THE EXPERIENCE OF MEN PROVIDING AT-HOME CARE FOR A DYING LOVED ONE

By

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ABSTRACT

The primary purpose of this study was to examine the experience of men who provide care to a dying loved one at home. A qualitative research method, Interpretive Description, was used as the experience had not previously been fully examined. The sample was taken from a larger study examining the social context of home-based palliative caregiving and thus, was a secondary analysis of the original data. Analysis of the data from 13 male caregivers provided a rich description of their experience of caring for a dying loved one at home. Three main themes including (a) leading in, (b) moving into action, and (c) outcomes of male caregiving emerged from the analysis and included several sub-themes. Findings suggest men entered the caregiving role in several ways: previous knowledge of caregiving, support for them as caregivers, a lack of other desirable options, and a strong sense of duty. As they became caregivers the men moved into action by developing strategies and ways of caring for their loved one, some of which were influenced by gender. Caregiving men became informed, learned and did the required tasks, assembled needed equipment, dealt with challenges, and tried to advocate for their dying loved one and themselves. Men also had to take care of themselves, which involved getting help, setting boundaries, and taking time off. A few men were unable and unsupported to take care and had less satisfactory experiences. Several outcomes were identified as a result of caregiving, including the rewards and toll of caregiving for men, outcomes for family members who were supporting the caregiver and outcomes for the dying person. Study findings point to a need to examine the structures and services currently in place and suggest improvements that could be made to more fully support men in a palliative caregiving role.
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DEDICATION

This thesis is dedicated to my husband Nick, who has shown me the utmost of support over the past five years and who, in the last two years has also became a dedicated caregiver for two of his family members.

I also dedicate this thesis to all the caregiving men who provided the original research team with their stories and shared their intimate journeys of caring for dying loved ones at home.
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to the fullest in my endeavour to accomplish my goals.
CHAPTER 1: INTRODUCTION

Who is caring for the dying at home and under what context? What is the evolution of the caregiving role? While women have traditionally carried out caregiving responsibilities in the home, statistics demonstrate that men are also in this role. In 1996 it was determined that 10% of all adult males over the age of 15 years were caregivers compared to 14% of females (Statistics Canada, 1997). Caregiving is undertaken in a variety of situations, including childcare, elder care, care of the disabled, care of the chronically ill, and care of the dying. The focus of this study was to describe men’s experiences of providing care to the dying at home. Examination of male caregiving roles within this context provides nurses with knowledge that could provide the basis for strategies and interventions to support male caregivers of the dying at home.

Background to the problem

With the population aging and the “baby boomer” generation now reaching retirement age, end-of-life care issues are rising significantly resulting in an increased need for caregivers of both the frail elderly (Robinson, 1997) and the terminally ill (Chochinov & Kristjanson, 1998). The National Cancer Institute of Canada (2001) predicts 134,100 new cases of cancer and 65,300 cancer deaths in Canada in 2001. In 1999 there were 49,800 cases of HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome), including 16,913 AIDS cases in Canada (Health Canada, 2002). Deaths due to cardiovascular disease totaled 78,942 in 1999 (Heart and Stroke Foundation of Canada, 2002). Statistics Canada (2000) reports 215,000 deaths by all causes in Canada in 1997, with 27.2% cancer deaths, 26.6% deaths due to heart disease, and the remainder of deaths (46.2%) resulting from chronic illnesses, hereditary diseases,
injuries/accidents, suicides, psychoses, and HIV infections. Much of the care required for people with chronic and terminal conditions will be assumed by family and friends (Ramirez, Addington-Hall, & Richards, 1998).

Several factors influence the current state of caregiving. Studies show that the majority of people with life-limiting, incurable illnesses, if given time to make decisions about end-of-life care, prefer to be cared for and die at home (Costantini, Camoirano, Madeddu, Bruzzi, Verganelli, & Henriquet, 1993; Dunlop, Davies, & Hockley, 1998; Gilbar & Steiner, 1996; Moore, 1993; Townsend, Frank, Fermont, Dyer, Karran, Walgrave, & Piper, 1990). This care has been and will continue to be borne by spouses, family members, and friends (Bowling, 1983; Ramirez et al., 1998). Nottingham (1995) concurs that approximately 80% of care at home is provided by family members or close friends. The trend to encourage care at home is expected to continue as costs for institutional care rise (Chochinov & Kristjanson, 1998; Di Mola, 1995; Roe, 1992). Thus, the need for caregivers at home is expected to rise in response to care demands of the terminally ill. Nurses working with these caregivers must have the knowledge and expertise required to support family caregivers and are, therefore, obligated to continue to expand this understanding by exploring gaps in the care-at-home experience.

Much of the current state of knowledge of caregiving is based on the female caregiving experience. Little is known about men who are caregivers of the terminally ill at home. In order for nurses to determine strategies that support male caregivers, a greater understanding of this experience is required. Since gender may play a role in caregiving experiences, it is imperative that the perspective of male caregivers be examined within the experience of caring for a dying loved one at home.
Research on the caregiving experience in palliative care has encompassed a wide range of topics. Caregivers are intimately involved in all aspects of the ill person's care, including physical, psychological, emotional, spiritual, financial, and social. These aspects of caregiving have been described by the terminally ill, family caregivers, and service providers, encompassing a broad view on the entire experience. In studies where gender was identified, the majority of caregivers were female (Hill, 1984; Hull, 1991; Jarrett, Payne, & Wiles, 1999; Robinson, 1997; Rose, 1998; Silveira & Winstead-Fry, 1997; Sisk, 1999). A few studies described the experience of male caregivers in the care of a person with cancer at home (Hilton, Crawford, & Tarko, 2000; Orsi, 1994). While these studies are important they are limited in fully addressing the knowledge gap in male caregiving in palliative situations.

Professionals' and caregivers' focus of caregiving is often directly related to meeting the needs of the dying person. Caregivers, however, also have needs including the need for information, support, practical advice and guidance in managing treatments, medications, physical care, and symptoms (Axellson & Sjödén, 1998; Beck-Friis & Strang, 1993; Conley & Burman, 1997; Hinton, 1996; Hull, 1989; Norum, 1995; Rose, 1999; Ryan, 1992; Silveira & Winstead-Fry, 1997; Skorupka & Bohnet, 1982; Stetz, 1987; Vachon, 1998a; Vachon, 1998b; Wright & Dyck, 1984). Caregivers may not have previously experienced this role and, therefore, may feel vulnerable, inadequate, overburdened, unsupported, lonely, and overwhelmed. As well, these caregivers are experiencing anticipatory grief as their loved one moves through the illness trajectory towards death (Thobaben, 1999; Walker, Pomeroy, McNeil, & Franklin, 1996). Both the
enriching and deleterious effects of caregiving have been documented with a predominately female perspective.

How much of an influence does gender have on caregiving? A brief examination on theories of gender roles and identity is discussed to provide the context for examining male caregiving. Brok (1992) stated that gender is "embedded in and linked to social and cultural reality" (p. 173) and consists of roles and identities. Gender roles are thought to be social prescriptions associated with each sex and gender identities to be gender-linked qualities seen in oneself. Wainrib (1992) concurred that gender roles have been affected by social change and life cycle development (p. xix). Gender identity or sense of self is theorized to begin in infancy. By adolescence, when biological physical development begins, identity is thought to be well established. However, males and females may follow different developmental pathways. The primary relationship with the mother of both males and females may encourage femininity early in life, however, in adolescent boys, an attachment to the father may promote masculinity by becoming more task-oriented and assertive (Barbieri, 1999). Houle and Kiely (1984) stated that women develop a greater feeling of intimacy than their male counterparts in young adulthood. Cosse (1992) concurred suggesting that males have greater concern for competency and mastery of the environment than females. In conclusion, Cosse stated:

For females, the pathway allows for development of the self as an empathic being in relationship to others. For males, concerns with occupation-one's place in the world of work-and with development of an ideology are driving forces (p. 13)...

Males follow a pathway defining and leading to autonomy. Operationally, males learn to think and stand alone, following an internalized set of rules applicable in all situations (p. 14).
In midlife, men are thrust into the role of mentor, teacher, and supervisor in work and personal life (Kovacs, 1992) thus establishing their autonomy. Some theorists believe that rigid gender roles begin to soften and blur in midlife for both men and women. O’Neil and Egan (1992) suggest that the gender role journey has five phases, including acceptance of traditional gender roles, ambivalence about gender roles, anger, activism, and celebration and integration of gender roles. Belsky (1992) states that people react to life events in a sex-stereotyped way demonstrating continuity not change in behavior (p. 168). Researchers continue to explore the theory that distinctions between genders blur as people age and the uncertainty of whether men and women shed or trade identities later in life (Belsky, 1992).

Theories on gender role socialization provide one framework for understanding male and female differences in caregiving. Clearly, these theories support the notion that women, more so than men, are socialized into caregiving roles, which require “female characteristics” of caring and intimacy. While it is known that men also carry out caregiving responsibilities, gender role socialization theories demonstrate that men may not be prepared in the same way as women. It seems useful, then, to gain a better understanding of men’s caregiving experiences. This type of information may contribute to a greater understanding of men who are palliative caregivers and thus, provide the basis for informing the development of strategies that nurses and other health care providers can use to support men in their roles.

A considerable body of knowledge has emerged on the basis of explorations of family caregiving within the context of various chronic and life limiting conditions. Most studies examining home-based palliative caregiving have drawn predominately on the
female perspective. Fewer studies have focused on the experiences of men who provide palliative care at home. Given that men may experience the caregiving role differently than women, specific studies of men in caregiving roles are warranted in order to gain a better understanding of the broad spectrum of caregiving experiences. Although implications for nurses supporting caregivers have been drawn from the existing research, they may not be applicable to the context of male caregivers. Thus, this study seeks to fill the knowledge gap in the caregiving literature in order to more fully understand the male experience and to provide direction for nurses and other health care professionals supporting men in a caregiving role.

**Statement of the problem**

The experience of male caregiving of the dying at home has received little attention and, therefore, our knowledge in this area is limited. Although men do not constitute the majority of caregivers (Statistics Canada, 1997), they do provide care in a variety of contexts. As the population ages and people are cared for in their own homes, the number of caregivers, both male and female, will rise dramatically. Men may not have been socialized in caregiving and may require different supports than women to fulfill this role. Professionals require knowledge to support these caregivers, demonstrating the need for research in this area. Giving voice to the male experience is necessary to gain a broader understanding and advance knowledge of the at-home caregiving role in palliative care.

**Purpose of the Study**

The aim of this study was to gain a better understanding of the experiences of male caregivers who provide at-home care to the dying. The specific objectives of this study were to describe male caregiving experiences and identifying potential strategies for nurses
and other health care providers to support male caregivers in their role. This broader understanding is imperative in expanding knowledge, improving clinical practice, and stimulating thought for further research.
CHAPTER 2: REVIEW OF THE LITERATURE

To determine the current state of knowledge, several dimensions of the literature were examined to inform this investigation including a discussion of (a) dying at home, (b) caregiving in palliative care, (c) male caregiving in a variety of contexts, and (d) gender roles and issues in caregiving. This review served to highlight current knowledge, identify knowledge gaps, and help to frame the research question and sub-questions which guided this study.

The literature search was done in a variety of ways. The main search was conducted using CINAHL (Canadian Index of Nursing and Allied Health Literature), Medline, and PsycInfo. By reviewing the reference lists of some of the more pertinent articles/theses, further literature sources were found. A hand search through the main journals in palliative care was also done. Various Internet web sites proved helpful, particularly in obtaining up-to-date statistics that provided context for this study. Scanning relevant newspaper stories, popular lay literature, and textbooks dedicated to one or more of the dimensions of male caregiving provided a variety of perspectives in this review.

Dying at Home

Death, like birth, is a naturally occurring event and the home is increasingly seen as the most natural environment for this event to take place (Bowling, 1983). Given a choice between home and hospital most people choose to die at home (Dunlop, Davies, & Hockley, 1989; Townsend et al., 1990; Wilson, 2000). However, oftentimes people who wish to die at home are admitted to hospital for the final days or weeks of life. In one prospective study Hinton (1994) found admission to hospital attributable, in part, to the
overwhelming complexity of terminal illness, demands on caregivers, or lack of caregivers and other needed support in the home.

The literature is rich in descriptions of where patients die and the variables that influence place of death. When death occurs at home, the availability of caregiver support has been found to be an indicator by several researchers (De Conno, Caraceni, Groff, Brunelli, Donati, Tamburini, & Ventafridda, 1996; Gilbar & Steiner, 1996; Grande, Addington-Hall, & Todd, 1998). Younger patients also have more likelihood of dying at home compared to the elderly (Grande et al.; Higginson, Astin, & Dolan, 1998). However, in a retrospective chart review, Leff, Kaffernarger, and Remsburg (2000) found that for frail elders living in the community, the presence of a plan for death in a particular place was not only common but frequently implemented successfully.

A limited discussion exists in the literature in relation to gender and dying at home. Two studies found that women are less likely to die at home (Grande et al., 1998; Higginson et al., 1998). In a review of research investigating home death and patient characteristics, Grande and colleagues suggested men are less able caregivers and postulated this as a possible reason for why fewer women die at home. Higginson and associates suggested that the larger numbers of aging women along with increasing age of death from cancer may limit our ability to care for women at home. Although Gilbar and Steiner (1996) hypothesized, in their quantitative study, that married, European females, over the age of 60 years, were more likely to die at home, findings revealed that age, rather than other demographic variables were the primary factors determining place of death. Thus, the literature concurs that in general, women are less likely to die at home.
Men's ability to be caregivers of the dying at home may be a factor in this trend that warrants further investigation.

**Caregivers in Palliative Care**

A vast amount of literature has focussed on family caregiving in palliative care. This discussion provides an overview of current knowledge including caregiving experiences/perceptions, needs identified by caregivers, strategies used by caregivers, and the effects/outcomes of caregiving. This portion of the review explores those studies where either the study sample consisted predominately of women caregivers or gender was not stated. Those studies where men dominated the sample are discussed further in this review under “male caregiving in a variety of contexts”. By drawing from the general literature on caregiving and then more specifically on male caregiving, I will be able to focus on those aspects most relevant in framing my study.

**Experiences/Perceptions of Palliative Caregivers**

The literature focused on several aspects of how caregivers perceive their role. Caregivers' perceptions and experiences are important to gain a better understanding from their point of view instead of a reliance on reports from health care providers. In her phenomenological study of the family cancer experience, Thorne (1985) stated that “families have a shared perspective of their experience with cancer, and that this perspective differs from one that would be predicted from the professional health-care literature” (p. 289).

Caregiver’s perceptions of the dying trajectory were investigated by Holing (1986). Study findings suggest that caregivers perceive the experience of caregiving as both joyful and difficult or stressful. Joyful events included the closeness experienced by
caregiver and patient having opportunities to visit with family and friends. Difficult events included physical care and witnessing the patient experience physical symptoms. This study also revealed that emotional intensity for the caregiver can be greater than physical output in the care of the dying.

Several studies examined congruencies in family caregivers’ and care receivers’ perception of distressing symptoms. Kristjanson, Nikoletti, Porock, Smith, Lobchuk, and Pedler (1998) found that most of the time, caregiver’s perceptions matched those of care recipients and that family members are a reliable source of information if patients cannot communicate their own distress. In a quality of life study, Curtis and Fernsler (1989) found no statistical difference between caregivers’ and care recipients’ reports of symptoms. However, the authors did note that “patients reported better sleeping and symptom control and considerably less fun and sexual satisfaction then their PCG [primary caregiver] reported for them” (Curtis & Fernsler, p. 52).

Several qualitative studies revealed phases or stages in caring for a dying loved one. Brown and Stetz (1999), in their study of family caregivers, conceived the labor of caregiving as the core theme and defined this as “the ongoing cognitive, emotional, and physical work of caregiving” (p. 186). The labor of caregiving was described as having four distinct phases including “becoming a caregiver, taking care, midwifing the death, and taking the next step” (p. 186). This study emphasized that caregiving is more than tasks associated with the role, but more accurately, a process of initially becoming a caregiver to contributions after the death. Davies, Chekryn Reimer, and Martens (1990) also studied families in the caregiving role and theorized families as being in a transition from living with cancer to dying with cancer. The transition of “fading away” included the ending, or
realization of the terminal phase of the illness, the neutral zone, which included uncertainty and loneliness, and the beginning, where some families were able to reorient to life. These phases were seen as hard work in redefining and making meaning of the situation, which not all families were able to achieve. Norum's (1995) study found that caregivers experienced "a deeper meaning", including "nothing is of value, increased life experience, death can be met with dignity, learning the importance of close relationships, knowledge about what is important in life, being a better fellow person, [and] nothing is obvious" (p. 159). Hull (1992) found families "restructuring the meaning of the event as beneficial in some way" (p. 1186), including being available, preparation for new roles, and minimizing fear of medical procedures.

Rose (1998) studied caregivers in relation to time and found their role to be a complex, time-consuming experience. Demands on time included the practical tasks, emotional tasks, and outside demands (housework, shopping, childcare, and paid employment). Managing and planning time had a significant effect on the caregivers, as did past, present, and future perceptions. Rose concluded that in order to achieve a balance in their personal lives, caregivers required help in managing time, accessing appropriate help and sensitive support, and gaining access to appropriate advice and information.

