808-817.
- Corbin, J. M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.
- Cowles, K., & Rodgers, B. (1991). The concept of grief: a foundation for nursing research and practice. *Research in Nursing and Health*, 14(2), 119-129.
- Crotty, M. (1998). *The foundations of social research* (pp. 1-17). London: Sage.
- Davis, B. D., Cowley, S. A., & Ryland, R. K. (1996). The effects of terminal illness on patients and their carers. *Journal of Advanced Nursing*, 23, 512-520.
- Decker, S. D., & Young, E. (1991). Self-perceived needs of primary caregivers of home hospice clients. *Journal of Community Health Nursing*, 8(3), 147-154.
- Demi, A. S., & Miles, M. S. (1986). Bereavement. *Annual Review of Nursing Research*, 4, 105 -123.
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research* (2nd ed.). Beverly Hills: Sage.

- Dirckx, J. H. (Ed.). (1997) *Stedman's concise medical dictionary for the health professions*. (6th ed.). Baltimore: Williams and Wilkins.
- Emlet, C. (1996). Assessing the informal caregiver: Team member or hidden patient? *Home Care Provider*, 1(5), 255-275.
- Ferrell, B., & Dean, G. (1995). The meaning of cancer pain. *Oncology Nursing* 11(1), 17-22.
- Fetterman, D. (1989). *Ethnography, step by step*. Newbury Park, CA: Sage.
- Ford-Gilboe, M., & Cohen, J. A. (2000). Hardiness: A model of commitment, challenge and control. In V. H. Rice (Ed.), *Handbook of stress, coping and health: Implications for nursing, research, theory, and practice*. Thousand Oakes: Sage.
- Gass, K., & Chang, A. (1989). Appraisals of bereavement, coping, resources, and psychosocial health dysfunction in widows and widowers. *Nursing Research* 38(8), 31-36.
- Gilbar, O., & Steiner, M. (1996). When death comes: Where should patients die? *Hospice* 11, 31-48.
- Given, B. (1995). Believing and dreaming to improve cancer care. *Oncology Nursing Forum*, 22(6), 929-939.
- Given, B. (1997). Response to: "Caregiver concept analysis outcomes". *Scholarly Inquiry for Nursing Practice*, 11(1), 77-79.
- Harrington, V., Lackey, N., & Gates, M. (1996). Needs of caregivers of clinic and hospice cancer patients. *Cancer Nursing*, 19(92), 118-125.

- Health Canada. (1999a). *A population health approach: Definitions and guiding principles*. Ottawa: Health Promotion and Protection Branch, Manitoba Saskatchewan Region.
- Health Canada (1999b). Rural palliative care: In the arms of the community. *Farm Family Health* 7(2). Retrieved February 2, 2002 from <http://www.hc-sc.gc.gc/pphb-dgspsp/publicat/ffh-sfavol7-2/>
- Hileman, J., & Lackey, N. (1990). Self-identified needs of patients with cancer at home and their home caregivers: A descriptive study. *Oncology Nursing Forum*, 17, 907-912.
- Hileman, J., Lackey, N., & Hassanein, R. (1992). Identifying the needs of home caregivers of patients with cancer. *Oncology Nursing Forum*, 19, 771 -777.
- Hinds, C. (1985). The needs of families who care for patients with cancer at home: Are we meeting them? *Journal of Advanced Nursing*, 10, 575-581.
- Hinton, J. (1994). Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliative Medicine*, 8, 183-196.
- Holing, E. V. (1986). The primary caregiver's perception of the dying trajectory. *Cancer Nursing*, 9(1), 29-37.
- Honing, A. S. (1986) Stress and coping in children. In J. B. McCracken (Ed.), *Reducing Stress in Young Children's Lives* (pp. 142-167). Washington DC: National Association for the Education of Young Children.
- Hull, M. (1992). Coping strategies of family caregivers in hospice home care. *Oncology Nursing Forum*, 19, 1179-1187.

- Hunt, C.K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship*. First Quarter, 27-32.
- Jacob, S. (1996). The grief experience of older women whose husbands had hospice care. *Journal of Advanced Nursing*, 24, 280-286.
- Jensen, S., & Given, B. (1991). Fatigue affecting family caregivers of cancer patients. *Cancer Nursing*, 14(4), 181-187.
- Jepson, C., McCorkle, R., Adler, D., Nuamah, I., & Lusk, E. (1999). Effects of home care on caregivers' psychosocial status. *Image: Journal of Nursing Scholarship*, 31, 115-120.
- Kinsella, G., Cooper, B., Picton C., & Murtagh, D. (2000). Factors influencing outcomes for family caregivers of persons receiving palliative care: Toward an integrated model. *Journal of Palliative Care*, 16(3), 46-54.
- Kobasa, S., Maddi, S., & Kahn, S. (1982). Hardiness and health: A prospective study. *Journal of Personality and Social Psychology*, 42, 168-177.
- Kristjansson, L. J., & Ashcroft T. (1994). The family's cancer journey: A literature review. *Cancer Nursing*, 17(1), 1-17.
- Kuhl, D. (2003). *What dying people want: Practical wisdom for the end of life*. Canada: Anchor.
- Lamont E.B., & Christakis, N. A. (2003). Complexities in prognostication in advanced cancer: "To help them live their lives the way they want to". *JAMA* 290(1), 98-104.
- LeCompte, M., & Schensul, J. (1999). *Designing and conducting ethnographic research*. Walnut Creek, CA: Alta Mira Press.

