

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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in South-Central Rural Manitoba**

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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; Pasacreata & 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 (Pasacreata & 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; Pasacreata & 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