These studies outline the complexity and time consuming role of the family caregiver. Family members experience transformation in their caregiving role, which involves not only tasks of caregiving, but also finding meaning in the experience, often extending into the bereavement stage. Studies examining the perceptions and experiences of family caregivers expand the knowledge in the caregiving literature and enable nurses to gain a better understanding of the family's perspective.
Needs of Palliative Caregivers

The needs of palliative caregivers have been studied extensively. Stetz (1987) categorized needs according to physical help, psychosocial concerns, role alterations, and financial alterations. Stetz found the most frequent caregiving demand was physical help, which included activities of daily living, treatment regimes, and coping with alterations in the physical and emotional state of the ill person. Norum (1995) supported this categorization of needs. Physical needs of the care recipient were also highly ranked by caregivers in studies by Skorupka and Bohnet (1982), Hull (1989), Ryan (1992), and Silveira and Winstead-Fry (1997).

Ensuring professional availability 24 hours a day, seven days a week was expressed as a need by caregivers in multiple studies (Axelsson & Sjödén, 1998; Beck-Friis & Strang, 1993; Brown, Davies, & Martens, 1990; Hinton, 1996; Hull, 1992; Norum, 1995; Raudonis & Kirschling, 1996; Skorupka & Bohnet, 1982; Wakefield & Ashby, 1993). Sixty five percent of respondents in the study by Axelsson and Sjödén expressed a need for assistance at night, as did a large number in Norum’s study. Other studies demonstrated that having a 24-hour number to call for assistance is a source of security for family caregivers despite the fact that they rarely call (Raudonis & Kirschling; Hinton, 1996). Although the need for 24-hour access to support families was clearly identified by caregivers, the majority of studies took place in areas where services already existed to support care at home. Caregivers may reside in rural areas where the limitation of palliative service providers may not be able to support 24-hour access. Thus, rural caregivers may find coping at home more challenging.
Caregivers expressed their own psychological and emotional needs as less of a concern than that of care recipients (Hull, 1989; Skorupka & Bohnet, 1982; Ryan, 1992). Schulz, Beach, Lind, Martire, Zdaniuk, Hirsch, Jackson, and Burton (2001) claimed that although levels of depression of strained caregiving spouses were higher than non-caregiving and unstrained caregiving spouses, these levels did not increase in the bereavement period. Other studies demonstrated that caregivers required higher emotional energy than physical energy (Holing, 1986), and that caregiving can affect mental health into bereavement (Grbich, Parker, & Maddocks, 2001; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). One study also demonstrated that caregivers may feel burdened by expressing their own need for emotional support (Wright & Dyck, 1984). Clearly, caregivers of the dying experience emotional and psychological challenges. However, the need for emotional support may not be explicitly expressed leaving the caregiver unsupported and, possibly, subjected to adverse mental health conditions.

Studies show that caregivers are in need of educational information related to the tasks of caregiving. Useful, pertinent, and understandable information has been shown to assist overwhelmed caregivers in fulfilling their role with less anxiety (Beck-Friis & Strang, 1993; Conley & Burman, 1997; Hinton, 1996; Houts, Nezu, Nezu, & Bucher, 1996; Rose, 1999; Silveira & Winstead-Fry, 1997; Vachon, 1998b; Wright & Dyck, 1984). These studies report families are in need of information on the illness trajectory, treatment options, advice on physical care of the patient, knowledge about the supportive services and equipment available, alternate care options (i.e. facility care), and progress/prognosis of their loved one. Beck-Friis and Strang found that family members needed clear, written and verbal information given and repeated on different occasions.
Conley and Burman found family members preferred verbal information and, at times, could not articulate their informational needs. Both these studies found stress and exhaustion affected the amount and type of information needed. Houts and associates found information on caregiving compiled in a manual plus a structured training program in problem solving empowered caregivers to provide competent care, thus improving coping skills and reducing caregiver stress. However, several studies found that information needs were not met consistently (Conley & Burman, 1997; Hinton, 1996; Norum, 1995; Stetz, 1987; Wright & Dyck, 1984). Wright and Dyck reported that obtaining information was a concern for 49% of cancer families. The concerns included difficulty getting information and the health care team controlling information. Hinton (1996) found that nurses and other providers more often reported giving information, advice or explanations to patients and family members than patients and family members reported on receiving. Hinton theorized this could have been due to recipients not consciously registering the information resulting in incomplete reporting. Information needs articulated by caregivers in these studies provide valuable knowledge for nurses in determining the need for and structure of this type of support.

Several studies suggested caregiving affects family members' social needs (Conley & Burman, 1997; Davies et al., 1990; Holing, 1986; Hull, 1991; Stetz, 1987). Stetz found a significant number of subjects (25%) reported role alterations that influenced their physical and social health. Other studies have also illustrated how caregiving can affect social needs (Davies et al. 1990) and have found that some caregivers under utilize support that could meet needs because of their difficulties of placing their own needs
before the dying person. Hull suggested that caregivers under use support services for a variety of reasons, including feelings of responsibility, reciprocity and vigilance.

Caregivers also identified a need for respite care. Respite care for an ill loved one enabled the caregiver some needed time alone as well as a break from the caregiving routine. Relief from care has been described as a few stolen moments (Hillman & Chappell, 2000) or time alone for personal care and rest (Wright & Dyck, 1984). In seeking social support, Hull (1991) found families were able to create windows of time where they were relieved briefly of the caregiving role.

Several researchers have examined economic needs. Beck-Friis & Strang (1993) found that 22% of their study participants were dissatisfied with the economic support they received, despite receiving an allowance provided for those who took a leave of absence from paid employment. Norum (1995) stated that two out of eighteen caregivers in their questionnaire reported financial loss during the home care period. Caregivers, in a study by Stetz (1987), rated the caregiving demand of managing the household and finances, including shopping and failing business as second most frequent demand. Because of the diversity of settings in different countries, varying health plans, insurance and personal circumstances, economic needs varied considerably. The economic impact of caregiving is discussed further in this proposal under effects/outcomes of palliative caregiving experiences.

Family caregivers’ needs in palliative care have been studied extensively. The literature suggests that caregiving is a complex, time consuming, demanding, and challenging role that requires support in order to fulfill it in a meaningfully way. Caregivers identify a myriad of needs for the accomplishment of their role including
physical assistance, 24-hour access to help, psychosocial/emotional support, appropriate/timely information, social support, respite care, and economic support. This knowledge is useful in understanding the intricacy of caregiving in relation to needs in accomplishing this role. A thorough understanding of this aspect of caregiving is necessary in order to apply this knowledge to further study of palliative caregiving.

**Palliative Caregivers' Coping Strategies**

The literature suggests methods of coping affect the experience of caregiving in the home environment. Thorne (1985), Davies et al. (1990), Brown et al. (1990), and Hull (1992) noted normalcy, or living life as normally as possible, as a coping mechanism for some families. “Normalcy” enabled the family to retain some sense of hope, distracted family members from the reality of the diagnosis for even brief time periods, and allowed for some form of self-expression. Normalcy included doing every day routines, hobbies, artistic endeavors, and future planning.

Another coping strategy included enlisting support from a variety of sources, including family members, friends, the dying person, professionals, and non-professional support services (Brown et al., 1990; Holing, 1986; Hull, 1992; Thorne, 1985). If the supports in place did not meet the family’s needs and they were unable to cope, feelings of frustration prevailed (Brown et al., 1990). In some studies, a lack of support may have led to hospital admission as the family’s ability to cope at home was jeopardized (Axelsson & Sjöden, 1998; Brown et al., 1990; Cartwright, 1991; Hinton, 1996).

Previous patterns of coping have been found to influence family members’ ability to care for a loved one. Thorne (1985), Davies et al. (1990) and Davies, Chekryn Reimer, and Martens (1994) all found that past life experiences and previous coping patterns
influenced family caregivers' roles in their present situation. Families in Thorne's study coped by articulating a shared philosophy of the family, characteristic coping style, or collective value system, with statements such as "diggers, fighters, and having a positive attitude" (p. 289). In another qualitative study, Davies and colleagues (1990) found past family experiences with loss and death significantly influenced current behaviors and responses. In a subsequent analysis of three qualitative studies focusing on family functioning, Davies and colleagues (1994) found both traumatic and pleasurable past experiences affected the coping strategies of caregivers.

Some studies have pointed out the coping strategies that help family caregivers deal with the stress and uncertainty of an often-unpredictable dying trajectory. One coping strategy for dealing with uncertainty was "taking one day at a time" (Hull, 1992, p. 1184). Thorne (1985) found cancer families "taking [the cancer experience] in their stride" (p. 288) and Davies et al. (1990) found families "had developed a perspective of living day to day" (p. 18).

Some studies have also demonstrated how anticipatory grief is associated with coping strategies. Chapman and Pepler (1998) described anticipatory grief as a complex, multidimensional phenomenon with some commonalities across individuals, including death anxiety, despair, anger/hostility, and somatic distress. These researchers found women use more emotional coping strategies than men, including anger/hostility and despair. However, somatic distress, defined in the study as "physical problems that occur under the stress of a situation" (p. 229) was not found to be gender specific. The study showed the more despair the family member had, the less hopeful they were. Walker and associates (1996) looked at the experiences of caregivers of people with AIDS (PWA) in
relation to anticipatory grief. Social stigma, multiple losses, and the chronicity of AIDS
effected the caregivers coping strategies. Grieving tasks included information acquisition,
expression of emotion, open communication, acceptance of needs and new roles of
caregivers, and saying good-bye. Caregivers of PWA, who were able to take care of
business, could complete the complex tasks of anticipatory grief (Walker et al., 1996).

These studies demonstrate that coping strategies affect the caregiver’s ability to
care for a dying loved one at home. Coping strategies include normalizing the situation,
enlisting support, taking a day-to-day perspective, and grieving. Strategies were found to
be based on previous patterns of coping. By examining coping patterns and strategies used
by family caregivers, a greater understanding of this experience is gained. Although some
studies described gender related coping strategies this was not an area widely examined in
this body of literature. However, general knowledge of caregivers’ coping strategies will
contribute to further study of gender specific caregiving.

**Effects/Outcomes of Palliative Caregiving Experiences**

The effect of caregiving on family members who care for a dying loved one at
home has several dimensions, including financial, emotional, physical, and psychological.
The literature describes this experience in negative/positive terms or cost/benefit analysis
with many variables affecting these outcomes. The financial cost of home caregiving has
been shown to have a negative effect on family caregivers. In one study of the demented
and terminally ill elderly, financing care at home included the purchase and/or rental of
equipment, medications, and home help (Grunfeld, Glossop, McDowell, & Danbrook,
1997). In another review of family caregiving, Robinson (1997) stated that, while the
monetary value of caregiving has not fully been studied, evidence existed that caregivers
alter their employment status (i.e., leave the labor force, take time off, and adjust work schedule) and make personal sacrifices (i.e., deprivation of necessities, decreased savings) to provide needed care at home for a loved one. The financial burden of caregiving at home may not be reflected in some studies where savings were seen in institutional care (Chochinov & Kristjanson, 1998).

Cost analysis studies for at-home care typically do not include hidden and indirect costs to families, such as deteriorating mental and physical health of the family caregiver and family functioning. Studies have shown, however, that caregivers often neglected their own physical and mental well being in the course of caring for their loved one at home resulting in caregiver burnout (York, 1995; Lemkin, 1995). Sisk (1999) found that caregivers who perceived their role as a greater burden demonstrated less health promoting behaviors than those caregivers who perceived less burden. Schulz and associates (2001) also found that strained caregiving spouses exhibited worse health practices and higher levels of depression than unstrained and non-caregiving spouses.

Kristjanson, Sloan, Dudgeon, and Adaskin (1996) studied caregiving families and found that their experience affected their own health and family functioning into the bereavement phase. Variables that affected caregivers physical and mental changes in health included prior health and family functioning status and quality of life of the dying loved one. Several other researchers have examined the effects of caregiving into bereavement. Koop and Strang (1997) found openness in planning for death and regular professional support contributed to caregiver’s satisfaction and adjustment during bereavement. Schulz, Newsom, Fleissner, Decamp, and Nieboer (1997) also found that social support and the quality of the caregiving experience facilitates bereavement in
former caregivers. Another study found increased psychological distress of spouses during bereavement when a loved one died at home (Addington-Hall & Karlson, 2000).

It appears that the effects of caregiving at home are directly related to perceived burden/strain, degree of social and professional support, the quality of life of the care recipient, previous health/financial status of the caregiver, and previous family functioning. The experience may, therefore, be viewed positively and/or negatively and may have both costs and benefits to the caregiver.

**Male Caregiving in a Variety of Contexts**

Men provide care in a variety of contexts, therefore, I examined the literature that focussed on the role of men in caring for someone with Alzheimer’s Disease (AD), Cancer and HIV/AIDS care.

**Alzheimer’s Disease**

Alzheimer’s Disease (AD) afflicts more women than men (Morano, 1998), implying that perhaps there are larger numbers of men taking on the caregiving role. While some researchers cite a predominance of the female perspective in this literature (Mathew, Mattocks, & Slatt, 1990; Parsons, 1997), other investigators have examined the perspective of male caregivers in recent years (Harris, 1993; McFarland & Sanders, 1999). The literature has mainly focused on caregiving roles (Harris; Mathew et al.; Parsons), role preparation (McFarland & Sanders), support systems (Coe & Neufeld, 1999; Kaye & Applegate, 1993), and needs of the male caregiver (Morano, 1998).

Mathew and colleagues (1990) examined male caregivers caring for a demented relative at home and made comparisons to men whose relatives were in a nursing home. The burden of care was not significantly different for either group. Both groups felt a
sense of duty and love towards their loved one. The researchers acknowledged that the relatives in nursing homes may have been more demented than those being cared for at home. The at-home caregivers were more involved in independent activities of daily living and received assistance from female relatives for the “hands-on” care. The researchers recognized that while men in both groups described themselves as “primary caregivers” the role was enacted differently in both groups. The criteria by which people categorize themselves as caregivers may affect a variety of aspects of the role, including the level of hands on care provided and support needed. As such, a greater understanding of this aspect of caregiving would contribute to current knowledge of the role as viewed by caregivers themselves.

In a phenomenological study of male caregivers of loved ones with AD, Parsons, (1997) examined the positive and negative aspects of caregiving as well as the meaning of the experience for the caregiver. Parsons articulated several themes including enduring, vigilance, a sense of loss, aloneness and loneliness, taking away, searching to discover, the need for assistance, reciprocity, and overstepping the normal boundaries. Parsons found the essence of the experience was the disease itself, with the profound deterioration and loss of cognitive and behavioral functions, thereby affecting the personhood of the loved one and profoundly effecting the caregiver. Suffering was viewed as affecting the caregiver more intensely than the ill person. Parsons asserted that, although many people with chronic and terminal illnesses experience both physical and mental changes, few affect the personhood and, thus, the caregiver with the same enormity as AD. Although this study revealed the suffering component of AD for both the caregiver and the afflicted individual, it is unclear that this suffering is any more significant in AD than in any other
terminal illness. Levels of delirium and dementia are evident in many life-limiting diseases and are not specific to AD. Thus, while it is acknowledged that suffering is a significant component of AD, caregivers and people with other diseases may also be severely affected by the suffering experienced by a loss of cognitive functioning within the illness trajectory.

Harris (1993) conducted an exploratory study to both describe the experiences of males caring for their loved one's with AD and to outline a typology of male caregivers. Harris found common themes in the experience including “commitment; social isolation / loss of companionship; coping strategies such as control, a structured routine combined with respite care, a problem solving approach, and outside activities; a sense of accomplishment; the need for specialized services for men; and limited expectations of help from their children” (p. 553). Four types of male caregiving were found in this study. The Worker was described as modeling the caregiving role after a work role, which created a new identity for these men. The Labor of Love group oriented the caregiving role with the deep and loving feelings the men had for their wives. Sense of Duty was the title given to the men who felt deeply responsible and dutiful in caring for their wives. At the Crossroads encompassed those men who were in the early stages of the caregiving role and who were often operating in crisis mode as this new role had yet to be clarified.

In a series of focus groups McFarland and Sanders (1999) explored male caregiver’s coping skills, needs, role development, tasks, and service provision in their experience of caring for women with AD. Coping included concentration on specific tasks and minimizing their emotional reactions to the role. A sense of control was provided through journaling and viewing the caregiving role as a second job. All the participants made financial and legal plans early in the caregiving role and had also looked into
facilities in preparation for the future. Accessing outside community resources for at-home care, however, was not utilized as a coping strategy but was seen by these men as an admittance of weakness or failure to the responsibility of caregiving. Learning the role was challenging to the men in this study as they saw caregiving as a female role and felt unprepared to handle these responsibilities. The men reported that more education and support would be beneficial in aiding them in their caregiving role. Although these men were caring for women with AD the findings demonstrate the need for specific strategies in the preparation to the caregiving role for men in a variety of contexts. The results of this study support the theory that society views caregiving as women's work (Baines, Evans, & Neysmith, 1998) and that men see caregiving as a job with duty, responsibility, planning and commitment.

The role of formal support systems was discussed in the AD literature in two different ways: formal support groups for caregivers and formal care settings for care recipients. Kaye and Applegate (1993) found that initially men entered formal caregiver support groups as a means to gain needed information. However, once the male caregiver was engaged in the group, the need for social support became increasingly evident. Many men, due to a reluctance of sharing personal feelings, preferred to remain self-sufficient, which was viewed as a deterrent to men joining and remaining in a support group. Kaye and Applegate also found that men empowered themselves through discussing, interacting, and processing information with other male caregivers rather than receiving the information from a health care professional “expert”.