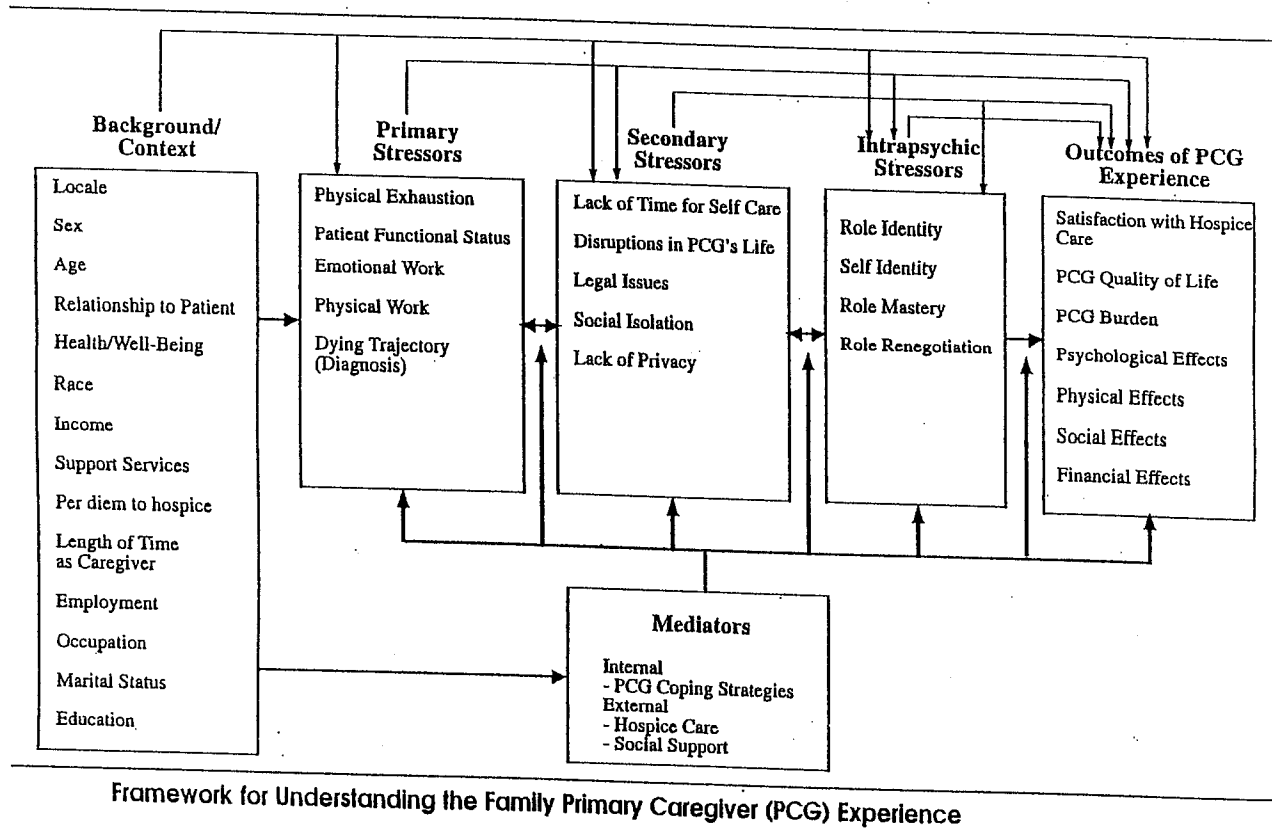
- Lin, H., & Bauer-Wu, S. M. (2003). Psycho-spiritual well-being in a patient with advanced cancer. An integrative review of the literature. *Journal of Advanced Nursing*, 44(1), 69-80.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills CA: Sage.
- Livadiotakis, G. (2002). *Palliative home care: The impact on seniors, family caregivers, and community health care*. Retrieved September 13, 2002 from <http://www.caregiver.on.ca/cgddca.html> [link from Health Canada website]
- Long, K. (1993). The concept of health: rural perspectives. *Nursing Clinics of North America*, 28(1), 123-130.
- Long, K., & Weinert, C. (1989). Rural nursing: developing the theory base. *Scholarly Inquiry for Nursing Practice*, 3, 113-121.
- Lynn, J., & Wilkinson, A.M. (1998). Quality end of life care: the Case for a Medicaring demonstration. *Hospice*, 13, 151-163.
- Manitoba Centre for Health Policy. (2002). Statistics on health for Manitoba's regional health authorities. Retrieved February 20, 2002, from <http://www.umanitoba.ca/centres/mchp/>
- Martens, P., Bond, R., Jebamani, L., Burchill, C., Roos, N., Derksen, S., et al. (2002). *The Health and health care use of registered First Nations people living in Manitoba: A population-based study*. Winnipeg: Manitoba Centre for Health Policy and Evaluation.
- Martin, D. G. (1991). *Psychology: principles and applications*. Scarborough: Prentice Hall Canada.

- Martin, R. A. (1989). Humour and the mastery of living. *Journal of Children in Contemporary Society*, 21(2), 135-152.
- Martocchio, B. (1985). Grief and bereavement. Healing through the hurt. *Nursing Clinics of North America*, 20(2), 327-341.
- Marrone, R. (1998). *Death, mourning and caring*. Toronto: Brookes / Cole.
- McRae, S., Caty, S., Nelder, M., & Picard, L. (2000, June). Palliative care on Manitoulin Island: Views of family caregivers in remote communities. *Canadian Family Physician* 46, 1301-1307.
- Mehta, A., & Ezer, H. (2003). My love is hurting: The meaning spouses attribute to their loved one's pain during palliative care. *Journal of Palliative Care*, 19(2), 87-94.
- Memmott, R. J. (1991). Developing hospice programs in frontier communities. In A. Bushy, *Rural nursing Vol. II* (pp. 63-75). Newbury Park: Sage.
- Meyers, J., & Gray, L. (2001). The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden. *Oncology Nursing Forum*, 28(1), 73-81.
- Miller, P. J. & Mike, P. B. (1995) The Medicare hospice benefit. *Death Studies*, 19, 531-542.
- Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research*, 5, 147-149.
- Nolan, M., Grant, G., & Ellis, P. (1990). Stress is in the eye of the beholder: Reconceptualizing the measurement of carer burden. *Journal of Advanced Nursing*, 15, 544-555.

- Nugent, L. (1988). The social support requirements of family caregivers of terminal cancer patients. *The Canadian Journal of Nursing Research*, 20(3), 45-58.
- Oberst, M., Thomas, S., Gass, K., & Ward, S. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing*, 12(4), 209-215.
- Pasacreta, J., & McCorkle, R. (2000). Cancer care: Impact of interventions on caregiver outcomes. In J. Fitzpatrick & J. Goeppinger (Eds.), *Annual Review of Nursing Research*, 18, 127-148.
- Polit, D. F., & Hungler, B. P. (1995). *Nursing Research: Principles and Methods*. Philadelphia: Lippincott.
- RHA Central Manitoba (1998). *Community needs assessment*. Retrieved October 14, 2001 from <http://www.rha-central.mb.ca/community.htm>
- Rhymes, J. A. (1991). Home hospice care. *Geriatric Home Care*, 7, 803-816.
- Romanow, R. J. (2002). *Building on values: The future of health care in Canada*. Ottawa: Health Canada.
- Sandelowski, M. (1991). Telling stories: Narrative approaches to qualitative research. *Image*, 23(3), 161-166.
- Sandelowski, M. (1995). Focus on qualitative methods: Qualitative analysis: What it is and how to begin. *Research in Nursing and Health*, 18, 371-375.
- Schachter, S. (1992). Quality of life for families in the management of home care patients with advanced cancer. *Journal of Palliative Care*, 8(3), 61-66.
- Schott-Bauer, D. (1993). Dependent care, caregiver burden, and self-care agency of spouse caregivers. *Cancer Nursing*, 16(3), 230-236.

- Seale, C., Addington-Hall, J., & McCarthy, M. (1997). Awareness of dying: prevalence, causes and consequences. *Social Science Medicine*, 45, 477-484.
- Silveira, J. M., & Winstead-Fry, P. (1997). The needs of patients with cancer and their caregivers in rural areas. *Oncology Nursing Forum*, 24(1), 71-76.
- Stajduhar, K. I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, 19(1), 27-35.
- Steele, R. G., & Fitch, M. I. (1996). Needs of family caregivers of patients receiving home hospice care for cancer. *Oncology Nursing Forum*, 23(5), 823-828.
- Steeves, R., & Kahn, D. (1995). Hermeneutical human science. In A. Omery, C. Kasper, & G. Page, *In search of nursing science*. Thousand Oaks: Sage.
- Stetz, K. (1989). The relationship among background characteristics, purpose in life, and caregiving demands on perceived health of spouse caregivers. *Scholarly Inquiry for Nursing Practice*, 3, 133-153.
- Streubert, H. J. & Carpenter, D. R. (Eds.). (1999). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Lippincott.
- Stroebe, W., & Stroebe, M. S. (1987). *Bereavement and health: The psychological and physical consequences of partner loss*. Cambridge: Cambridge University Press.
- Swanson, E. A., Jenson, D. P., Specht, J., Johnson, M. L. & Maas, M. (1997). Caregiving: Concept analysis and outcomes. *Scholarly Inquiry for Nursing Practice: An International Journal*, 11(1), 65-76.
- Vachon, M. (1998). Psychosocial needs of patients and families. *Journal of Palliative Care*, 14(3), 49-56.

- Wainwright, M. (2000). Partnership building in a rural community: El Dorado, Arkansas. In E. T. Anderson & J. M. McFarlane (Eds.), *Community as partner: Theory and practice in nursing* (pp. 342-359). Philadelphia: Lippincott.
- Weinert, C., & Burman, M. E. (1994). Rural health and health-seeking behaviours. In J. J. Fitzpatrick & J. S. Stevenson, *Annual review of nursing research, Vol. 12*, (pp. 65-92). New York: Springer.
- Weinert, C., & Long, K. A. (1987). Understanding the health care needs of rural families. *Family Relations*, 36, 450-455.
- Weinert, C. & Long, K. A. (1991). The theory and research base for rural nursing practice. In A. Bushy, *Rural nursing, Vol. I* (pp. 21-38). Newbury Park: Sage.
- Weitzner, M., Jacobsen, P., Wagner, H., Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index – Cancer (CQOLC): Development and validation of an instrument to measure quality of life. *Quality of Life Research*, 8(1,2), 55-63.
- Weitzner, M., & McMillan, S. (1999). The Caregiver Quality of Life Index – Cancer (CQOLC) scale: Revalidation in a home hospice setting. *Journal of Palliative Care*, 15(2), 13-20.
- Winnipeg Regional Health Authority. (2002). *Palliative care sub program: Principles and descriptions*. Winnipeg: Author.



From : Meyers, J L., & Gray, L. N. (2001). The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life and burden. *Oncology Nursing Forum*, 28(1), 73-81.