Formal support was examined in a study, which focused on the institutionalization of the person with AD (Coe & Neufeld, 1999). The findings of this qualitative study
described four phases within the central phenomena of making concessions for care. In the first sequential phase caregivers opposed formal help while managing care independently. Next, gave in reluctantly to the need for formal help. The third phase described the initial contacts with sources of formal support. Finally, the last phase involved fine tuning the choices of care that best met individual needs. The study also examined these male caregivers following admission to a facility and found the role only somewhat altered as they continued to be involved in the care of their loved one.

Studies specific to the needs of male caregivers were not found. However, opinion articles were identified, demonstrating a need for further research in this area. Opinion articles including stories and vignettes, can complement the empirical knowledge base by enlightening researchers to relevant aspects of caregiving that have not been formally examined. For example, Morano (1998) used a series of vignettes to dispel myths about the needs of male caregivers. Illustrated needs included instructions to perform hands-on care, involvement in discharge planning with regards to services needed to support care at home, identification and balance of the needs of the caregiver and patient, recognition of the emotional attachment that men have to their wives, and understanding coping strategies and emotions of the male caregiver.

The AD literature provides a significant contribution to the current knowledge base on male caregiving. In this literature, men view caregiving as women’s work, structure caregiving into tasks, responsibilities, and duties as in a second job, and require support, education, and a sense of accomplishment to fulfill the role. The findings in the AD literature contribute to the knowledge base of male caregiving and provide a useful framework for examining male caregivers in palliative care.
Cancer

In cancer care few studies were found on the topic of male caregiving. One descriptive study was done on male caregivers’ responses to caring for a family member with cancer (Orsi, 1994). The results of this study show that men were more involved in the independent activities of daily living (IADL), which included transportation and medication administration and less in dependent activities of daily living (ADL), such as bathing and dressing their loved one. The investigator explained the possibility of gender role socialization influencing men in their not being comfortable with personal care and thus less involved with ADL. Further explanation included higher levels of physical functioning of the care recipients may have indicated less need for this type of caregiving involvement. Male caregivers in this study accessed social work and counseling support more frequently than nursing support. Caregiver involvement was also associated with the type of treatment the loved one was receiving and the use of nursing and formal support services, thus, the higher the degree of treatment, the more likelihood of support services. Men with higher incomes were also more likely than lower income men to hire nursing services. The research findings also suggest caregiving men experienced significant adverse changes in their state of health, particularly if they did not have adequate family support. Another stress for men was the balance between working at an outside job while caring for the loved one at home. The men showed more stress when outside assistance was provided, given their initial feelings of incompetence at caregiving, and, also, lower self-esteem with increased involvement in the independent activities of their loved one. Orsi explained that “a sense of mastery and control appears to be crucial to the male caregiver’s sense of well being” (p. 89). Depression was also related to lower self-esteem.
However, most of the men reported high self-esteem and Orsi explained this finding as a natural move towards nurturing as these men reached the mid-life stage in their life cycle.

Hilton, Crawford, and Tarko (2002) also examined men in a caregiving role within the context of cancer care. The men in this study were caring for wives with breast cancer as well as providing childcare. Through naturalistic research methods, the findings revealed that men focused on their wife's illness and care as well as on keeping their families going. The men in this study were also struggling with the demands of work life and finances but tried to keep a positive view, which acted as a buffer to the reality of their situation. Wives in this study were receiving active cancer treatment and thus, were not in the terminal stage of their illness.

These studies provide a contribution to the knowledge of male caregivers' experience with a cancer family member. Care recipients in these two studies consisted mainly of high physically functioning women with breast cancer (60% of Orsi's sample) receiving chemotherapy (80% of Orsi's sample) thus suggesting care was provided within a non-terminal phase of illness. The care of a person in earlier stages of cancer may be different, both physically and emotionally, than caring for an actively dying person in the terminal stages of the illness. Pattison (1977) described three phases in the experience of dying including the acute crisis phase, the chronic living-dying phase, and the terminal phase. With advances in treatment, people with cancer often experience a prolonged illness trajectory, focusing on the acute and chronic phase rather than the terminal phase. Caregiving research studies may not explicitly state or describe the phase of the illness trajectory that the care recipient is experiencing. Thus, caregiving in various phases may be experienced in different ways. The care recipients in these two studies appear to have
been in the acute crisis phase or the chronic living-dying phase as described by Pattison. A gap in the knowledge of the male caregiving experience in general is evident but specifically in the late chronic and terminal phase of illness. In addition, caring for the dying at home may encompass any end-of-life chronic condition including, but not limited to, cancer. Thus, the experience of male caregivers caring for a dying person in the late chronic and terminal stages is largely unknown and requires further investigation.

**Acquired Immune Deficiency Syndrome**

Research studies conducted with male caregivers of PWA have been abundant and have focused, to a large degree, on the experience of men as caregivers. This review will provide a brief examination of the AIDS literature encompassing the caregiving experience with a male perspective. Therefore, only studies where gender was explicitly stated to determine male dominance in the sample are outlined in this review.

Several qualitative studies have outlined the caregiving role in stages or phases. In a cross-sectional, longitudinal study of 20 caregivers (12 men), Reynolds and Alonzo (1998) found three emerging phases in the AIDS caregiving role using inductive research techniques. The first phase included transitions to care which demonstrated the changing relational roles in the dyad, obligations to care, and weighing the risks and benefits of caregiving. Next, living with the burden involved contending with uncertainty and conflict, managing stigma and risk, and enduring loss and sorrow. Finally, facing the void meant giving up the role, enduring the grief and regret, and feeling a sense of growth and meaning.

Brown and Powell-Cope (1991) explored the AIDS caregiving role in a grounded theory study. The research revealed transitions in the uncertainty of the caregiving role,
and outlined several stages and strategies within five subcategories in their substantive theory. Caregiving, oftentimes, is structured around managing the illness and renegotiating roles within the caring relationship. However, Brown and Powell-Cope found that uncertainty in AIDS caregiving also pertains to loss and dying, revealing the illness, and containing the spread of the disease.

In another grounded theory study Stajduhar and Davies (1998) examined the at-home experiences of caregivers of persons with AIDS in the terminal phase. This qualitative study demonstrated the complexity of caregiving in this context. The experience of these caregivers began with a promise to fulfill the wishes of their loved one, a description of the significance of the work involved in caregiving, and the context of uncertainty and stigma in which the care was provided. Caregivers developed strategies to help them cope with their situation including, (a) being with the loved one, (b) getting out for a break, (c) maintaining a balance between self care and caregiving, (d) seeking both formal and informal support, (e) working as part of the team with service providers, (f) taking charge in times of dissidence and (g) planning for death. Several conditions influenced caregiving in this study including the structure, accessibility, and nature of formal support systems. The researchers reported the consequences of caregiving in the study as including a sense of pride, making sense of the loss and the caregiving experience, and a renewed inner strength in those who received support. Conversely, feelings of anger, isolation, mistrust, cynicism, and unresolved grief were the consequences for those who experienced unsupportive networks.

Support networks were found to have a bearing on the caregiving role. Turner, Pearlin, and Mullan (1998) studied AIDS caregivers in two categories: traditional family
caregivers, which were 80% female (mothers, spouses, other relatives) and non-traditional caregivers, which were 90% male (friends, homosexual partners). Findings demonstrated the importance of social support to the emotional well being of the caregiver. Female/friend caregivers demonstrated the highest level of emotional support, while same-gender traditional family caregivers and spouse/partner caregivers received lower levels of emotional support. The researchers suggested that when traditional family members undertake the AIDS caregiving role, they may become socially isolated by withdrawing from normal social networks. In addition, partners' perceived lack of support might be due to the extensive involvement of caregiving activities. However, friendships were a primary source of support for all caregivers, most particularly in the “gay community”, where friends often took on functions of the traditional family.

Several researchers have studied psychological stress in AIDS caregivers (Folkman, Chesney, & Christopher-Richards, 1994; Irving, Bor, & Catalán, 1995; Meadows, Le Maréchal, & Catalán, 1999; McCann & Wadsworth, 1992; Pearlin, Aneshensel, & Leblanc, 1997). Irving and colleagues examined distress among gay men who were the primary caregiver of their partner with AIDS. This cross-sectional study revealed strong evidence that AIDS caregiving may have an adverse effect on the caregivers own psychological health, including significant psychiatric morbidity. Factors contributing to this included the premature loss of a partner, demands of the caring role, and financial difficulties. Dementia was an occurrence in about 15% of AIDS patients (Meadows et al., p. 47). This cognitive impairment added to the burden of care and had an effect on the caregiver. Meadows et al. conducted a small observational study and concluded that caregivers experience similar burden in caring for people with dementia,
whether it is AD or HIV related. However, the caregivers in Meadow and colleagues’
study seemed to lack information and communication with service providers, which may
be a result of the stigma attached to HIV and AIDS.

Caregiving in relation to AIDS may also have an affect on the physical health of
the caregivers. Leblanc, London, and Aneshensel (1997) studied this aspect of the role and
found that poor physical health was directly related to care related demands and stressors.
In this study HIV seronegative caregivers had fewer health problems than their HIV
seropositive counterparts. However, the seronegative male caregivers in this study had
fewer health problems than the seronegative female caregivers. Mental health problems
including depression were seen as directly related to poorer physical health in all of the
AIDS caregivers.

The male caregiving experience in AIDS was succinctly framed by Folkman and
associates (1994) who asserted that the experience has dimensions that distinguish this
role from the traditional caregiving role. First, AIDS caregivers were usually younger than
other caregivers. Most people in the 20 to 40 age ranges are building relationships and
developing careers. Second, the stigmatizing nature of AIDS often separated caregivers
and their partners from their families of origin. Next, caregiving was seen by society as a
feminine role, thereby male AIDS caregivers received no public support or recognition for
their role. Finally, caregivers of people with AIDS may also be HIV positive which
highlighted their own vulnerability in the caregiving situation.

The literature on male caregiving in the AIDS population demonstrates distinct
differences as compared to other populations such as caregivers for people with AD and
cancer. These differences are relevant when examining the male caregiving role and
reinforce the danger of generalizing the findings from one group to another. As in other literature, the nontraditional role of male caregiving is recognized. The AIDS literature also highlights the high degree of emotional adjustment in the care of someone dying. Not only are caregivers adjusting to care demands and the impending loss of a loved one, but also to their own vulnerability to the disease. Although the AIDS literature contributes greatly to the current state of knowledge in male caregiving, further knowledge is needed in palliative care, where caregivers may be older and may not be vulnerable to disease and stigmatization as is the case of AIDS caregiving men. Thus, men who take on a caregiving role in non-AIDS situations may have different challenges and require different forms of support. This study aims to contribute to this knowledge gap.

In summary, the knowledge gained from studies on men who are caregivers in AD, cancer, and AIDS situations highlight several elements of this experience. While there are distinct differences across these three contexts, there are also similarities to consider. Men report the high emotional aspect of their caregiving and, at times the negative affect on their own health. Men require help to accomplish this role satisfactorily, including support, information, and education. Further study of this area, focussing on men who provide home-based palliative care would provide more depth and understanding of the experience and may serve to enhance the ability of nurses and others to interpret male caregiver’s needs.

**Gender and Caregiving**

Although the previous studies examined men’s experiences in a variety of caregiving roles, they did not focus on specific aspects of gender and caregiving. Several studies, as are reviewed here, have explicitly focused analysis on the issue of gender as it
affects the caregiving experience in a variety of contexts. In a longitudinal study of caregivers of people with dementia, Cossette, Lévesque, and Laurin (1995) found gender to be an influencing factor in aspects of informal support given to the caregiver. Men in this study seemed to receive help whether or not they asked for it. The researchers assert this is perhaps because providers felt men are uncomfortable with “a woman’s task” and offer help spontaneously. Men also were more satisfied with information provided to them to support their caregiving role than women were in this study.

Hibbard, Neufeld, and Harrison (1996) also examined support networks in relation to gender in a series of longitudinal studies of caregivers of older, cognitively impaired people. These researchers found that older men and those of lower socioeconomic status experienced fewer sources of support than did their younger and wealthier counterparts. The researchers explained that older men may no longer have contact with a workplace and may have lost social contacts if their spouse was ill or incapable of initiating social activities. The researchers concluded that these men may be at risk for inadequate support which could negatively impact their caregiving experience.

Similarities and differences of caregiving demands and gender were examined in a qualitative study of spousal caregivers (Stetz, 1987). Both males and females reported the same primary demand of managing the physical care, treatment regimes, and imposed changes but males reported managing the household and finances as the second most frequent demand. Another difference was found in the number of demands where males reported an average of 1.9 demands while females reported and average of 2.5 demands in the caregiving role. While female caregivers in this study were more concerned with their inability to change the course of their spouse’s condition and to observe this deterioration,
male caregivers were more concerned with managing day-to-day household activities. The researcher proposed no explanation about these differences. This study may serve to support the theory that females are expected to cope with caregiving by virtue of being female (Baines, Evans, & Neysmith, 1998) whereas males may hold no claim to the caregiving role, and thus, not only have fewer demands, but are also more concerned with traditional male activities, such as management and financial issues.

Gender socialization may also explain some aspects of congruency between men and women in caregiving roles. In a qualitative study of elderly, frail, spouse-spouse caregiving relationships, Chappell and Kuehne (1998) examined husband-wife dyads and reported more positive affect congruence when husbands are caregivers than wives. Positive affect congruence was determined by words such as satisfactory, good, great, excellent, as stated by spouses in the interviews. Caregiving husbands were less likely than caregiving wives to express negative sentiments about their partner or their relationship. This was explained by the possibility of men’s perceived choice in the caregiving role as opposed to women’s obligation of caregiving.

This relatively small set of studies on gender and caregiving contribute to the current body of knowledge of caregiving men and women. The studies in this review examined the role of men as caregivers in a variety of situations and demonstrate gender-based differences in their experiences. Given that gender may affect caregiving experiences, studying male caregivers’ experiences further will contribute to this area of knowledge. Therefore, an examination of male caregiving in palliative care, which is a context that has received relatively little systematic analysis, will provide a greater understanding and serve to advance knowledge in this area of study.
Summary of Literature Review

I chose to do a comprehensive review of the caregiving literature from a variety of perspectives. The caregiving literature in palliative care is largely framed from a female perspective. This part of the review was critical because this is the knowledge by which palliative care has structured present programs and supports for families in caregiving roles. Male caregiving experiences in a variety of contexts, including AD, AIDS, and cancer, were also closely examined. No literature was found specifically on male caregiving in the care of a dying loved one at home.

The current state of knowledge of male caregiving stems primarily from gerontology, specifically AD, and from the literature on cancer and AIDS care. While some of these care recipients may be in the terminal dying phase, most are living with a chronic illness thus, the caregiving experience may extend over a long time period. In palliative care, people may be dying from a variety of illnesses over a short or longer time period. Some palliative experiences are brief but extremely intense and these also may not be reflected in caregiving for the chronically ill. Conversely, studies done in cancer care may be more reflective of the chronic living-dying phase than the terminal phase. Experiencing a home death as a caregiver is another under-studied area. Therefore, the literature does not fully address the experience of male caregivers caring for a dying loved one at home.

Research Question

Little is known about the male caregiving experience in home-based palliative care. Many aspects of caregiving are described in the literature with a female perspective. To address the complexity and various aspects of this role a broad question guided my study:
what is the experience of male caregivers caring for a dying loved one at home? In order to answer this question, several sub-questions were identified, including:

1. What factors influence men's entry into the caregiving role?

2. What supports and resources do men identify as being helpful in assisting them in their caregiving role?

3. What are the outcomes to men and others when men provide palliative care at home?

Describing the overall experience, entering the role, identifying helpful supports and resources, and describing outcomes of male caregiving are consistent with the overall question articulated in the primary study: "What is the experience of family members who provide palliative care at home and how does the social context influence these experiences?" (Stajduhar, 2001, p. 8).

**Definition of Terms**

Several terms are used throughout this study, which are consistent with the primary study, and are outlined as follows:

- *Palliative care* is defined as "the combination of active and compassionate therapies intended to comfort and support individuals and their friends and families who are living with, or dying from, a progressive life threatening illness, or are bereaved" (Canadian Palliative Care Association, 1995).

- *Family Caregiver* refers to "any individual who has significant ties to, and who was providing or had provided care to, a person dying at home, regardless of kinship ties, common household, biological relationships, or marital status" (Stajduhar, 2001, p. 9).
• *Home* is defined broadly as "any dwelling in which family caregiving takes place including traditional 'homes' as defined by Western society (e.g. a house, apartment) and non traditional dwellings as hot plate hotels and shelters" (Stajduhar, 2001, p. 9).

• *The Dying Period*, as defined in the primary study includes "the end of living with a life-threatening illness; when a person is expected to die within one to three months [used as a guideline by the investigator for the purpose of sampling caregivers]. This study focused on caregivers who had provided care at home to a dying family member or who were doing so at the time of the study" (Stajduhar, 2001, p. 9).
CHAPTER 3: RESEARCH METHOD

To provide excellent end-of-life care, a greater emphasis must be placed on palliative care based research (Grady, 1999). Research provides knowledge and a greater understanding of the phenomenon under study. Interventions and services that best serve people who are experiencing the phenomenon may then be constructed within a knowledge-based framework. Although many aspects of palliative care have been studied, there is currently a dearth of knowledge in the area of male caregiving.

Design of Study

Secondary Analysis

This study was conducted as a secondary analysis of a data set collected for a larger ethnographic study. Permission from the principal investigator (Dr. K. I. Stajduhar) was granted for this secondary analysis. As a member of the research team of the primary study, I gained valuable experience in a qualitative research project. My role as a research assistant consisted of attending an orientation to the primary study, meeting with health care providers to explain the study, recruiting participants, participating in monthly team meetings to discuss and review the data, facilitating a focus group, interviewing participants, and co-presenting at a provincial conference. My experience was not only educational but also enriching both personally and professionally. Being part of the primary study has enabled me to be familiar with the methodology used, purpose of the study, sample selection, and data collection, which benefited my undertaking of this secondary analysis.