Appendix B

Initial Contact Statement (Recruiter)

There is an opportunity for you to participate in a research project that is looking at the experiences of those persons who have assisted in the care of a terminally ill person at home. Peggy Martens is a nurse who is doing a study for her Masters of Nursing degree and is looking for persons who have cared for a family member or friend dying with cancer in the community. This person may have been cared for at home until death or perhaps until a final hospitalization. Peggy is willing to explain her project to you, should you be interested. This does not mean you have to participate, she will only explain the project and you can decide if it is something you would want to take part in.

~~~~~

**Would it be okay for me to give your name and phone number to Peggy so that she can set up a time to meet with you and explain her project?**

If YES, please fill out the information below:

Name

\_\_\_\_\_

Phone number (204) \_\_\_\_\_.

**Peggy will contact you at the phone number given in the next few days.**

If NO, caller thanks the person for their time and concludes the call.

**Recruiter: Please call Peggy at (204) 324-5509 or email her at**

**[rmartens@mb.sympatico.ca](mailto:rmartens@mb.sympatico.ca) to let her know if there is another interested individual.**

## Appendix C

## Information and Consent Form

**Research Project Title:** The Lived Experience of Informal Caregivers of the Terminally Ill in South-Central Rural Manitoba

**Researcher:** Peggy Martens

This consent form, a copy which will be left with you for your records and reference, is only a part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully to understand any accompanying information.

This research study will focus on understanding the experiences of people who provide care and support for family members or friends as they were dying. In the Central Health Region where you live, there are about 190 deaths every year from cancer. Many of these persons chose to be cared for at home in the final, days, weeks, or months leading up to their deaths. Very little is known about the caregiving experiences of the persons caring for the dying. I am conducting this research as part of my Masters of Nursing degree at the University of Manitoba. It is hoped that what is learned from this study will help nurses in relating to family members and friends who are caring for dying persons at home. It is hoped that by sharing your experience with me we can help and understand others who are going through the same experience.

In doing this research I will be interviewing persons living in the Central Health Region who have informally cared for a friend or family member who was dying from cancer. This research will consist of an interview. I will ask you some questions about your experience. The interview will be tape-recorded. The tape-recording will be transcribed (typed out). A transcriptionist will type while listening to the tape. The interview will take 1 to 2 hours.

All the meetings will be arranged at a time that is good for you. It would be preferred that we meet in your home, but should this pose a problem we can meet at a health care facility near your home. If that is the case, I will pay for your travel costs to the health care facility (mileage at the rate used by the Central RHA).

All information will be kept confidential. Your name, address, or any information that could identify you will not appear on the questionnaire or interview material. Instead a code number will be used to identify it. This consent form will be stored separately from the interview material. All the notes and tapes will be kept in a locked filing cabinet. After seven to ten years this information will be confidentially destroyed. The only people who will have access to the information from the tape-recorded interviews will be Peggy Martens, two of her advisors from the University of Manitoba, Dr. Lynn Scruby, and Dr. Sue McClement and the typist.

Participation in this study is completely voluntary. Whether you chose to be a part of this study or not will in no way affect any care or services you are now receiving or might receive in the Central Health Region. By signing this form you are agreeing to participate. However, should you at any time want to stop being in the study you may do so. No harm is

anticipated by participating in this study. Should you feel uncomfortable with any questions you can choose not to answer them.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and / or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

*Should you wish to contact the researcher or her research committee the numbers are:*

*Peggy Martens*

*nurse researcher – (204) 324-5509*

*Dr. Lynn Scruby*

*(thesis committee chair) – (204) 474-6659*

This study has been approved by the University of Manitoba, Education/ Nursing Research Ethics Board. Should you have complaints you may call Dr. Lynn Scruby (phone number above) or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent has been given to you to keep for your records and reference.

The Central Region Health Authority Palliative Care Program has approved this study.

*Thankyou for your time and participation.*

I, \_\_\_\_\_, agree to participate in this study about the experiences of caregivers of the terminally ill.

I have read the above information explaining this study. I am aware that participation is voluntary and I may chose not to answer certain questions or withdraw from the study at any time without penalty. I give permission to Peggy Martens to use anonymous information from my interview in any presentations or publications that result from this study.

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_  
Printed Name \_\_\_\_\_

Researcher \_\_\_\_\_ Date \_\_\_\_\_

The findings of this study will be made available once the study has been completed. Would you like a copy of the results mailed to you?

YES ☐

NO ☐

If "yes" please include your mailing address.

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Appendix D

## Demographic Information

The information below will be kept confidential. Please answer all of the questions below. Should you have questions, please ask the investigator.

Participant Code #: \_\_\_\_\_

1. Birthdate: \_\_\_\_\_

Day/ Month/ Year

2. Gender:    Male ☐      Female ☐

3. What is your ethnic origin? E.g. German, Dutch French, Aboriginal

---

4. Education (check highest level attended or completed)

Elementary only \_\_\_\_\_

High school \_\_\_\_\_

College or trade school \_\_\_\_\_

University \_\_\_\_\_

5. Where do you live? Choose one of the following with a check mark

\_\_\_\_\_ City of 10,000 to 40,000

\_\_\_\_\_ Town or city of between 5000 to 10,000 people

\_\_\_\_\_ Town – between 1000 and 5000 people

\_\_\_\_\_ Town of less than 1000 people

\_\_\_\_\_ Farm in a rural municipality

\_\_\_\_\_ a yard or homestead in a rural municipality

\_\_\_\_ Other. Describe

---

6. Employment status at the time of caregiving (check one)

Working full-time \_\_\_\_