Secondary analysis has become a popular method of inquiry and one that is ethically responsible given the time and resources required for data collection (Clarke &
Cossette, 2000; Szabo & Strang, 1997). Thorne (1994) asserts that "a secondary analytic tradition ought to be built into our expectations for managing the continuance of all our important research findings" (p. 265). My study of male caregivers fits with one approach of qualitative secondary analysis espoused by Hinds, Vogel, & Clarke-Steffen (1997) where an analysis is conducted on a subset whose characteristics are distinctly different from the larger sample. The original study examined the social context of family caregivers caring for a dying loved one at home. My study analyzed only the interview transcripts of 13 male caregivers within a narrower context. Using Hind and colleagues' Criteria for use in a Secondary Analysis of Qualitative Data Assessment Tool I felt confident that this proposed secondary analysis met all the requirements for using the data set of an original study (Appendix A).

The fit between the original study and this secondary analysis was strong. The primary study used ethnographic methods to examine family caregivers within the social context of caring for a dying loved one at home. Over 90 participants were interviewed for the study and a small number of these participants were male caregivers (n=13). The 13 typed transcripts made up the sample for the secondary analysis which provided data to examine their experiences of caregiving using the qualitative approach. Since the question for this secondary analysis originated from the data following analysis by the principle investigator, I believe the data provided me with sufficient depth to fully develop this inquiry. Hinds, et al. (1997) and Thorne (1994) view close involvement with the original researcher as advantageous to the secondary analyst in accessing data and understanding analytic processes used in the original research. This was a good "fit" with the original
ethnography and made "optimal use of hard-earned, costly, and valuable human data" (Thorne, 1994, p. 269) collected in that study.

Participants

Participant Recruitment and Data Collection

The original sample was found in a variety of ways. The research team recruited caregivers throughout the Capital Health Region of Victoria, British Columbia, either through word of mouth, presentations at meetings, or written invitation. Participants were identified via Victoria Hospice Society employees, community nurses, newspaper announcements, the Family Caregivers’ Network Society, and various other community agencies. The principal investigator or research assistant contacted the participants following demonstrated interest in the study and arranged for participation. Ninety-two people participated in an in-depth, face-to-face interview which was facilitated by the use of trigger questions (Appendix B). Other data collection techniques used was in the primary study included focus group interviews, participant observation, participant memorabilia (i.e. letters, diaries), media reports, and documents. For this study, a subset of the original data, namely typed interview transcripts of the thirteen male participants, formed the sample.

Description of Sample

Demographic information (Appendix C) was collected on all caregiver participants as part of the original study. Of the 13 men who participated, 11 had previously cared for a dying loved one at home and two were currently in the caregiving role. Most of these experiences were within the previous 10 years, although one took place in 1980. Nine of the care recipients died at home, one in a hospice setting, and one in an acute care setting.
The remaining two were at home at the time of the interviews. Diagnosis of the loved one included cancer (n=10), Cerebral Vascular Accident (n=2), and Amyotrophic Lateral Sclerosis (ALS)(n=2). All the male caregivers but four were the spouse of the dying person. Two men cared for their fathers and two men cared for their mothers. All of the men were Caucasian and ranged in age from 36 to 73 years at the time of caregiving. All but two men were educated beyond high school. Religious affiliation was variable. Employment status ranged from self-employed (n=2), employed full-time (n=3), and retired (n=8). Two of the 13 men did not wish to disclose income and, of those remaining, the incomes were as follows: $10,000-20,000 (n=2); $30,000-40,000 (n=1); $40,000-50,000 (n=2); $50,000-60,000 (n=2); $60,000-70,000 (n=2); and >$70,000 (n=2).

Data Analysis

In recent years Thorne, Kirkham, & MacDonald-Emes (1997) have introduced a new approach for the development of nursing knowledge named interpretive description which "acknowledges the constructed and contextual nature of much of the health-illness experience, yet also allows for shared realities" (p. 172). As interpretive description constructs itself in the shared reality of the health-illness experience, it is fitting to use as a guide for examining male caregivers' experiences in this secondary analysis.

Several strategies were required in this secondary analysis to ensure themes and interpretations were accurate. Thorne and associates (1997) support inductive rather than deductive thinking during data analysis. Inductive analysis is accomplished through analyzing individual experiences, constantly comparing incidents and evolving themes, and conceptualizing into clearly differentiated categories. Initially, I examined each transcript to get a sense of the whole experience. Next, as I re-read the data, I made impression
notes and notes in the margins of each transcript and began a reflective process, which was recorded in my analytic notes. I then began to create early themes with interview segments from each interview and kept them in document files. Some of the quotes seemed to fit in more than one theme and, as I did not know where they would best fit, I left them in multiple themes. During this process I began to see similarities and differences in the men’s experiences which I tracked in my notes. I was also noting any specifics that seemed to be gender related as well as biases and assumptions I had during the analysis.

At this point I met with the principle investigator of the original data set, who determined that my early themes and observations of similarities and differences were consistent with her perceptions with the data. She also provided me with further ideas for analysis and suggested we collaborate closely during the next phase of analysis. The next step was to put the themes into categories that captured the essence of those themes. This process required constant comparison between the themes I created and the original data. As my analysis progressed, I continually asked questions of the data to ensure that premature categorization did not occur. One method I found useful was to draw a conceptual map of the categories and themes. From this I was able to gain further insight into how the categorization was occurring. When all the themes were appropriately categorized, I developed a schema to frame the writing of my findings. As I wrote the findings and collaborated with the principle investigator, I began to see some of the themes did not quite capture the meaning I was intending for that category, so some adjustments had to be made. As I continued to write, I began to feel more confident about the categorizations as the themes and subthemes flowed together to describe the experience. Close association and collaboration with the principal investigator was maintained throughout this analysis.
All data in the primary study had been transcribed verbatim and had been made available for my study both in electronic and hard copy form. Management of the data text was accomplished by creating files and folders in Microsoft Word®. Emerging themes, supporting quotes from the original text, and my analytic notes were organized in respective folders to enable easier management of the text. Retrieval of specific pieces also assisted in writing the findings of this study.

Interpretive description provided a framework on which to construct this secondary analysis of male caregivers in this study. In chapter 2 of this study I critically examined the current state of knowledge in this area, which represented the beginning point of my inquiry. Inductive analysis of the data provided the basis on which logic, reasoning, and understanding meanings were structured (Thorne et al. 1997). Common themes extracted from individual cases were used to produce new knowledge applicable to other cases (Thorne et al.). The development of this new knowledge through description and interpretation of male caregivers' experiences provided a structure for nursing application of findings. The basic tenets of this methodology provided the structure to ensure rigor necessary for sound nursing research.

Rigor

Adhering to rigor in secondary analysis can be challenging. Thorne (1994) recommends complete immersion into the data as if it were the primary study. Inductive analysis, using constant comparison of text over time is applicable to secondary analysis as is the systematic examination of relationships between concepts, themes, and linkages between these (Thorne, 1994). Clearly identifying not only the process of the inquiry but also biases of the researcher is essential in adhering to rigor in a qualitative study. The
biases of the researcher are recognized in all qualitative research, however this effect may be magnified in secondary analysis (Thorne, 1994). Strictly attending to scientific rigor and recognizing my biases in journaling and memoing were beneficial in addressing this danger. As discussed earlier, my close association to the primary investigation was advantageous and positioned me favorably in examining the data with another set of questions.

Lincoln and Guba (1985) posed terms applicable to naturalistic research including credibility, transferability, dependability, and confirmability. Creswell (1998) offered verification techniques to ensure rigor of the study is maintained. One technique for checking credibility, member checks, involves participants in the review of findings and interpretations. Lincoln and Guba asserted that the member check is most decisive for establishing credibility. Thorne et al. (1997) stated that challenging emerging themes “permits the nurse researcher to come away with confidence that the conceptualizations are, indeed, grounded in data and representative of shared realities…” (p. 175-6).

Transferability or fittingness can be achieved through thick rich descriptions in the findings (Lincoln & Guba, 1985) and with the intention of reflecting a shared reality in the experience of male caregivers in the care of the dying. These descriptions may also provide meaning in similar situations external to the study. Dependability serves to create confidence in the verification of the findings and is intrinsically linked to credibility (Lincoln & Guba, 1985). Prolonged engagement in the field builds trust with the population and engages the researcher in the culture of the informants. In a secondary analysis, engagement in the field consisted of immersion in the data and with the original researcher. Confirmability, or auditability, refers to consistency in documentation of the
process to ensure that the “findings, interpretations and conclusions are supported by the data” (Cresswell, 1998, p. 203). Thorne et al. (1997) support the use of a reflective journal “to make an interpretive description of the phenomena convincing” (p. 175).

To ensure rigor in this secondary analysis of a qualitative study, several strategies were employed. The process of this inquiry was guided through the use of a reflective journal (analytic notes), which served to document my initial and ongoing analytical reasoning processes, identify my biases, and ensure the analysis was grounded in the data. Since I interviewed some, but not all, the participants in the original study, I discussed my ongoing analysis with the original research investigator and team. This process served to stimulate new thought and pose new questions to the data, thereby reducing my own biases. In secondary analysis member checks are not accessible, however, I approximated this by sharing my findings with the primary investigator of the original study to ensure my claims were consistent with findings of the whole study.

**Ethical Considerations**

Researchers using human subjects must ensure ethical responsibility. In this study ethical considerations included informed consent and confidentiality.

**Informed Consent**

Consent for using the data set for secondary analysis was initially obtained by the principle investigator from all the participants (Appendix D). The consent outlined the purpose and nature of the original study and was introduced verbally and in written form to the participants prior to each interview. Following explanation, the participant signed the consent and kept one copy. Participants were also informed of their right to cease audiotaping at any time or request to erase any part of or the entire recording.
The assumption that participants who provide informed consent for an original study also provide informed consent to a secondary analysis of the data, even when explicitly stated on the consent form, may be problematic. The secondary analyst must ensure that analysis is conducted in a manner which is not "a radical departure from that [original] stated purpose" (Thorne, 1998). For my research, several safeguards were in place to help ensure that consent was not violated. I conducted the research in a manner that was ethically responsible and not a radical departure of the original intent for this data set by maintaining continual close dialogue with the principle investigator and by sharing my analysis, findings, and future publication submissions with the principle investigator.

Confidentiality

During the original data collection a code number was assigned to all transcripts and any identifying information removed throughout the entire transcript. Demographic information was stored separately, to ensure the names of the participants could not be linked to the data. Transcripts and audiotapes were kept in a locked cabinet. Transcripts were only available to the original research team and dissertation committee. For this study, transcripts were also available to my thesis committee. Any published findings, including my thesis, will not include identifying information of the participants involved and will be shared with the principle investigator prior to submission for publication.

The researcher of a secondary data set may be less sensitive to delicate issues with-in the population under study and unknowingly violate confidentiality (Thorne, 1998). Several safeguards to ensure the confidentiality of participants was not violated were in place for my study. First, I was on the original research team and conducted several of the interviews for this data set, thus sensitizing me to the issues of those
participants. Secondly, my close association with the principle investigator and original team further ensured sensitivity towards participants and the issues disclosed during the original interviews. Finally, my professional life allowed my close and active role in the palliative care area, thus further sensitizing me to the delicate issues pertaining to this population.

Limitations of the Study

This study was conducted using secondary analysis of data collected for the primary study “The idealization of dying at home: the social context of home-based palliative caregiving” (Principal Investigator: Dr. K. I. Stajduhar, Ph.D., 2001). Interviews were conducted in the primary study using the trigger questions provided by the principal investigator. Thus, I am unable to ask further questions of participants that may explore, in depth, any queries that arise out of my analysis. However, the process of engaging in depth with the data and the original team allowed a thorough analysis, which resulted in credible findings.

One method of assuring representation of a phenomenon in a secondary analysis may be to gather primary data (Thorne, 1998). This study does not include any primary data, however, considering the safeguards discussed previously, I feel confident that the findings are reflective of a representative group of male caregivers caring for a dying loved one at home. The representative group for this study consists of men, living in the Greater Victoria area of British Columbia, Canada, who are caring for or have cared for a dying loved one at home. The loved one had, primarily, a cancer diagnosis, although two had end-stage CVA and two had ALS. No caregivers in my study were caring for loved ones with AIDS or AD. The study was also limited to a sample of Caucasian, English speaking
men and, therefore, not representative of other cultures. The findings are reflective of only 13 men's experiences and I acknowledge this as a further limitation to the study.

**Potential Significance of Study**

More knowledge of how men experience the caregiving role within a dying-at-home context may provide a more thorough understanding of the meaning that this experience holds. Understanding this experience may provide information for men who are either contemplating this role or who are currently in the role. The knowledge gained may also serve health care providers, including nurses, in the process of developing services, programs, strategies, and supports that best serve male caregivers and, ultimately their care recipients. As well, the dying may benefit from this knowledge about caregiving as they make critical decisions on where and how they receive care and how this may potentially effect their family members. It is my hope that this study has contributed to current knowledge of these specific aspects of at-home palliative caregiving.
CHAPTER 4: RESEARCH FINDINGS

The purpose of this study was to examine the experiences of men who provide care for a dying loved one at home. Data analysis from the interview transcripts of the thirteen men in this study revealed many commonalities and differences in men’s experiences. Main themes have been identified, highlighting the uniqueness of each man’s circumstance. Three main themes emerged from the data, including, (a) leading in, (b) moving into action, and (c) outcomes of male caregiving, with sub-themes (see Figure 1). The first theme describes the factors that lead men into a caregiving role and includes role knowledge, role support, option insufficiencies and duty to care. The second theme, moving into action, describes how men learn and fulfill the caregiving role, including an illumination of men’s endeavor to balance giving care to their loved one while taking care of themselves. The final theme describes the outcomes of male caregiving for the men themselves and their families, including the dying loved one. Outcomes for these men were both positive, described as rewards of caring, and negative, described as taking its toll. These themes, along with their sub-themes, provide a description of the experiences of men who care for a dying loved one at home.

By describing men’s caregiving experiences in this way, I am able to reflect on my original research question and sub-questions. Throughout the experience men described their needs, supports and resources within the context of their unique situations. I have chosen not to separate these from the whole but rather to describe and interpret them as they emerge within the themes and subthemes of this analysis.
Leading In: Factors Influencing Men’s Entry into Palliative Caregiving

1. Role Knowledge
   a. Informal Learning
   b. Formal Learning

2. Role Support
   a. Positive Experiences with Health Care Providers
   b. Family Nurse Support

3. Option Insufficiencies
   a. Facility Care Experiences
   b. Caring by Default

4. Duty to care

Moving into Action: How Men Give and Take or Not Take Care in a Palliative Caregiving Role:

1. Giving Care
   a. Becoming Informed
   b. Learning and Doing Tasks
   c. Getting Equipment
   d. Dealing with Challenges
   e. Being an Advocate

2. Taking Care
   a. Mobilizing Help
   b. Setting Boundaries
   c. Taking Time Off

3. Not Taking Care

Outcomes of Male Caregiving:

1. Outcomes for Men
   a. Rewards of Caregiving
   b. Taking its Toll

2. Outcomes for Families
   a. Enduring Own Burden
   b. Easing Caregiver’s Burden

3. Outcomes for Dying
   a. Protecting
   b. Teaching
   c. Planning

FIGURE 1: Outline of Themes and Sub-themes of Men’s Caregiving Experiences
Leading In: Factors Influencing Men’s Entry into Palliative Caregiving

I began this analysis seeking to understand how men become palliative caregivers. Several factors seemed to influence men’s entry into this role, including (a) role knowledge, (b) role support, (c) option insufficiencies, and (d) duty to care. Role knowledge was gained through formal and informal preparation. Role support, including both health care system support and family support, influenced men’s ability to provide care at home. Care options, which were seen to be insufficient, such as institutional care and an absence of alternate caregivers, often led men into providing care by default. Finally, a duty to care for their dying loved one influenced some of the men to enter caregiving.

Role Knowledge

Having caregiving knowledge seemed to be a factor that led some men into the palliative caregiving role. This knowledge was gained informally through their own personal caregiving experience or formally through nursing or medical education and professional experience.

Informal learning.

Some men began caregiving while their loved one was chronically ill and continued the role into the palliative stages. One participant claimed to have been his wife’s “asthma caregiver” for many years prior to her having a series of strokes. He explained how this led him into his current palliative caregiving role:

So this stroke thing was obviously unexpected but I think the asthma caregiving, in its minor role, helped me because I think I knew if I could do that…. I figured that was sort of good training…. So it was a good lead in.
Another man, upon learning of his wife’s ALS diagnosis, said he was “retired and getting prepared full time to be a caregiver”. He subsequently became deeply involved with the ALS Society where he had supported other caregivers and gained insight into the caregiving role. When his wife also developed cancer, he continued to care for her at home until she died. Another caregiver said that his caregiving “goes way back” as his wife had numerous chronic illnesses and debilities spanning many years. Upon reflecting on the factors that led him into caregiving he said, “that’s when I really started [caregiving] because there were things she couldn’t do…”

Through the experience of caregiving a loved one with a chronic illness, these men learned about the caregiving role and continued to provide care when their loved one’s condition became palliative. These men did not clearly differentiate their role between the chronic and the palliative stages of their loved one’s illness. It seemed that caregiving their chronically ill loved one through to death was a natural extension of a role they had assumed long before the palliative stages.

**Formal learning.**

Some men gained formal knowledge of caregiving through nursing and medical education and by working professionally in health care. This education provided these men with knowledge about care provision and the health care system. One man reflected on how his previous nursing experience contributed to his providing at-home care for his dying father:

Because being an LPN there was that part of it sort of came into it... I don’t think I ever really regretted not having him put in [facility care] because I felt that I got to use my skills, you know, even more....
Two of the participants in this study were physicians caring for a dying parent. Both of these men indicated that their specialized experience and background was a factor in their becoming caregivers. One physician, who was caring for his mother, felt his specialized knowledge and experience in palliative care enabled him to be better equipped to deal with the at-home care situation than other caregivers who may not have the benefit of this knowledge. This caregiver indicated that he was prepared to provide medical direction and guidance for his mother’s at-home care. Having this knowledge and experience influenced this man into becoming an at-home caregiver.

Another lead in to caregiving for physicians was their specialized knowledge about medications. One physician caregiver, who went out-of-country to provide care for his dying father, had decided prior to going, that he “... would be handling this man’s [his father’s] morphine” and “... was very scrupulous about that”. As this physician specialized in cancer care, his knowledge about pain and other symptom-controlling medications placed him in a favorable position of influencing the medical management of his father’s symptoms. As such, men who have gained formal knowledge and experience in caregiving may feel themselves to be positioned more favorably to become palliative caregivers.

**Role Support**

Confidence in having at-home support from the health care system or family members was another factor in men’s entry into the caregiving role. This confidence arose from satisfactory past experiences with health care providers and the presence of family support, specifically from family nurses.
Positive experiences with health care providers.

Satisfaction with previous encounters with health care providers made some men confident that the system would support them in their caregiving role. For example, one man and his family had previously experienced support from the local hospice staff during the death of another family member. This experience seemed to influence this man entering the caregiving role when his father was dying. Receiving support "almost right away" contributed to this man’s confidence and his positive outlook on the support system, which ultimately influenced his decision to take on the caregiver role:

And so we almost right away, hospice took him in and said, "Okay, these are the meds we need. This is what we need to do".... But there was constant, almost right from square one. The Thursday support group, going up [to the hospice] one-on-one to see counsellors, talking to [the doctors], [palliative care providers] coming out to the home, the home care worker coming in, almost right from go, you know. [They would ask] "How are things going?" and [they would] keep monitoring, sort of keep a tab on things. So yes, pretty much from the time he was diagnosed we had support and then probably the last six months, you know, was when it really all gelled and we got even more support.

Other men experienced support at home early in their loved one’s illness. One caregiver and his wife had previously received community nursing care and hospice counseling support. During the final stages of her illness, she was admitted to hospital for symptom management. As her condition began to rapidly change and place of death was being discussed, this man felt he would be supported in his at-home caregiving role. Positive experiences with supportive health care providers early in the illness trajectory of this man’s wife influenced his ultimate decision to provide care for her at home.

Sometimes men entered caregiving only after they did their own research on the availability of at-home support. One man, caring for his dying father, entered caregiving
feeling confident that his role would be supported from both a home care agency and the local hospice. He discussed his discovery of the support available for him:

I had searched out a home care facility that knew about palliative care and said they had RNs experienced in that. Plus the head nurse at hospice at the time said that she was willing to give us one of her LPNs on call plus an RN based on her availability and feeling comfortable about coming into the home. So they were there a lot of the time. So we said “That’s it. The decision’s made. He can be at home”.

Sometimes men received information from health care providers on the services available to support them at home. One man’s dying wife had been in a long-term care facility when he and his wife decided to bring her home to die. This man talked about receiving information from the visiting nurse and stated that “the health nurse explained all the details and things and said that they would come at least twice a day to help, morning and afternoon”. Thus, some men entered the role on the basis of support from health care providers.

Family nurse support.

Seven of the thirteen caregivers in this study had family members who were nurses and all of these men talked about the informal role their family nurse played in supporting them as caregivers. Family nurses included caregivers’ wives, daughters, sisters, and friends. These men seemed influenced by their own family nurse presence which gave them the confidence to become a caregiver. For example, one man’s wife’s condition deteriorated and, as the sudden realization of what her care entailed became more explicit, the presence and support of his family nurse seemed to influence his entry into the caregiver role. In this interview segment, this man explained how one night he made the decision to enter the role with knowledge of his sister’s nursing support:

P: So we decided at that point, no more radiation.
I: And she was at home? And is that why things started to change for her, quickly?

P: Yes. I guess ever since I came home [from working out-of-town] the worst thing was that one night I passed an exponential curve.

I: So how did you manage the caring part? Did you have someone giving you some advice?

P: Well, my sister would come over from [out-of-town] quite often. She’s a retired nurse. She was able to help me quite a bit.

Role support influenced some men to become palliative caregivers. Men’s confidence in available support was based on past at-home experiences with supportive health care providers or gaining information about available support. The family nurse was also an influencing factor that led men into the role and, by their presence and support, instilled confidence in men to feel more prepared in becoming a caregiver. Thus, previous positive experiences with home help by health care providers as well as the assurance that family support would be present enabled men to feel confident in entering a caregiving role.

**Option Insufficiencies**

Another factor that led men into the caregiving role was the lack of appropriate options for care that men were given. Unsatisfactory experiences in the health care system made facility care options undesirable to some caregivers. As well, in some situations there was no other person available to provide care and the men became caregivers virtually by default.

**Facility care experiences.**

Some of the men had previously experienced unsatisfactory care or had concerns that facility care would not be satisfactory for their loved one. These experiences and
concerns led some men into their palliative caregiving role. For example, one man had a previous experience in hospital while his father was dying. He recalled witnessing his father’s transition from “... pain and suffering... in the hospital... screaming” to getting him home and seeing “how quiet and relaxed he was”. This experience led him to believe he could provide better care at home for his dying wife than could be provided in hospital. Another man became quite upset when talking about hospital care of the dying, which he had previously experienced with dying friends and acquaintances. He also spoke of the indignities of institutional care:

Hospital, I think hospital is terrible. To be in the hospital and die in the hospital, it’s not very dignified. You’re just a number. Terrible... yeah, you can die in the hospital alright, but I don’t think it’s very dignified. You’re a number...

Caregivers not only talked about the unsatisfactory care in hospital but also about their experiences and concern with care in long-term care facilities. One of the participants, for example, was contemplating long-term care facility placement for his dying father. As this participant implied, however, facility staff may not have the time to provide the care for his father, requiring the family to be in constant attendance, as he stated here:

And also the thought of, well, who’s going to care for him? The social worker said that staffing was an issue at that time. Were we going to have to be down there just as much as having him at home? And even though there would be a lot of inconveniences, we could work around them. So we thought it was better to bite the bullet and have him at home than put him into care.

Another man had similar views on facility care and said: “I can tell you now, she’s not getting one-tenth of the care [in facility] that she’s getting here [at home]. Other concerns expressed by caregivers included the lack of prompt response to answering call
bells, loved ones not getting medications on time, and concerns about getting nutrition and hydration. One man, whose wife’s relatives had received unsatisfactory care in long-term care facilities in another province implied that the indignities associated with facility care influenced his lead into the caregiving role:

We looked at one another and we summoned up our experience of what we know goes on in these places, and we said, ‘We can’t do it.’... We’ve been through the clothes stolen, all of the indignities that can occur...

Caring by default.

Some of the men in this study entered the caregiving role by default. In some instances the primary caregiver became incapable of doing the role but at times, there was no other person available to provide care. One man took on caregiving for his mother only after his wife became “too tired and burned out” to do any more caregiving. In this couple interview, the wife explained some of the circumstances of how her husband entered the caregiving role:

It began with that [grandma falling]. Grandma needed more and [husband] was concerned that my back might give out. And so he offered to do the bath. The [home care providers] were not permitted, of course, to do that... Grandma’s bath is adjacent to our quarters. She loves it so much that we were determined to try and do it as long as we could. So [husband] offered. And at that point I had learned to accept offers because I was really getting very tired. But before that I was bathing her and getting her to the table and then sometimes starting right in to breakfast. But [husband] was doing the breakfast for quite a while. So then we just, he offered to take over to learn because I was maybe going to be away or something. So it started out he just wanted to learn.

In this situation, the husband became the primary caregiver and his wife became the “supporter”. Although initially this man “just wanted to learn”, he entered the caregiving role due to the inability of his wife to continue caregiving.
Other men entered this role by virtue of the absence of an alternate caregiver. In some instances, the men had no family at all to share in the role. In other cases, no one lived close enough to provide care. In one situation, the caregiver had to make considerable arrangements for a distant niece to stay with his wife while he was in hospital for surgery. Another man, with no other family or potential caregiver, had been caregiving his wife for several years and recalled how he originally came to be in the role:

She virtually collapsed in my arms.... I rushed to the hospital.... They did an ECG and I thought they would keep her overnight for observation.... They said, ECG looks all right. Take her home. And I sort of threw up my arms and I thought, whoa. And I sort of came home and she was pretty debilitated from then on.... It [caregiving] started then, basically five and a half years ago. So I guess I’ve been doing it [caregiving] since then.

Some men were led into caregiving because they felt there was a lack of other options including appropriate care settings and other caregivers. Some men had unsatisfactory past experiences or concerns about the level of care in institutions. This ultimately led these men into deciding that at-home care was a preferred option thus entering them into the caregiving role. Other men become caregivers either by the initial caregiver leaving the role or by an absence of other caregivers. Caring by default was not a clear choice by these men to enter the role, but seemed to arise from a lack of other options.

**Duty to Care**

Many of the men in this study entered the caregiving role because of a sense of duty and obligation they felt toward their loved one. Factors that influenced this sense of duty included a commitment to their loved one, a desire to maintain their loved one’s
dignity and privacy, and a belief that it was normal to die at home in familiar surroundings.

Obligation to the dying person was a factor for some men entering caregiving. Some men felt a spousal obligation to care for their dying wives and stated "... it was my place to do it" and "duty is something, possibly". Duty and obligation to care also arose from a desire to reciprocate, as illustrated in this son's comments about caring for his dying father:

There was a lot of obligation there.... Dad had been there when I was sick so why can't I be there when he was sick?

A duty to care was also reflected in the men's desire to respect their loved one's wishes. Referring to respect for his mother's privacy, one man talked about how staying at home, and ultimately providing her care, would support his mother's wish:

She was also a pretty private person. She was very proud. She had dentures that nobody was ever allowed to see her without them and of course, in the hospital, they were probably going to take them away from her. You know, little things like that which were really, really important to herself. So we respected that and she stayed at home. Of course, she stayed there until she died.

Supporting a loved one's desire to die in familiar surroundings was also an influencing factor for some men entering the caregiving role. A desire to respect his dying father's wishes influenced this man to become his father's caregiver:

Basically, dad said that he did not want to die at hospice, even though as I mentioned previously that my sister died on the program about four or five years previous. He still had some reservations about not being at home in his bed, familiar surroundings that sort of thing. And so we said, at first we said, 'Yes, no problem. We really understand that. We'll support you through that'.

One man's dying wife had been deeply involved as a facilitator with a breast cancer support group. As a result, his wife had supported a number of women to die at
home supporting the idea that dying at home is “normal”. When she became terminally ill, her husband said, “It was perfectly normal that she and the family would want her to die at home, if that was feasible”. This seemed to be an influencing factor for this man’s entry into caregiving.

Most of the caregiving men were influenced by more than a single factor. For example, one man was influenced to provide care at home by both positive past experiences with health care support and their daughter’s professional nursing background. Previous experience plus duty to care together were influencing factors for some men. Sense of duty and a lack of other options influenced other men. Clearly, these men were often led into the caregiving role by multiple influencing factors.

In summary, men who provide at-home care for a dying loved one are led into caregiving through several factors, including role knowledge, role support, option insufficiencies, and a duty to care. Some men gained experiential caregiving knowledge during their previous experiences of caring for loved ones at home, oftentimes beginning in the chronic stage of their loved one’s illness and continuing into the palliative stage. As well, some men acquired knowledge of the caregiving role through formal education and experience, such as nursing and medicine. A second factor contributing to men’s entry into the caregiving role was role support. Here, the men gained confidence in their ability to provide care by having previous satisfactory experiences with health care providers and through the support of family members, many of whom were nurses. A lack of suitable care options was also influential in men’s entering the role. Some men’s previous encounters with facility care led them to conclude that this was an insufficient option and thus, they became the caregiver. The absence of an alternate at-home
caregiver, such as other family members, led some men to become palliative caregivers by default. Finally, a sense of duty and obligation led some men to care for their dying loved one at home. Most of the men were led into the caregiving role by a combination of these influencing factors rather than by a single factor.

Moving into Action

The second main theme, moving into action, describes men’s experience in providing palliative care at home. During this time, men learned how to give care, and most men learned how to take care of themselves. A few men, however, were not able to take care of themselves, which made their experience more challenging. When men found a way to balance giving care and taking care of themselves, their experiences seemed generally more positive. During this experience men were able to talk about their needs as caregivers as well as the supports and resources that were helpful to support them in their role.

Giving Care

In order to provide care to their loved ones, men needed to gain the knowledge and skills to be able to give care. The men who had previous experience or knowledge of caregiving also found they needed to enhance their abilities for this role. Learning and doing this role required the men to become informed, learn to do tasks, get the needed equipment, deal with challenging times, and advocate for their loved one. Men used a variety of strategies to meet their learning and caregiving needs. At times, they were able to draw on their own strengths and past experiences to help them provide care for their dying loved one.
Becoming informed

Throughout the course of giving care some caregivers felt they had to become informed in order to provide quality care to their loved one at home. Men became informed in a number of ways including reading health-related material, using the media for information, attending workshops/groups, and getting information from health care providers, family members, or friends.

Some of these caregiving men read about their loved one’s illness and treatments so that they could improve their loved one’s quality of life. One man "read a lot about ovarian cancer" after his wife, who also had ALS, was diagnosed; he felt being informed was a way of dealing with the stress of the situation. Another man and his dying wife read an at-home palliative care manual and found the information "handy”. One very industrious man, whose wife had suffered multiple strokes, engaged in “self-educating” himself through a wide variety of methods. He had been providing care for a number of years and had undertaken extensive research to improve his wife’s condition and general quality of life as this interview segment suggested:

I read about it [wife’s illness]. So what I’ve done is, I research and access all the media on the TV, the radio, and sort of watched all the health shows and read Alive magazines for the last 5 years, and read all the alternative health magazines....

Another man became very involved in learning about energy work, which he firmly believed improves quality of life for dying people and may help to ameliorate issues with inter-family dynamics. He attended workshops, joined groups and read extensively on the topic. He had a strong belief that energy work could improve quality of life for the dying as he explained:
Energy work in a palliative situation will vastly increase the comfort level of the dying. Make it much, much easier. ... And have dying people in the space where they can be loving, instead of all the other things that you've experienced much more than I. Primarily the terror. And the grudge carrying and the angers, the inter-family dynamics, all of that could be ameliorated to a greater or lesser extent if the energy work was applied broadly. And my limited experience still suggests that there are profound psychological, emotional changes that happen with continued energy work, whether it's in a palliative situation or outside of it.

Learning and doing tasks.

Caregiving men were required to do a variety of tasks in their role, including household chores, personal care, and nursing tasks. While some men had previous preparation for such tasks, other men had to learn them. For the most part, ADL tasks and nursing tasks were new to the men. Men who had gained previous role knowledge also had to learn new tasks related to their palliative caregiving role. At times, drawing on their own strengths and past experiences helped the men provide care for their loved one.

Learning and doing care was also a process of trial and error for some men.

Many of the men in this study had to learn to do household tasks including cooking, cleaning, laundry, ironing and shopping. Some of the men who were retired at the time of caregiving had already taken on some of these tasks and did not find this to be a particular "drudge", as this interview segment demonstrates:

I'm also pretty handy. One of my real joys is cooking and I like cooking. It wasn't that part of it. In fact, when I retired in 1977, the first thing I said to my wife, I said, 'You don't have to cook any more dinners and you don't have to do any more shopping for groceries. I'll do it all'. And so I did. So that part wasn't a drudge, you know.

While some of the men seemed to adjust well to taking on household tasks, others had more difficulty. Some of the men, for example, had little previous experience with
running a household or doing household tasks prior to the illness situation. Some of the men learned from their dying wives and were appreciative of this opportunity:

She told me how to do the laundry and do the ironing... the baking I helped with... I never did it alone. Laundry and ironing, I have never done before. That was while she was sick. I got a binder and she tells me and I use that still. All how you do your laundry. I mean, this kind of towel now, and your underwear then. This goes with that, and so forth. This setting and this setting. If I didn’t have that [binder], I wouldn’t know how to handle it....

At the same time, learning to do certain tasks left some of the men feeling frustrated and regretful that they had not paid more attention to their wives’ instructions:

We have no children and we did everything together always, except cooking. I’ll never forgive myself. She told me, ‘Look over my shoulder, do this, do that’. I did the dishes. I helped with cleaning the vegetables and so forth, but cooking, I hate it still with a passion... I can never coordinate it properly. I make something ready and then another part you have to get out of the freezer.... Well, she always did the cooking, but I mean I should have listened to her. Oh yes, definitely.