Working part-time \_\_\_\_

Took leave to provide care \_\_\_\_

Unemployed \_\_\_\_

Retired \_\_\_\_

7. How were you connected to the patient? The patient I was caring for was my
- 

(Examples: husband, wife, son, neighbour, mother-in-law).

8. Living arrangements (Check one)

Shared a household with the patient \_\_\_\_

Lived independent from patient \_\_\_\_

Moved from permanent residence to share household \_\_\_\_

9. What type of illness did the patient have?
- 

10. Approximately how long was the time period you were the primary caregiver? If there were intermittent hospitalizations include this time as a total.
- 

11. Number of months since the caregiving experience \_\_\_\_\_.

## Appendix E

## Guide for Interview Questions

1. Tell me how it came about that you became the care provider for \_\_\_\_\_  
(name of patient)?
2. Tell me about the experience. What was it like for you?
3. What were positive aspects of the experience? What "lightened the load" or made it easier?
4. What were negative aspects of the experience? What obstacles or barriers did you face?
5. What was a typical day like for you during this time?
6. What advice would you have for others caring for a dying person in their home?
7. Were the resources in your community adequate? Which resources were used?
8. What would you like to see in your community to support caregivers of the terminally ill?

# Appendix F

## Sample: The Demographical Summary

| Name    | Age | Sex | Ethnic Origin      | Education               | Size of Rural Area   | Employment                   | Relation to patient | Living arrangement          | Type of illness Participants descriptions | Time provided care in months | Months lapsed since care-giving | Place of death |
|---------|-----|-----|--------------------|-------------------------|----------------------|------------------------------|---------------------|-----------------------------|-------------------------------------------|------------------------------|---------------------------------|----------------|
| Mary    | 49  | F   | Irish / Scottish   | College or trade school | Town: 1000 to 5000   | Quit to become a caregiver   | Daughter            | Moved patient to her home   | Ovarian cancer                            | 1 ½                          | 14                              | Home           |
| Sally   | 72  | F   | French             | High School             | Town under 1000      | Retired                      | Wife                | Shared                      | Co-morbidity Bipolar disorder, emphysema  | 6                            | 7                               | Hospital       |
| Paula   | 40  | F   | English / Scottish | High School             | Yard in rural area   | Part-time                    | Sister              | Lived independently         | Kidney cancer                             | 3                            | 24                              | Home           |
| Grace   | 80  | F   | Dutch              | College or trade school | Town under 1000      | Retired                      | Wife                | Shared                      | Congestive heart failure                  | 7                            | 18                              | Home           |
| Helen   | 38  | F   | French             | University degree       | Yard in a rural area | Took a leave to provide care | Daughter            | Lived independently         | Cervical cancer                           | 5                            | 10                              | Hospital       |
| Gloria  | 51  | F   | French / Polish    | College or trade school | Farm                 | Part-time                    | Grand-daughter      | Moved into patient's home   | Uncontrolled pain (no diagnosis)          | 1                            | 8                               | Home           |
| Phyllis | 67  | F   | German             | University degree       | Farm                 | Retired                      | Wife                | Shared                      | Lung cancer                               | 6                            | 15                              | Hospital       |
| Peter   | 57  | M   | English            | High School             | Farm                 | Working full time            | Son                 | Moved patient into his home | Bone cancer                               | 8                            | 12                              | Hospital       |
| Allan   | 78  | M   | German             | Elementary              | Town 1000-5000       | Retired                      | Husband             | Shared                      | Muscular dystrophy and emphysema          | 48                           | 15                              | Hospital       |

## Appendix G

## Thesis Committee Members

*Committee Chairperson*

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- Hunt, C.K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship, First Quarter*, 27-32.
- Jacob, S. (1996). The grief experience of older women whose husbands had hospice care. *Journal of Advanced Nursing*, 24, 280-286.
- Jensen, S., & Given, B. (1991). Fatigue affecting family caregivers of cancer patients. *Cancer Nursing*, 14(4), 181-187.
- Jepson, C., McCorkle, R., Adler, D., Nuamah, I., & Lusk, E. (1999). Effects of home care on caregivers' psychosocial status. *Image: Journal of Nursing Scholarship*, 31, 115-120.
- Kinsella, G., Cooper, B., Picton C., & Murtagh, D. (2000). Factors influencing outcomes for family caregivers of persons receiving palliative care: Toward an integrated model. *Journal of Palliative Care*, 16(3), 46-54.
- Kobasa, S., Maddi, S., & Kahn, S. (1982). Hardiness and health: A prospective study. *Journal of Personality and Social Psychology*, 42, 168-177.
- Kristjansson, L. J., & Ashcroft T. (1994). The family's cancer journey: A literature review. *Cancer Nursing*, 17(1), 1-17.
- Kuhl, D. (2003). *What dying people want: Practical wisdom for the end of life*. Canada: Anchor.
- Lamont E.B., & Christakis, N. A. (2003). Complexities in prognostication in advanced cancer: "To help them live their lives the way they want to". *JAMA* 290(1), 98-104.
- LeCompte, M., & Schensul, J. (1999). *Designing and conducting ethnographic research*. Walnut Creek, CA: Alta Mira Press.

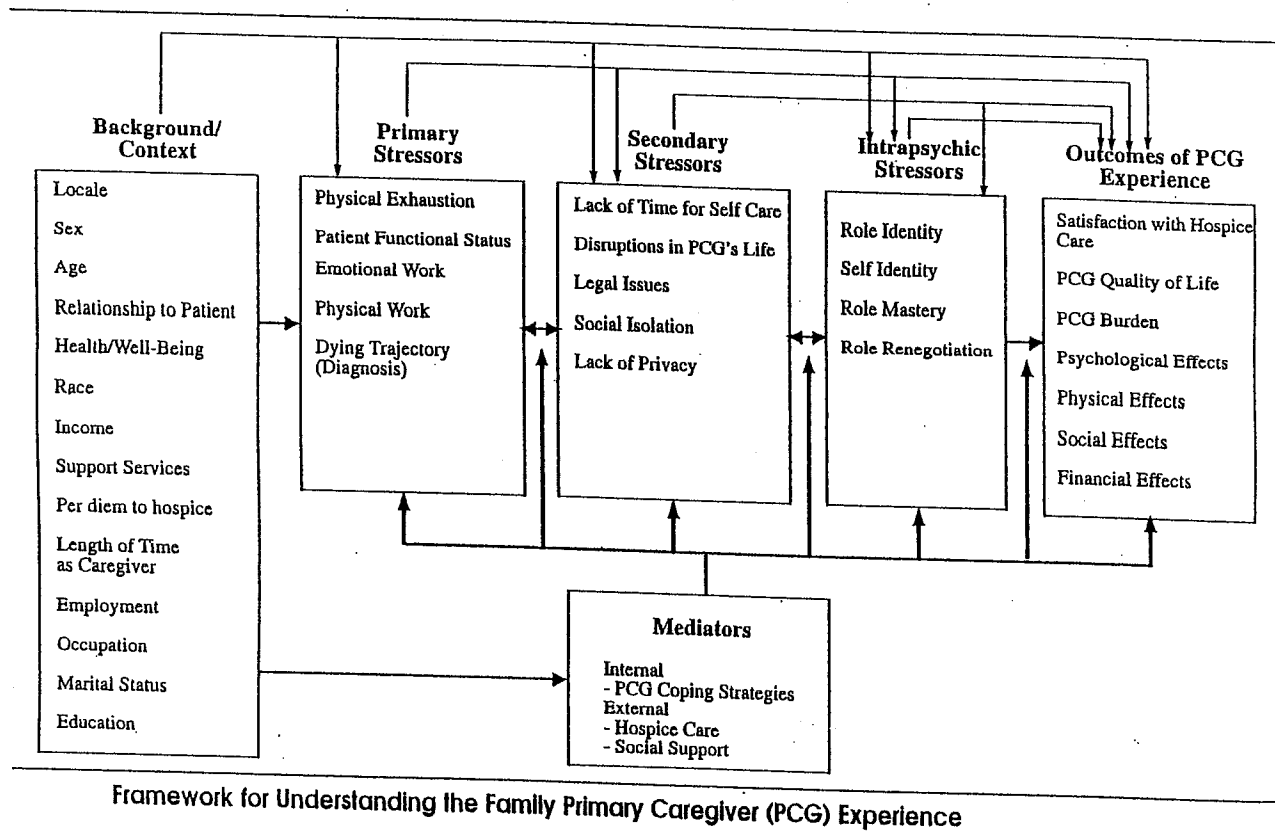
- Lin, H., & Bauer-Wu, S. M. (2003). Psycho-spiritual well-being in a patient with advanced cancer. An integrative review of the literature. *Journal of Advanced Nursing*, 44(1), 69-80.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills CA: Sage.
- Livadiotakis, G. (2002). *Palliative home care: The impact on seniors, family caregivers, and community health care*. Retrieved September 13, 2002 from <http://www.caregiver.on.ca/cgddca.html> [link from Health Canada website]
- Long, K. (1993). The concept of health: rural perspectives. *Nursing Clinics of North America*, 28(1), 123-130.
- Long, K., & Weinert, C. (1989). Rural nursing: developing the theory base. *Scholarly Inquiry for Nursing Practice*, 3, 113-121.