Besides household tasks, men also learned how to provide ADL including bathing, lifting, toileting, feeding, as well as nursing skills, such as incontinence care, skin/wound care, nutritional care, and giving medications. Men talked about the importance of learning these skills in order to be able to provide care. One man, who cared for his wife with ALS, explained how proper instruction from health care providers assisted him in learning some essential aspects of physical care:

[The therapist] taught me. I didn’t even know how to lift properly and how to sit people down in bed, get them out of bed, get them into the bathroom, having a bath, washing their hair. My wife had hair down to her waist. Eventually, that had to be cut short. Oh, so many things you’ve got to learn.

Some caregivers stressed that nursing skills are “not that simple” and are not possessed by “average people”. While some men took the tasks in stride, others found they were “not familiar with nursing” and needed guidance. Since many men had little
formal knowledge of these tasks, they endeavored to learn them in a variety of ways. Most commonly caregivers talked about receiving instructions from health care providers. Unfortunately, at times the instructions came too late:

I asked my doctor if we could get insulin for her, and he said ‘Oh, no problem’. So he prescribed the insulin for her. We got back and I got the doses of insulin, but at no time had they ever shown me how to use this thing. So I thought, well, I can just inject it the same site as the morphine. You know, it goes into the vein, so why can’t the insulin go into the vein? Then, it was the home care nurse…. We found that we could not do this.

While most of the instruction came from health care providers, caregivers also took advice from others. For example, one man got a suggestion from a neighbor for giving pills to his wife. He explained that his wife’s paralysis had caused increasing difficulty with swallowing and that caregiving “hints” were very useful:

As things got worse, she had much difficulty in swallowing. Pills would get stuck in her throat and she had so many to take…. So finally a neighbour came up with the idea which worked beautifully, of getting empty gelatin capsules from the health food store and putting the pills in these, and where the pills are big, cutting them, and putting them in pieces into these capsules. She had much less difficulty swallowing these capsules…. They worked wonderfully…. Little hints like those were very useful.

Some of the men drew on their professional experiences to help them cope with the demands of caregiving. Having prior nursing experience, for instance, was an asset to one of the men when it came time to administer medications to his dying father. As this man reflected on his experience, he began to see how being a nurse allowed him to become more involved in his father’s care. With support from health care providers, he gained further confidence in his role:

For a long time there, almost right to the end, Dad could take his own pills, as long as he knew this little box at a certain time, this is what he took. And so every week I’d have to fill them up and make sure there was more pills on order and that sort of stuff. So it felt like because I was an
LPN I could be more involved. And then also that one time when Dad had a bad spell at home, the [hospice team] came out and left a 911 kit [with medications], and they said, ‘You know, even though you’re an LPN, we’ll teach you how to use it if it becomes necessary’. Now, this is why I became a nurse. You know, to be of help.

One man explained how working shift work while in the military helped him to prepare for providing long hours of care for his wife. Despite his experience being years prior to his caregiving, he felt his previous work experience had prepared him for the anticipated demands of caregiving:

Even at the end, when I was giving her morphine injections fairly regularly…. A few nights and days…. I was getting catnaps and waking up and doing this stuff…. I stayed in the Navy quite a long time. I was in from 1942 to 1956, so I was used to sort of watchkeeping as it were, and losing sleep in the days and nights. So that wasn’t a particular hardship.

Another man, who was arranging 24-hour care for his dying wife’s final days, also felt his shift work experience benefited his situation, as he recalled, “I am the only one that has ever worked mid-night shifts so I’ll take the mid-night shift”.

While some men learned from others or drew on their previous experiences, others relied on trial and error to learn about the tasks associated with caregiving:

I must admit I have to learn to work smart as opposed to a stab in the dark. That’s what I learned early on was stabbing in the dark because I must admit I was just going over and buying all kinds of pills thinking that they were going to work…. So I’ve got to figure out something that I know is going to help her…. So what’s the alternative?…. So I just keep experimenting…. 

Getting equipment.

Preparing the house for caregiving required the men to gather equipment and supplies. Some men referred to the accumulation of supplies and equipment in their home as turning “into a hospital”. However, equipment was needed to assist with caregiving and men sought a variety of ways to get what they felt they needed. One man, with the
guidance of a community physiotherapist, “rigged up stuff above the bed that would help, mostly lifting [his paraplegic wife] from the bed to the wheelchair”. Another man obtained free dressings from a charitable organization when his wife required twice a day dressing changes on her legs. Another caregiver had to phone around to various agencies in order to secure a wheelchair, a bath lift, and catheter supplies for his wife. Another caregiver used the analogy of preparing for a baby with the preparation of caring for a dying loved one at home.

All the equipment you need [for caregiving at home]. And you’re going to have to drive around to the Red Cross or those other places and go to McGill and Orme to their home care department and equip yourself with all this stuff. It’s like having a baby.

While the gathering of equipment and supplies could be time consuming, some men were helped by community people who could get them needed supplies. For example, one man involved in the ALS Society used their equipment loan cupboard and another man’s sister-in-law was a nurse who brought him supplies.

One man recognised the need for flexibility and timeliness in meeting equipment needs given the sudden physical changes that accompany dying. He recounted his experience in caring for his father and reflected on how changes in the disease trajectory sometimes necessitate having the right equipment at hand:

And of course, the physical things we talked about. You need a certain amount of flexibility as well I think. I mean, the fact that I could perceive that my father was close to dying. I didn’t know how quickly he was going to die. I didn’t realize how quickly his needs were going to change over time from being up and about to being bed-bound over five or six days. And all the pieces of equipment that you need, you know. A person stops making trips to the bathroom so you need a commode, and the bottle, and all these other things. I mean, lots of equipment, you need to be able to get hold of and access it, in relatively short order. Not just say, ‘Well, bring it around tomorrow or the day after’. Because you need it right away, it’s hard to plan for it. You can’t deliver a truckload of equipment on day one
and say, 'Well you don't need all this stuff, so we'll just park it here and you call when you need it'.

Dealing with challenges.

Caregivers were often confronted with particularly challenging situations that left them feeling frightened. Many times these challenges occurred as their loved one's condition changed suddenly and was oftentimes accompanied by an escalation of symptoms like pain and confusion. Caregivers were also challenged in their encounters with the health care system and with health care providers they perceived as unhelpful.

One of the most challenging situations for caregivers was dealing with the sudden and unpredictable changes in their loved one's health status. When symptoms got out of control or when their loved one's mentation suddenly changed some of the men felt "panicked". These men often dealt with sudden changes by calling for help from health care providers and family. A loved one's confused mental state was often a particularly distressing symptom that caregivers faced. One man described his wife's "psychotic state" as "a dark night of the soul" and, in an emotional recollection, described how the police were called to take his wife to hospital. A health care provider told one man, who described his situation as "scary and frightening", that his wife's confusion was "a sign that they're close to dying" and, subsequently, provided him with advice. Another man felt his wife's confusion was "very hard" because he had "never dealt with that sort of thing before" and had regrets that he "should have been more patient". These men were not prepared for the challenges of caring for a person with a confused mental state and found they needed help to deal with these frightening situations.

Another "scary" incident occurred as one man and his mother got his dying father up on the commode, whereupon he began choking and shaking. Their first instinct was to
call 911 but they managed to "talk him through" and then realized he had a full bladder. This caregiver had been a nurse and had experienced family deaths but realized that although he had a good idea of the dying process, there were still incidences that were new to him in the care of the dying. This man's experience implies that even with knowledge, some caregivers may still not be fully prepared for all the challenges that caregiving may present.

Sometimes challenges with symptoms were not from sudden changes but from ongoing problems. One man had difficulties managing his wife's bowel regulation, requiring him to constantly change her medications. He felt managing the bowel routine was one of the biggest problems in his caregiving role but he persevered in dealing with it even towards the end of her life, as he explained:

One of the biggest problems that I had was trying to balance my wife's laxatives because, when you take morphine, it is terribly, terribly constipating. So at one point, my wife was taking 13 pills a day related to stomach and bowel functions, and trying to have a bowel movement every two days. You work on getting her the laxatives. Well, very often they would not work, so then you have to give the enema. And sometimes that worked, sometimes it worked only too well, and then you're faced with the opposite problem. The best that the doctors or the nurses could say was just to keep working at it, a little bit less now, and little bit more there.... Toward the end, I had to have the adult diapers because she'd have a bowel movement during the night sometimes. That caused all kinds of problems.

Another challenging symptom for caregivers to deal with was pain. Challenges in pain management included dealing with escalating pain and system problems in achieving assistance for pain control. One man stated his wife's "pain control was a real issue" and we "ran into a crisis" when his wife's pain began escalating and the medication doses required adjusting. After attempts at using the medication at hand failed to control the pain and there were no alternatives, the caregiver spoke to the family doctor
who subsequently arranged for an anesthetist to insert an epidural to achieve pain control. When pain control was finally achieved, this caregiver reflected on the events and felt that had his wife received the epidural intervention earlier in her illness, she may have had a better quality of life during the proceeding months prior to her death.

Sometimes health care system processes also posed barriers and delayed access to appropriate symptom control. One man’s wife needed an injectable form of medication to manage her pain. This caregiver described how rules and regulations might sometimes be barriers to timely symptom control:

There was one point when my wife’s pain got out of control. She was at home. We had two kinds of morphine - fast-acting morphine, the quick release morphine, and the regular morphine. So, between her regular doses her pain got worse, so she took the quick-release and it didn’t do any good. Took more quick-release, it didn’t do anything. We had mentioned this to the doctor before that the quick-release did not really help her. So I called the oncologist on call at the [hospital]. It was a lady, and she called me back, and I guess this was in the morning around 10:00 o’clock. She called me back and she said, ‘Well, I’ll write you a prescription for injectable morphine, but you’re going to have to get the home care nurse to do the injection, and you’re going to have to come down and pick up the prescription. You can’t just call for it over the phone’. So I had to make sure my son would stay with my wife. I called the home care nurse beforehand. I went out to the [hospital], picked up the prescription, got back to the [pharmacy], got the prescription, and came back home, waited for the home care nurse. That was 5:00 o’clock before she got her injection. So that wasn’t very good.

Another challenge came when a routine check turned into an unexpected occurrence which led to an unsatisfactory encounter with a health care provider. This participant had become adept at caring for his wife’s catheter. However, one day the appearance of blood in the catheter bag alarmed him. Because he had “no medical knowledge”, he called for help to deal with the problem but was less than pleased with the home care nurse’s suggestions on how to proceed:
I woke up one morning and my wife's catheter was hanging beside the bed so I had a look at that because I always had to check, and it was full of blood, and not just little shreds that you see from the catheter, it was all solid red. So I called the home care nurse and I was really not impressed with the response I got because she didn't seem very sympathetic. She said, 'Well, there's not much I can do about it'. Those were her exact words. 'There's not much I can do about it.' She said, 'Take her to emergency'. I said, 'She can't walk'. 'Well, call an ambulance.'.... Well, she was very blunt. It was nothing she could do anything about, so, you know, get her to hospital. Or even if I had called an ambulance, I know what emergency's like. My wife could not have been there for the two hours that it would have taken to get around to looking at her.

After this incident, this caregiver called another health care provider who intervened with the nurse and the problem was resolved. However, this caregiver felt that some nurses dealing with dying patients may have a lack of knowledge and thus, may not be able to advise caregivers in helpful ways.

Being an advocate.

Many of the male caregivers became advocates for their dying family members, particularly when their loved ones became too weak and debilitated to advocate for themselves. Previous work experiences prepared some men for this role. Men who had medical or business careers seemed to be more at ease with advocacy than others. For example, physician caregivers spoke of how their prior work experiences and knowledge gave them certain advantages when communicating with other health care providers and facilitated their ability to become advocates for their dying loved ones:

Certainly it [being a physician] facilitated communication with the other health care professionals. I was able to call up the GP's office and get through to the GP, able to call up the consultant, get through to the consultant to call me back, you know. You never expect them to do that. And so that was a big advantage. He'd actually been booked for some radiotherapy a couple of days after I had arrived.... I could see there was no way, no benefit to him.... He wouldn't get any benefit. Speaking to the consultant on the phone, she obviously agreed. So it was easy for me to communicate, that was the fastest and most assistance to him. There was
going to be no benefit. And my dad was quite relieved not to have to go as well. If I hadn’t been there, probably, none of us would have known the situation and they probably would have taken him, you know typical situation. So that certainly was an advantage to him, I think.

One of the physician caregivers was persistent and successful in advocating for adequate home support for his dying mother:

First of all, we met the nurse manager who went through this thing, pulled out the 5-page thing [assessment forms]. After we had stressed to her [manager] really that she [mother] couldn’t be left alone because she [mother] wasn’t safe to be left alone, she [manager] said, ‘Well, I’ll arrange for somebody to come in once every 2 weeks to bathe her’. And I said, ‘I don’t think you’re quite getting it, you know. We both work. We can’t leave her and my understanding is that you can provide for a home support worker’. So eventually, we got the message across to her, I think, and she arranged for this young woman to come in.

Men with a business background also spoke about how background influenced their advocacy role. One man felt his business experience enabled him to be “strong” and a “people person” which prepared him to speak out for himself and his wife. This caregiver felt he needed to “take the bull by the horns” in advocating for and providing his wife’s care, as he described in this situation of finding a new physician:

I decided she still needed a conventional doctor. So it took about another two years to find another doctor who was looking to some kind of compassionate approach to helping people, could make house calls…. It could be just somebody who wanted to heal. We found somebody…. Gave him all the information and of course, he wanted her records, and the records would show these diagnoses. We just said, ‘We don’t want these misdiagnoses to be looked at as some sort of indication of what’s wrong with her’. So this guy said…. and this was when [wife] was having a really bad December. She was in bad, bad shape. So I called him and I said, ‘Can you come? [Wife] is really bad’. So he said, ‘Well, I’ll need her records first’. I said, ‘Well listen, we’ve been through this when I talked to you two years ago. I mean, can’t we start from a clean slate, an open book, like chapter one, page one?’ And his nurse or his secretary called back two days later and said, ‘We’re not interested in helping. Goodbye’.
In some of the interviews, men talked about their lack of "medical or nursing knowledge" and felt this may have affected their ability to advocate. One man, whose wife became paraplegic, regretted not being more insistent with the emergency room physician in having his wife's leg weakness investigated. He felt guilty that he had not taken matters into his own hands: "I felt guilty that I should have consulted the cancer clinic myself". Another man had an encounter with the emergency room where his wife had laid on a cold, bare stretcher for hours. He also regretted not advocating for her then: "I will never forgive myself that I didn’t open my big mouth and vent and then pick up my own [stretcher] pad". These men felt that with more knowledge they may have been better able to advocate for their loved ones.

In summary, there were a number ways men became prepared and gave care to their dying loved one. First, many men endeavored to inform themselves about various aspects of the disease process and therapies to improve the quality of life. They became informed through reading, the media, and obtaining information from health care providers. Through their caregiving experiences, these men came to realize the complexities of learning and performing the tasks of caring for a dying person. Besides household tasks, caregivers needed to learn how to assist with ADL’s as well as do nursing skills. Men learned these skills from health care providers, family and friends, and at times, through a process of trial and error. Securing equipment was another way men were assisted to provide care and this was also done in a variety of ways, depending on what equipment and supplies were needed. Men had to deal with presenting challenges, often needing outside help. Some challenges were especially frightening like sudden changes in their loved one’s condition; others were frustrating when they did not
get the support they needed. Finally, men became advocates for themselves and their
dying loved one. They advocated for stopping medical treatment, arranging home help,
and finding appropriate health care providers. At times their lack of knowledge and
confidence led to feelings of regret at not fulfilling the advocacy role. Giving care was a
complex phenomenon that men undertook with a firm resolution to provide the best
possible care to support their dying loved one at home.

Taking Care

Most men in this study tried to balance their caregiving tasks with taking care of
themselves. A number of strategies helped them to accomplish this. Oftentimes health
care providers, such as nurses, were instrumental in men’s taking care. Most men
developed strategies of taking care by mobilizing help, setting boundaries, and taking
time off. Achieving a balance of giving care while taking care seemed to contribute to
men’s overall positive caregiving experiences.

Mobilizing help.

Mobilizing help for hands-on care and companionship for their dying loved one
was one of the ways men took care. Nurses, home support workers (HSW’s), and others
were accessed from private agencies, community health programs, and local hospices.
Help was either specifically asked for or just seemed to appear. Oftentimes, the visiting
nurse encouraged help be arranged for the caregiver.

Several of the men arranged for regular help in providing personal care for their
loved one. Most often HSW’s were utilised but sometimes nurses were hired by the
caregivers to provide this care. Nurses were often influential in suggesting times and
situations when they felt help was needed. One man appreciated the help he received from home care nurses:

It was excellent. You know, right through the whole thing, they [home care nurses] saw the needs. They were here daily, or every other day, or once a week, depending on the [needs].... And I had no quarrels with the frequency at all.

At times, help arrived seemingly without the caregiver having asked for it.

According to caregivers, nurses played a central role in assisting them to mobilise help.

One physician caregiver recalled the help that he received as a result of nurses’ involvement in his situation:

I think the system went pretty well the way it was going to go. That’s right, the home care nurse, the sister, as they call her, the supervisor of home care nurses, was checking in very regularly. She, I think was the one who directed the resources. So she was the one who decided when he should have, you know, night-time care, and so forth. So she was pretty much on the ball. I don’t think I needed to ask for anything of that sort, it was all done.

This man, whose sister-in-law was a home care nurse, also realized the extent of nursing care that is involved in the care of someone at home. He came to appreciate not only family nurse help but also help from visiting nurses. He reflected on his experience in this way:

Another issue which came home to me is that unless you happen to have family who are trained nurses, and I think nursing care is 90% of the care at home, you can’t expect to do without the home care nursing program.

A few of the men who initially did all the care for their loved one seemed to be relieved when HSW’s took over for part of the time. One man explained how he came to eventually balance the home help with his own caregiving. He said: “The home help eventually took over her bathing and personal care which was quite useful, although I would do it on a Sunday because, of course, they didn’t work Sunday”.
An important factor in taking care was the caregivers’ ability to get a good night’s sleep. Several caregivers valued night help as this allowed them to “detach” from caregiving and feel well rested in order to meet their caregiving demands. As one man explained, “In my case, the biggest thing was the overnight nursing…. Because if you don’t get a night’s sleep, I don’t know how you manage the next day”. One caregiver described his relief with the twenty-four hour help from hospice in the following statement:

But I think the good part was, especially when we got 24-hour care, and even more so knowing that we had two staff that were coming through hospice, was a real relief, you know. It was like now we can do our own thing, feel like we can have a respite, know that there’s somebody there that is well-trained, knows what’s going on.

Often family and friends were mobilised to help with some aspect of caregiving. The men especially valued their own family nurse’s contributions to supporting them in their role. The men found family nurses helped in a variety of ways including providing direct care, calling physicians, getting equipment and supplies, providing respite, and offering advice to the caregiver. Many family nurses offered their nursing expertise and actively participated in the care of the dying loved one, as one man described:

[Mother] got a sore on her bum because she would lie on her back. [Wife], being a nurse, would go in and say, ‘you have to lie on your side’ and she would tip her over on her side and shove a pillow against her back…

Mobilizing help also included non-task oriented aspects such as meeting loved one’s social needs. As their loved one’s ability to meet their own social needs became increasingly difficult, some men sought companionship for their loved one. When this need was met, the caregiver’s burden seemed to lessen somewhat. One man found he was able to mobilize social help by moving into a “care-o-minium” where his wheelchair-
dependent wife, whom he described as “a very sociable person”, could move around easily and meet some of her own social needs. In these surroundings his wife could “take herself downstairs to the dining room in the wheelchair and go for coffee with people which she enjoyed”.

Sometimes health care providers who came into the home also provided companionship. Caregiving men seemed to value the help they or others mobilised for meeting social needs as much as the task-oriented aspects of caregiving:

So she [HSW] spent a lot of time reading to my mother, writing letters and so on, bathing her when she needed bathing and so on. She really took to her and we sort of adopted her as a member of the family.

While mobilizing help was one aspect of taking care, caregivers also had many comments about abilities of the helpers. Many of these caregivers felt health care providers and other helpers in the home needed to have “a good idea of what they’re doing”, as well as the ability to be “well organized” and “settle in” to the home situation easily. Some men valued helpers that could “take on even more duties” like “TLC” to the family. Others valued help that arrived promptly when it was needed, especially when their loved one had symptom problems like pain. Thus, caregiving men not only discussed a variety of ways that help was mobilized but also aspects of how help was delivered.

Setting boundaries.

As caregiving was often accompanied by physical and emotional strain, some men set boundaries as a way to take care of themselves. Not only did setting boundaries enable the men to protect their own comfort levels, but also to remember the dying person as they were prior to caregiving.
One man was clear about his own comfort level in his caregiving role for his father. Setting boundaries in providing personal care such as bathing was, in part, due to their previous relationship and, in part, because he wanted to remember his father as he was before the illness. Bathing was also viewed as "symbolic" by this caregiver and thus, he set boundaries on that aspect of providing care:

But there's also the issue of not wanting to, the comfort level of knowing you don't have to do that [bathing], in the sense that you can preserve an image of memory. My father was a very private man. We never went into his bedroom when he was in bed, for example. The same, I never saw him in the bathroom, or I never even saw him in his swimming trunks. I don't think.... He [brother] was helping with the diaper off and on my father and we [family] just co-operated and did it.... Again, I don't know why, but that sort of care [incontinence] seems to be different from bathing someone. I guess there's something symbolic about bathing somebody.

Another caregiver felt comfortable with bathing his wife but not with changing a catheter. By being clear with the home care nurses about his discomfort with certain tasks he was able to set boundaries in his caregiving role and thus contribute to his taking care of himself.

Taking time off

Most of the men in this study were able to develop ways of taking a break from the caregiving role. Some of the methods used were described as "creating rituals" which consisted of short periods of time away from the caregiving situation. Many men also took off longer periods of time described as "respite". These breaks in caregiving served to enhance the day-to-day lives of caregivers and allowed them the opportunity to take their minds off caregiving for awhile.

Some of the rituals that enhanced caregivers’ lives included going for coffee, socializing, playing sports, walking, napping, gardening, watching TV, and visualizing.
One man who had been caregiving for several years explained how important his rituals had become to him:

You have to find rituals in your life. Now I found that out by ritualizing my life, it's helped.... I've got to do that [play tennis]. That's part of my schedule.

Another man did energy work on himself through a process he referred to as "visualization". This process, along with night support, enabled him to maintain a balance throughout his caregiving experience:

But being able to get a night’s sleep, and also using the energy work to stay on an even keel... You know I could feel myself going off the rails and I’d just lie down and do that visualization and I’d be back on the rails. And then the home support and the whole system worked well for me.

Other men had simpler rituals that they used to take care of themselves. One man who was employed would often go out for coffee after his evening shifts prior to going home. For another man, a daily ritual was just "going downtown and hanging around, hanging out" while home support workers cared for his wife. Creating rituals was a way for men to "stay on an even keel". These rituals enabled the men to balance their giving care with their taking care, many times without being physically away from the place of care.

While creating rituals was beneficial for many caregivers, taking longer "respite" breaks was also helpful in balancing their lives while caregiving. The men were frequently encouraged by health care providers and family members to take time off from caregiving. Respite was done in a variety of ways including utilizing home support, family members or friends for respite care, and placing the dying person into a facility respite bed. Most of the men needed encouragement to take time for themselves, but once they did, they felt it enabled them to carry on in their caregiving role. Health care
providers usually arranged respite, but in one situation, a thoughtful neighbor made the arrangements.

At times some men felt they did not need help. After caring for his ALS wife for several years, one man said he “was a big strong SOB and could do all the things...” His family nurse suggested, “You’ve got to take care of yourself”, which she supported by staying with his wife. This man commented on feeling rejuvenated and ready to carry on following his weekends of respite.

Another man did not want to ask for help and declined it when first offered. Again, health care providers persisted and, after experiencing regular respite, he said, “It was quite a relief.... It was a good break”. Support group members and health care providers convinced another man that respite was important. He recalled his struggle with deciding to have a break:

[Support group] people said, you know, ‘Just get out for a walk in the morning’... There was I’d say, quite a bit of support from hospice saying, ‘Okay, we’ve got this week off in here, it’s yours, take it and make sure you do things for you’. And it was a struggle sort of thing, Okay, I’ve got this week, like, what do I want to do for me? Like, I don’t really need it, but even just to be able to sleep in and not have to listen for the buzzer call. We had been visiting.... which was really stress was they [health care providers] would come up every day to visit, and it was amazing, especially after the second or third time how you almost look forward to [respite], Okay, I’ve got a week coming and these are the things I can do. Whereas the first week, was, like ‘What do I need this for? Let’s get back home and get on with his care’.

For one man, who “took it to heart” when “I had been repeatedly told by every care person I came in contact with that I had to take care of myself “, having four hours of daily home support gave him respite and that “was really important”. He also took longer periods of time off when his daughter was able to take over his role.
One physician caregiver, who also had experience in palliative care, suggested the idea of respite in a person’s home as opposed to respite in a facility. He claimed that some families feel they need to be at their loved one’s side to ensure the provision of proper care in the facility. He suggested that when this occurs, families do not get the break from caregiving that they need. Another suggestion from this caregiver included expanded respite options, for example, increasing time periods for respite and offering more home-like care settings. He felt that these options might be more appealing for caregivers in meeting their respite needs.

In summary, taking care was done in several ways, including mobilizing help, setting boundaries, and taking time off. Help was mobilized primarily through nurses, but also through family members and friends. Helpers contributed to tasks such as personal care but also became companions for dying loved ones. Night help was especially valued as it enabled caregivers to sleep. Helpers that were knowledgeable, organized, and those that could settle in and provide "TLC" were also valued by caregivers. Caregivers sometimes set boundaries according to comfort level, which contributed to them taking both physical and emotional care. Finally, taking time off was seen by many caregivers as important in continuing their role. Many caregivers felt they could not have done the role without rituals and respite, however, most men initially needed to be convinced of this need. Taking time off provided a break from the tasks of caregiving and gave caregivers a renewed sense of ability to carry on.

Not Taking Care

All the men experienced caregiving in their own way and most balanced caregiving with taking care of themselves. When men took care of themselves they
seemed more satisfied with their experience. Three of the men in this study, however, struggled in their caregiving role. Balancing giving of care with self-care was difficult and sometimes impossible for these men to achieve. Strategies that enabled other men to balance their caregiving role often were unavailable or inadequate for these men. For example, they frequently felt let down by the health care system because of the dissatisfaction with the help they received. This contributed to feelings of isolation in their caregiving role. As well, these men did not get a break from caregiving as the options presented did not seem appropriate. Overall, they seemed less satisfied with their experience than did the other men and often expressed feelings of hopelessness, anger, frustration, exhaustion, and burnout. One of the men said his caregiving had "been a hell of an experience". Each of these experiences is summarized to demonstrate how each context, illness experience, and system factors contributed to creating caregiving situations that were challenging and less satisfying than other men in this study. Although these men did not intentionally neglect themselves and their situations by "not taking care", the way in which their unique situations unfolded over the caregiving period did not support them in "taking care".

The first man had provided care for his chronically ill wife for many years prior to her cancer diagnosis. Together, they had experienced many emergency room and hospital admissions for her chronic health issues and were very familiar and comfortable with the acute care hospital system. In addition, she had become wheelchair bound and was dependent on her husband for many day-to-day tasks. Although home care nursing, hospice, and home support were all involved in this situation, the services offered did not seem to meet this couple's needs and, in fact, were often felt to be unsatisfactory. The
caregiver frequently made references to feeling let down by the system. The overall tone of his experience was one of sadness and frustration. This man had hoped for his wife to be cared for in hospital, but she remained at home through to her death.

The second man, whose experience was also less satisfactory, felt that because his wife’s condition changed steadily, they were robbed of time to enjoy life, even momentarily. He was consumed with a sense of profound hopelessness. He also had support from family, home care, and hospice, but the help offered often did not meet his needs as he repeatedly stated that no one could help them. His feelings of hopelessness and lack of support left him discouraged and frustrated in dealing with challenges in the care of his dying wife. Furthermore, his wife died in a facility setting and he had hoped for her to be at home.

Finally, the third man whose experience was not satisfying, became his mother’s caregiver only after his wife became exhausted. His chronically ill mother had been living with them for an extended period of time and had gradually required more care as her condition declined. As this man took over the caregiving for his mother, he realized that he was also not coping and approaching physical and emotional exhaustion. In addition, this caregiver’s wife was leaving the home and he was also feeling pressured by demands from his at-home business. He also felt angry at the health care system for not allowing his choice in care options for his mother, which was to have a home-based care system operationalized by the family.

In summary, a few men struggled to balance their caregiving role and thus, seemed to have less satisfying experiences with caregiving. Although health care providers and services were often offered or in place for these caregivers, they were not
meeting these caregivers' needs and were generally felt to be unsatisfactory. These men felt unsupported in their and seemed to have more difficulty in taking care.

**The Outcomes of Male Caregiving**

Caregiving affected the men, their families, and the dying person in many ways. Both during and following the experience, men experienced positive and negative consequences of caregiving. The majority of this theme describes outcomes of this experience for caregiving men, with a brief discussion on outcomes of male caregiving on family members, as well as the dying loved one.

**Outcomes for Men**

**Rewards of caregiving.**

Many of the men felt being a palliative caregiver had enriched their lives. Rewards included gaining life-long skills and knowledge, feeling a sense of accomplishment, and spending quality time with the loved one.

Caregiving contributed to gaining life-long skills and knowledge for some men. One man, who had remarried and had to care for his new wife following surgery, felt having the knowledge and skill of wheelchair transfers was a result of his previous caregiving experience. Some men felt they had gained a greater acceptance of death since the experience and could offer their support for others in similar situations. For example, one man joined a bereavement walking group following the death of his wife and felt he was more prepared to support others and “relate to the people” because he “went through the trauma” himself. Men learned caregiving as part of fulfilling their role but knowledge gained became instrumental in other aspects of their lives.
For other men, being a palliative caregiver resulted in a personal sense of accomplishing a role generally perceived as "non-male". One man commented that his sense of accomplishment resulted from challenging a prevailing societal belief, whereby "women are better caregivers than men". Another man said he would become a caregiver again for someone he cared about because he had "proven" he could do it. Sometimes, proving to themselves or others that they could provide care became a goal in itself, as this man explained:

It's like a mission. It's like a mission because I have to prove to myself that I can do it [caregiving]. It's part of my belief that I should do it too, because if no one else will, if anyone's going to do it, you're going to do it. I'm determined to do as well as I can...

Other men also gained "a certain sense of satisfaction" from caregiving with the feeling they could accomplish the role successfully. One man had a celebration of his at-home caregiving success:

We'd had a curry party in his house the last night. [It was] the first [time] that he'd had a nurse in for the full night. We were able to detach ourselves. We ordered in curry for the evening. So I think it was a sense of achievement for me.

Besides gaining a sense of accomplishment, some men also said their caring contribution enabled their loved one to maintain dignity and preserve person-hood. The majority of the men in this study were providing care for their spouses. Often, in these couple situations, men were highly dedicated to caring for their wives. As one husband said, "I was glad I could do it.... I did it with love... we were childless and always done everything together". Another man, who expressed a sense of duty to provide care for his wife, felt he "didn't feel heroic by any means but contributed a little towards making her last days comfortable". Although some of these men initially felt obligated to provide at-
home care, as the caregiving evolved, they felt they had truly made a difference in their
dying loved one’s final days. Thus, the caring obligation became a final offering for
caregivers to give their dying loved ones.

Caregiving at home also provided some men the opportunity to spend more time
with and get closer to their loved one. Spending time together allowed these men to
resolve old issues and develop nurturing qualities. For example, one man talked about his
years growing up with an alcoholic father. When his father became palliative and he was
providing care for him, he was able to spend time “talking feelings out” and “becoming
closer” to his father. Some men reconciled differences with their loved one or
encouraged family members to do so. One man felt that his caregiving experience
enabled him and his father to reconcile their long-standing differences, as he explained:

In the personal sense, it’s an immeasurable benefit to be able to have that
reconciliation and opportunity to spend time with my father. It’s hard to
measure how I would have done that if he hadn’t been dying. He never
tried to talk about anything open, or talk about anything in a sort of give
and take way, while he was [well]. But in the week we spent together, we
did talk about all sorts of things and he was very mellow.

Another man felt that he and his wife had never had a close and loving relationship but
when she was dying she seemed to be able to accept his love. He described how the
relationship developed and how their final time together became meaningful for them
both:

In the last six months we had this beautiful, beautiful time together....
From that period until the end, it was one of the most beautiful... We had
the most beautiful relationship we’ve ever had. She was filled with love.
She could accept my love, which had not occurred before. And so, we’d
really learned to live in the ‘now’. You know, really now. And enjoy every
day.
Gaining the ability to nurture another person was expressed positively by some caregivers. One caregiver had not realized that he was capable of nurturing, especially since he had never had children. He seemed pleasantly surprised that caregiving developed his nurturing qualities. He stated that nurturing another person "was good and sound" and felt that caregiving "brings out a part of you that you don't know is there... The nurturing part".

Taking it's toll.

Not all aspects of palliative caregiving were rewarding for these men. Caregiving did take its toll on men and affected them socially, emotionally, physically, and financially. These outcomes were experienced both during and following the caregiving experience.

Often, outcomes in the social sphere were recognized early in the caregiving role. As the men's lives became more enmeshed in the tasks of providing care, their social life became more curtailed. Some men found caregiving resulted in being "somewhat restricted in what we could do [socially]", especially when the caregiver also was employed outside the home. As a way to meet their social needs, some men would have guests in to their home. However, this often "gave [the caregiver] more work" as they felt they had to entertain their guests by preparing and serving refreshments.

Sometimes caregiving was a lonely experience, especially if men did not have other supports. One man, who went to his father's home out-of-the-country to care give, felt particularly lonely. He commented on caregiving alone and the effect it had on him prior to other family members joining him:

I'd get a bit lonely too, if you're on your own during the night and on your own during the day... You can't go out and get anything if you're on your
own. You can’t leave. You can’t open the door, you can’t go out and go down to the shops to get food or medications, whatever.

Another participant recognised the caregiving role could lead to social isolation which could be detrimental to both the caregiver and the dying person. This man commented that once social isolation occurs “it’s pretty well over” and went on to reflect on reasons to avoid social isolation:

The idea is to not become socially isolated. Bring people to your home for a good reason, not to say, ‘come over for a drink’. Bring them for a good reason. Bring the right kind of people for a reason. Have a good stimulating evening because whatever stimulates you will stimulate life. If you don’t get stimulated, you don’t feel like keeping on going. That’s the name of the game.