- Lynn, J., & Wilkinson, A.M. (1998). Quality end of life care: the Case for a Medicaring demonstration. *Hospice*, 13, 151-163.
- Manitoba Centre for Health Policy. (2002). Statistics on health for Manitoba's regional health authorities. Retrieved February 20, 2002, from <http://www.umanitoba.ca/centres/mchp/>
- Martens, P., Bond, R., Jebamani, L., Burchill, C., Roos, N., Derksen, S., et al. (2002). *The Health and health care use of registered First Nations people living in Manitoba: A population-based study*. Winnipeg: Manitoba Centre for Health Policy and Evaluation.
- Martin, D. G. (1991). *Psychology: principles and applications*. Scarborough: Prentice Hall Canada.

- Martin, R. A. (1989). Humour and the mastery of living. *Journal of Children in Contemporary Society*, 21(2), 135-152.
- Martocchio, B. (1985). Grief and bereavement. Healing through the hurt. *Nursing Clinics of North America*, 20(2), 327-341.
- Marrone, R. (1998). *Death, mourning and caring*. Toronto: Brookes / Cole.
- McRae, S., Caty, S., Nelder, M., & Picard, L (2000, June). Palliative care on Manitoulin Island: Views of family caregivers in remote communities. *Canadian Family Physician* 46, 1301-1307.
- Mehta, A., & Ezer, H. (2003). My love is hurting: The meaning spouses attribute to their loved one's pain during palliative care. *Journal of Palliative Care*, 19(2), 87-94.
- Memmott, R. J. (1991). Developing hospice programs in frontier communities. In A. Bushy, *Rural nursing Vol. II* (pp. 63-75). Newbury Park: Sage.
- Meyers, J., & Gray, L. (2001). The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden. *Oncology Nursing Forum*, 28(1), 73-81.
- Miller, P. J. & Mike, P. B. (1995) The Medicare hospice benefit. *Death Studies*, 19, 531-542.
- Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research*, 5, 147-149.
- Nolan, M., Grant, G., & Ellis, P. (1990). Stress is in the eye of the beholder: Reconceptualizing the measurement of carer burden. *Journal of Advanced Nursing*, 15, 544-555.

- Nugent, L. (1988). The social support requirements of family caregivers of terminal cancer patients. *The Canadian Journal of Nursing Research*, 20(3), 45-58.
- Oberst, M., Thomas, S., Gass, K., & Ward, S. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing*, 12(4), 209-215.
- Pasacreta, J., & McCorkle, R. (2000). Cancer care: Impact of interventions on caregiver outcomes. In J. Fitzpatrick & J. Goeppinger (Eds.), *Annual Review of Nursing Research*, 18, 127-148.
- Polit, D. F., & Hungler, B. P. (1995). *Nursing Research: Principles and Methods*. Philadelphia: Lippincott.
- RHA Central Manitoba (1998). *Community needs assessment*. Retrieved October 14, 2001 from <http://www.rha-central.mb.ca/community.htm>
- Rhymes, J. A. (1991). Home hospice care. *Geriatric Home Care*, 7, 803-816.
- Romanow, R. J. (2002). *Building on values: The future of health care in Canada*. Ottawa: Health Canada.
- Sandelowski, M. (1991). Telling stories: Narrative approaches to qualitative research. *Image*, 23(3), 161-166.
- Sandelowski, M. (1995). Focus on qualitative methods: Qualitative analysis: What it is and how to begin. *Research in Nursing and Health*, 18, 371-375.
- Schachter, S. (1992). Quality of life for families in the management of home care patients with advanced cancer. *Journal of Palliative Care*, 8(3), 61-66.
- Schott-Bauer, D. (1993). Dependent care, caregiver burden, and self-care agency of spouse caregivers. *Cancer Nursing*, 16(3), 230-236.

- Seale, C., Addington-Hall, J., & McCarthy, M. (1997). Awareness of dying: prevalence, causes and consequences. *Social Science Medicine*, 45, 477-484.
- Silveira, J. M., & Winstead-Fry, P. (1997). The needs of patients with cancer and their caregivers in rural areas. *Oncology Nursing Forum*, 24(1), 71-76.
- Stajduhar, K. I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, 19(1), 27-35.
- Steele, R. G., & Fitch, M. I. (1996). Needs of family caregivers of patients receiving home hospice care for cancer. *Oncology Nursing Forum*, 23(5), 823-828.
- Steeves, R., & Kahn, D. (1995). Hermeneutical human science. In A. Omery, C. Kasper, & G. Page, *In search of nursing science*. Thousand Oaks: Sage.
- Stetz, K. (1989). The relationship among background characteristics, purpose in life, and caregiving demands on perceived health of spouse caregivers. *Scholarly Inquiry for Nursing Practice*, 3, 133-153.
- Streubert, H. J. & Carpenter, D. R. (Eds.). (1999). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Lippincott.
- Stroebe, W., & Stroebe, M. S. (1987). *Bereavement and health: The psychological and physical consequences of partner loss*. Cambridge: Cambridge University Press.
- Swanson, E. A., Jenson, D. P., Specht, J., Johnson, M. L. & Maas, M. (1997). Caregiving: Concept analysis and outcomes. *Scholarly Inquiry for Nursing Practice: An International Journal*, 11(1), 65-76.
- Vachon, M. (1998). Psychosocial needs of patients and families. *Journal of Palliative Care*, 14(3), 49-56.

- Wainwright, M. (2000). Partnership building in a rural community: El Dorado, Arkansas. In E. T. Anderson & J. M. McFarlane (Eds.), *Community as partner: Theory and practice in nursing* (pp. 342-359). Philadelphia: Lippincott.
- Weinert, C., & Burman, M. E. (1994). Rural health and health-seeking behaviours. In J. J. Fitzpatrick & J. S. Stevenson, *Annual review of nursing research, Vol. 12*, (pp. 65-92). New York: Springer.
- Weinert, C., & Long, K. A. (1987). Understanding the health care needs of rural families. *Family Relations*, 36, 450-455.
- Weinert, C. & Long, K. A. (1991). The theory and research base for rural nursing practice. In A. Bushy, *Rural nursing, Vol. I* (pp. 21-38). Newbury Park: Sage.
- Weitzner, M., Jacobsen, P., Wagner, H., Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index – Cancer (CQOLC): Development and validation of an instrument to measure quality of life. *Quality of Life Research*, 8(1,2), 55-63.
- Weitzner, M., & McMillan, S. (1999). The Caregiver Quality of Life Index – Cancer (CQOLC) scale: Revalidation in a home hospice setting. *Journal of Palliative Care*, 15(2), 13-20.
- Winnipeg Regional Health Authority. (2002). *Palliative care sub program: Principles and descriptions*. Winnipeg: Author.



From : Meyers, J L., & Gray, L. N. ( 2001). The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life and burden. *Oncology Nursing Forum*, 28(1), 73-81.

## Appendix B

## Initial Contact Statement (Recruiter)

There is an opportunity for you to participate in a research project that is looking at the experiences of those persons who have assisted in the care of a terminally ill person at home. Peggy Martens is a nurse who is doing a study for her Masters of Nursing degree and is looking for persons who have cared for a family member or friend dying with cancer in the community. This person may have been cared for at home until death or perhaps until a final hospitalization. Peggy is willing to explain her project to you, should you be interested. This does not mean you have to participate, she will only explain the project and you can decide if it is something you would want to take part in.

~~~~~

Would it be okay for me to give your name and phone number to Peggy so that she can set up a time to meet with you and explain her project?

If YES, please fill out the information below:

Name

Phone number (204) _____.

Peggy will contact you at the phone number given in the next few days.

If NO, caller thanks the person for their time and concludes the call.

Recruiter: Please call Peggy at (204) _____ or email her at

rmartens@mb.sympatico.ca to let her know if there is another interested individual.

Appendix C

Information and Consent Form

Research Project Title: The Lived Experience of Informal Caregivers of the Terminally Ill in South-Central Rural Manitoba

Researcher: Peggy Martens

This consent form, a copy which will be left with you for your records and reference, is only a part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully to understand any accompanying information.

This research study will focus on understanding the experiences of people who provide care and support for family members or friends as they were dying. In the Central Health Region where you live, there are about 190 deaths every year from cancer. Many of these persons chose to be cared for at home in the final, days, weeks, or months leading up to their deaths. Very little is known about the caregiving experiences of the persons caring for the dying. I am conducting this research as part of my Masters of Nursing degree at the University of Manitoba. It is hoped that what is learned from this study will help nurses in relating to family members and friends who are caring for dying persons at home. It is hoped that by sharing your experience with me we can help and understand others who are going through the same experience.

In doing this research I will be interviewing persons living in the Central Health Region who have informally cared for a friend or family member who was dying from cancer. This research will consist of an interview. I will ask you some questions about your experience. The interview will be tape-recorded. The tape-recording will be transcribed (typed out). A transcriptionist will type while listening to the tape. The interview will take 1 to 2 hours.

All the meetings will be arranged at a time that is good for you. It would be preferred that we meet in your home, but should this pose a problem we can meet at a health care facility near your home. If that is the case, I will pay for your travel costs to the health care facility (mileage at the rate used by the Central RHA).

All information will be kept confidential. Your name, address, or any information that could identify you will not appear on the questionnaire or interview material. Instead a code number will be used to identify it. This consent form will be stored separately from the interview material. All the notes and tapes will be kept in a locked filing cabinet. After seven to ten years this information will be confidentially destroyed. The only people who will have access to the information from the tape-recorded interviews will be Peggy Martens, two of her advisors from the University of Manitoba, Dr. Lynn Scruby, and Dr. Sue McClement and the typist.

Participation in this study is completely voluntary. Whether you chose to be a part of this study or not will in no way affect any care or services you are now receiving or might receive in the Central Health Region. By signing this form you are agreeing to participate. However, should you at any time want to stop being in the study you may do so. No harm is

anticipated by participating in this study. Should you feel uncomfortable with any questions you can choose not to answer them.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and / or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Should you wish to contact the researcher or her research committee the numbers are:

Peggy Martens

nurse researcher – (204)

Dr. Lynn Scruby

(thesis committee chair) – (204)

This study has been approved by the University of Manitoba, Education/ Nursing Research Ethics Board. Should you have complaints you may call Dr. Lynn Scruby (phone number above) or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent has been given to you to keep for your records and reference.

The Central Region Health Authority Palliative Care Program has approved this study.

Thankyou for your time and participation.

I, _____, agree to participate in this study about the experiences of caregivers of the terminally ill.

I have read the above information explaining this study. I am aware that participation is voluntary and I may chose not to answer certain questions or withdraw from the study at any time without penalty. I give permission to Peggy Martens to use anonymous information from my interview in any presentations or publications that result from this study.

Participant Signature _____ Date _____

Printed Name _____

Researcher _____ Date _____

The findings of this study will be made available once the study has been completed. Would you like a copy of the results mailed to you?

YES ☐

NO ☐

If "yes" please include your mailing address.

Address _____

Appendix D

Demographic Information

The information below will be kept confidential. Please answer all of the questions below. Should you have questions, please ask the investigator.

Participant Code #: _____

1. Birthdate: _____

Day/ Month/ Year

2. Gender: Male ☐ Female ☐

3. What is your ethnic origin? E.g. German, Dutch French, Aboriginal

4. Education (check highest level attended or completed)

Elementary only _____

High school _____

College or trade school _____

University _____

5. Where do you live? Choose one of the following with a check mark

_____ City of 10,000 to 40,000

_____ Town or city of between 5000 to 10,000 people

_____ Town – between 1000 and 5000 people

_____ Town of less than 1000 people

_____ Farm in a rural municipality

_____ a yard or homestead in a rural municipality

____ Other. Describe

6. Employment status at the time of caregiving (check one)

Working full-time ____

Working part-time ____

Took leave to provide care ____

Unemployed ____

Retired ____

7. How were you connected to the patient? The patient I was caring for was my
-

(Examples: husband, wife, son, neighbour, mother-in-law).

8. Living arrangements (Check one)

Shared a household with the patient ____

Lived independent from patient ____

Moved from permanent residence to share household ____

9. What type of illness did the patient have?
-

10. Approximately how long was the time period you were the primary caregiver? If there were intermittent hospitalizations include this time as a total.
-

11. Number of months since the caregiving experience _____.

Appendix E

Guide for Interview Questions

1. Tell me how it came about that you became the care provider for _____
(name of patient)?
2. Tell me about the experience. What was it like for you?
3. What were positive aspects of the experience? What “lightened the load” or made it easier?
4. What were negative aspects of the experience? What obstacles or barriers did you face?
5. What was a typical day like for you during this time?
6. What advice would you have for others caring for a dying person in their home?
7. Were the resources in your community adequate? Which resources were used?
8. What would you like to see in your community to support caregivers of the terminally ill?

Appendix F

Sample: The Demographical Summary

Name	Age	Sex	Ethnic Origin	Education	Size of Rural Area	Employment	Relation to patient	Living arrangement	Type of illness Participants descriptions	Time provided care in months	Months lapsed since care-giving	Place of death
Mary	49	F	Irish / Scottish	College or trade school	Town: 1000 to 5000	Quit to become a caregiver	Daughter	Moved patient to her home	Ovarian cancer	1 ½	14	Home
Sally	72	F	French	High School	Town under 1000	Retired	Wife	Shared	Co-morbidity Bipolar disorder, emphysema	6	7	Hospital
Paula	40	F	English / Scottish	High School	Yard in rural area	Part-time	Sister	Lived independently	Kidney cancer	3	24	Home
Grace	80	F	Dutch	College or trade school	Town under 1000	Retired	Wife	Shared	Congestive heart failure	7	18	Home
Helen	38	F	French	University degree	Yard in a rural area	Took a leave to provide care	Daughter	Lived independently	Cervical cancer	5	10	Hospital
Gloria	51	F	French / Polish	College or trade school	Farm	Part-time	Grand-daughter	Moved into patient's home	Uncontrolled pain (no diagnosis)	1	8	Home
Phyllis	67	F	German	University degree	Farm	Retired	Wife	Shared	Lung cancer	6	15	Hospital
Peter	57	M	English	High School	Farm	Working full time	Son	Moved patient into his home	Bone cancer	8	12	Hospital
Allan	78	M	German	Elementary	Town 1000-5000	Retired	Husband	Shared	Muscular dystrophy and emphysema	48	15	Hospital

Appendix G

Thesis Committee Members

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