Many men in this study expressed the emotional toll of caregiving. Feelings of frustration, fear, anxiety, inadequacy, anger, and emotional fatigue were some of the emotional outcomes of palliative caregiving expressed by men. One care provider summed up how quickly he became overwhelmed with expectations of the role:

I think I was overwhelmed faster than I expected. I don’t know whether it was the second or third day. Overwhelmed by trying to look after myself, look after him and look after the people coming in and out of the house was part of it. I remember thinking, ‘How will I get into the bathroom today?’ Because he couldn’t answer the door and people were coming to the door and the phone was ringing and all sorts of things and he would call out. Eventually someone did come that particular day and wondering how I was managing and I asked, ‘Would you mind staying on an extra 15 minutes so that I can have a shower?’ That was overwhelming. I think that was at the point when I was overwhelmed... I think I lost perspective on what was happening and how much of a strain it was for me....

Some men felt the emotional fatigue was greater than the physical fatigue of caregiving. One man, who found the term “compassionate fatigue syndrome” on the Internet, felt an instant recognition with its description. As well, this caregiver felt extremely sensitive to how people communicated with him and felt this fatigue may have
influenced his interactions with others. He talked about the emotional fatigue he experienced during caregiving:

That is being innovative [naming it compassionate fatigue syndrome] or whatever. The caregivers, without labeling it or getting [it] treated, do have that [compassionate fatigue syndrome]. It's a fatigue, you know... The emotional thing has taken a lot out of me. I don't think it's been sort of a physical thing. The emotional kind of drain has been incredible. Not just the frustrations on the outside, but just sort of the developments on the inside seeing my wife suffer so much because it's been kind of sad.... I really find that maybe that is a sign of compassion fatigue that the smallest little criticism feels like a major, major destructive attack on you. And you're not looking for that and all those small ones add up after awhile which takes its toll on you. And when in fact, you're looking for but you're not actually asking for, is constructive support.

Burnout was another term used by men to describe the emotional of caregiving. One man, who had experience with ALS caregivers, felt burnout occurred when the caregiver “just can't do it anymore” and said it happens when “the stress of knowing someone is going to die is compounded by the fact that you are physically gone”. One man felt his burnout was an “accumulating” result of overwhelming tiredness and inability to cope with his situation. In essence, he felt burnout was a combination of both physical and emotional exhaustion.

Although many men recognized the emotional toll of caregiving, some men also commented on how they kept their emotions inside. One man felt that his accumulating frustrations in dealing with what he considered a low level of compassion in society might have been due to his “suffering from the male tendency to hold everything inside”. Other men also made comments about preferring to keep their emotions to themselves and not wanting anyone to lean on. Men recognized some characteristics in themselves that may have predisposed them to the emotional toll of caregiving. While three men
sought and received help in dealing with emotional stress, prior to or following the death, the majority did not.

The physical toll of caregiving was challenging for some caregivers. Some men described caregiving as “an exhausting experience”. The combination of caregiving and household duties led one man to feeling he was “running ragged trying to look after everything”. While men frequently commented on the physically tiring aspects of providing care, some felt caregiving also had a specific effect on other physical problems. For example, one man started to lose all his head hair shortly after his wife’s terminal diagnosis and, by the time his wife died, had lost his eyebrows, eyelashes, facial and head hair. This hair loss was at least partially felt to be a result of stress while caring for his dying wife. He always wore sunglasses and a hat when going out and commented how the hair loss had affected his current life:

I’ve always been a bit anti, you know. I don’t like selfishness, you know and I don’t like greed, but I suppose what I’m doing, I suppose is isolating myself. In some ways, although when I go to the theatre, I go with a lady. I suppose I should, but this is the part... I lost my damn hair. I’m still embarrassed by it. When I go out to eat and stuff like that, I take my hat off. I always feel at first, and it’s not vanity, it’s just that I think... I always think, who are you, you twit, you know, sort of thing.

Two of the men discussed the health problems they encountered and suggested they were caused by the physical strain of caregiving. For instance, they both developed hernias, which was felt to be from physically moving their loved one. Another man said he had a weight loss of twenty pounds during caregiving as he felt he was not caring for himself. Following caregiving he was able to gain back his lost weight.

Some men also experienced the financial toll of providing care at home. Almost every man in this study commented on this, recognizing the potential or real costs of at-
home caregiving whether or not they were experiencing difficulties themselves. The men used comments such as, "financially draining", "paying the shot", "financial burden", "financial shell game", and "financial disincentive" when they spoke about caregiving costs. One participant, who had regular overnight nursing support, was "beginning to become concerned about the situation because I was approaching the $15,000 limit that my insurance would pay for nursing care". Others found that their financial situations changed as they were forced into a premature end to their work lives to begin caregiving. For example, some men retired early because their wives were ill and they could no longer manage an outside job along with caregiving expectations. One of these men stated that he had to "become fiscally conservative" in order to meet their financial demands.

One physician caregiver felt that providing care at home could be "financially crippling" with the high costs of medications, equipment, and help often required to care for the dying. He felt people who provide care at home are actually penalized for non-institutional caregiving:

People are actually penalized for being at home in effect by…… They have pay for their HSW. They don’t pay for the nurse in the hospital. They have to pay for their drugs, they have pay for any food supplements or whatever they’re on.

In summary, rewards for caregiving men came during the course of caregiving and following their experience. Rewards included (a) learning valuable skills and knowledge useful in other situations, (b) gaining a sense of accomplishment as men achieved success in a non-male role and positive feelings of contributing to loved one’s final days and, (c) reconciling and developing nurturing tendencies through spending time with loved ones. At times, caregiving also took its toll on men. Some men became
socially restricted, emotionally exhausted, physically unwell, and financially burdened to varying degrees. While some men had severe outcomes, such as burnout, others seemed only temporarily burdened by these outcomes.

Outcomes for Families

Some of the men made specific references to how their caregiving affected family members, including enduring their own financial and emotional burdens and easing the caregiver’s burden by offering support. Since family members were not interviewed for this study, these outcomes are based on caregiver’s perceptions of family outcomes.

Enduring own burden.

Though financial pressures were mainly felt by the caregivers, some family members also experienced this burden. For example, some family members lived out-of-town and traveled to the place of caregiving in order to support the caregiver. Family member’s ability to travel required flexibility and affordability. If these were not readily accessible, caregivers felt family members were either not involved in supporting the caregiver or would make financial or work sacrifices to be available. One man talked about his out-of-town daughter’s involvement in supporting her parents through the process:

One of them in particular, the one from [out-of-town], was able to do the most. I know how much time she spent over here and how much earning power she gave up at the time because she and her husband were both self-employed. So that was a very profound sacrifice, a financial burden on her, some of which was alleviated by the other sister who does not have financial problems but couldn’t be here either. I see that as a major issue.

If the caregiver was also the primary wage earner in the family this also affected other members. One man, who still had sons at home, had to take early retirement to care for his wife. His sons took over some of the household tasks and one son, in college, had
a part time job. The caregiver felt these to be supportive for the household and family and enabled him further in his caregiving role.

Emotional stress and worry was another outcome for families. If they were not close by, some families were constantly coming and going between their homes and the place of caregiving. One man’s brother and sister were in another city and would “come when they could”. Another man had two daughters who would come to help. Sometimes family member’s “inexperience” led to stressful situations when they offered help to the caregiver. This man described one incident with his daughter:

She [wife] turned a corner right then, and I was still over at my daughter’s. The [other] daughter was here. She wasn’t nearly as experienced. So when [wife] turned the corner, she got fairly panicky because she was on her own. So she called me on Friday night. I left on Wednesday and she called on Friday and said I didn’t have to come home until Saturday, but I thought, ‘Oh, I’d better go home’.

Even for families who were close by, stress and worry about the caregiver was a factor. One mother wanted her caregiving son to continue to work, “because you’ve got to have a life outside this [caregiving] life”. Another man said his family also voiced numerous concerns for him to take care of himself.

**Easing caregiver’s burden.**

Some families’ concerns about the caregiver led them to offer support to ease the strain of caregiving. Another outcome for families, therefore, may be that they felt the men needed help and support in caregiving and, thus, availed themselves to the caregiver. While some families offered support and help throughout the caregiving experience, others did so at the time of and following the death. For example, some family members helped with tasks following the death, such as making funeral home arrangements and removing equipment, as this caregiver described:
We just sort of moved into action like a well-oiled machine. We had the GP out within an hour to pronounce him. The funeral home came less than an hour later. We had another couple of brothers came up, turned up and we made trips across town to bring all this equipment back to where it came from, and so forth. I went and got the Death Certificates and we had the funeral home organized, and we were so well organized.

Families endured both financial and emotional burdens in their attempts to support the caregiver. While not all men had families who became involved, the ones that did spoke about their family’s involvement with the situation and reflected on possible outcomes as a result of the male caregiving experience.

**Outcomes for the Dying**

Some men talked about their role as caregiver with regards to how it influenced their dying loved one. Outcomes of male caregiving for dying loved ones seemed to include an attempt at easing their caregiver’s burden by protecting the caregiver and maintaining independence. Dying wives tried to help men learn how to cope on their own and participated in planning for death. Perhaps by engaging in this way, the dying could be reassured of caregiver’s ability to cope and this may have contributed to a more peaceful transition from life to death.

**Protecting.**

Some men may have felt protected by their dying loved one by avoiding the subject of dying. The dying person may have felt that their caregivers would be unable to cope with talking about dying. The outcome for the dying in these instances may have been a sense of relieving some of the burden and thus enabling the caregiver to cope. One man and his dying wife never talked about dying as they had “a kind of tacit understanding” between them. Although he knew she would die, he felt they did not want to talk about it as they hoped for a change in her disease process. In a sense, it
seemed that not talking about dying offered hope to live. One man said his wife, who had become paraplegic in the course of her terminal illness, had an optimism that he felt was a way of protecting him. He explains in this interview segment:

Curiously enough, you know, in my mind, my intellect told me it was terminal and yet my wife, she seemed to be fairly optimistic for some reason. It even got into me a bit, you know. So we thought ultimately, we'd be able to get her home, sort of thing. Even with becoming paraplegic, this is the curious thing. I'm a pessimist by nature and yet, with her optimism, we even thought she could gain the use of her legs again.... And yet with [wife] it was strange. As I say, she didn't lie or anything and she seemed to be damned optimistic, which gave me optimism, but she must have known. But she was probably doing that for me. That's the only conclusion I can reach on that subject.

Some caregivers implied that their dying loved one protected them in other ways. For instance, some dying people continued to do their own self-care or made their own arrangements for care or companionship; they tried to maintain their independence for as long as possible. Some men reflected on the effect this had for them. For example, one man's dying wife arranged for her friends to come in every afternoon, primarily for companionship but also to ease her caregiving husband's worry. These "rainbow ladies" allowed her caregiving husband to continue working and concentrate on a "very stressful job", as he explained:

It made me feel so good because I could not worry; I was in a very stressful job, management in a police department. I needed all my wits about me to not have to worry about her. So it was great.

When the dying person could maintain their independence for as long as possible, the burden of care for their caregiver seemed to lessen. To illustrate, one man recalled how his wife continued to do personal care and how he came to appreciate that. In this situation the caregiver recognized the value of maintaining his loved one's independence while at the same time relieving him of providing this care:
She could still look after herself, her own physical self, which was
good…. she could still do her own personal care at that point. In fact, she
did quite a lot of her personal care all the way through…. It took the load
off me.

Teaching.

Opportunities for the dying to teach men how to live on their own presented in
many caregiving situations. Dying wives, for example taught their caregiving husbands
household chores, providing them with further reassurance of their ability to cope on their
own.

Planning.

Another way the dying influenced the future of their loved one was planning for
companionship. For example, one man’s wife encouraged companionship for her
husband by assisting him in getting a dog and by encouraging potential marriage partners.
Some of the dying participated in the plans for death, including funeral and burial
planning and death announcements. One woman, unbeknownst to her caregiving husband
at the time, made all her funeral and burial plans. Another woman wrote her own death
announcement with the assistance of her caregiving husband. These times of planning
and teaching may have been the dying person’s contribution to supporting their
caregivers and may also have been reassurance for a more peaceful transition from life to
death.

These outcomes of male caregiving for the dying can only be assumed through
interpretations of reflections by caregivers. The dying may have needed some sense of
knowing that their caregiver could cope both during and following the caregiving
experience, which may have contributed to a more peaceful death transition. This
reassurance of easing the caregiver's burden may have been done by protecting them, maintaining independence, teaching them and planning for after-death events.

**Summary of Research Findings**

This study highlighted men's experiences in caring for a dying loved one at home. The experience began as men were led into caregiving, influenced by factors such as knowledge and experience with caregiving, support for the role, a lack of appropriate options, and feeling a sense of duty to become the caregiver.

As the men actively moved into being a caregiver, they learned how to give care as well as take care. Giving care required learning and doing a variety of unfamiliar tasks, gathering supplies and equipment, dealing with challenging situations, and becoming an advocate for themselves and their dying loved one. Taking care required the men to develop strategies that enabled them to endure their caregiving roles. Strategies included mobilizing help from health care providers and family members, setting boundaries within the role, and taking time off for adequate rest and rejuvenation. Some men were not able or supported to take care of themselves, due to the complexities of their unique situations, sometimes resulting in these men having less satisfying experiences.

Finally, men had both positive and negative outcomes from their caregiving experience. Caregiving men experienced the rewards of caring as learning life-long skills, experiencing personal success of achieving the role while also contributing to loved one’s final days, and developing relationship healing and nurturing abilities. The negative aspects of caregiving for these men included social life restraints, emotional and physical ramifications, and financial strains. Family members sometimes endured their own financial and emotional burdens. If they were able to, families helped and supported the
caregiver in the care of the loved one. The dying person sometimes seemed to be protecting the caregiver by avoiding death talk, being optimistic, and maintaining independence. In addition, some dying wives in this study seemed to develop strategies to ensure husbands could cope following their death, and often participated in after death planning. The dying person may have needed a sense of reassurance that their caregiver could cope, which in turn may have assisted their own transition from life to death.
CHAPTER 5: DISCUSSION OF FINDINGS

The primary purpose of this study was to describe the experiences of men who provide at-home care for a dying loved one. Three major themes arose from the data analysis including factors influencing men’s entry into the palliative caregiving role, a description of their experiences of providing care and an illumination of the outcomes of caregiving to both the men themselves and their family members. Studies to date have provided knowledge of palliative caregiving primarily from a female perspective and a chronic illness perspective. Fewer studies have focussed explicitly on male caregivers’ perspectives when providing terminal care at home. This study has extended our understanding of men who provide care in palliative situations. This chapter aims to place the study findings in a broader context by focussing my discussions on gender role influences, major challenges for caregiving men, and men’s perceptions as successful caregivers.

Men as Palliative Caregivers: Gender Influences

While women have traditionally functioned as primary family caregivers, more men are now taking on these roles. Studies on gender influences in caregiving, most notably in the gerontological literature, provide some insight into this experience for men. This discussion highlights some aspects of male caregiving of the dying that may have been influenced by gender, including entering the role, developing the role, enacting the role, and reacting to the role.

The men in my study took on the role of primary caregiver, both by choice, through acts of love and obligation, and by default, through perceived lack of other options. These men undertook caregiving because they were committed to their loved one
and wanted the best possible care. Thus, even though these men may not have been socialized into the caregiving role, they endeavored to undertake the care of their loved one. Several researchers have found the quality of past or present relationships (Aranda & Peerson, 2001; Brown and Stetz, 1999; Mathew, Mattocks, & Slatt, 1990), commitment to care (Enyert & Burman, 1999; Harris, 1993; McFarland & Sanders, 1999; Stoller, 1990), and reciprocity (Aranda & Peerson, 2001; Enyert & Burman; Neufeld and Harrison, 1998; Parsons, 1997) influences caregiver’s decisions to provide care or to continue in the caring role. These studies suggest men may accept caregiving for loved ones with whom they previously had or presently have a close and committed relationship. In my study, men provided care to close family members, mainly wives, although some cared for parents. Even though they may have felt some obligation or duty to care, there were clearly close family bonds between these caregiving men and their care recipients and this may have influenced them to provide care to a greater degree. As well, although some of the men in my study talked about negative relationship issues, all of them expressed a desire and sought ways to resolve these disparities within their family throughout the caring experience. Some participants in my study were asked if they would be a caregiver again and they replied that they would, if the care recipient was someone about whom they cared. My findings support previous studies of male caregivers in the gerontological literature and caregivers in the palliative care literature that found the closeness of the relationship with the care recipient as a strong influence in caregivers’ entry into the caregiving role.

One theory suggests that as men and women age, their gender roles begin to blur and become less sex-stereotypical (Belsky, 1992). This theory suggests that in mid to later
life, both sexes may be freer to express other qualities, possibly because they no longer have the same pressures of work and family life as younger people do. For example, men may become more nurturing and passive as they age, while women may become more assertive. Harris (1993), in a study of men caring for loved ones with AD, found that men felt they had become more compassionate with caregiving. The men in Harris' study were all retired with the exception of one man. The findings in my study lend some support to this theory in that employed men may not be given the opportunities to develop the nurturing tendencies associated with caregiving, whereas the retired men were more able to develop these qualities. In my study some of the men continued to work at outside employment (5/13) but the majority were either retired or chose retirement upon becoming a caregiver (8/13). My findings showed caregiving and employment demands placed on working men were challenging and, at times, very stressful. Studies of AIDS caregivers, where men are usually younger and are building careers, discuss the associated stresses of this role conflict (Pearlin, Aneshensel, & Leblanc, 1997; Folkman Chesney, & Christopher-Richards, 1994). Men who care for loved ones with cancer also feel the stresses of caregiving, family and work life, and finances (Hilton, Crawford, & Tarko, 2000; Orsi, 1994). Some of the employed men in my study reflected on the difficulties of maintaining their job and career along with caregiving, particularly when the caregiving period was prolonged. Some men commented on their employer’s understanding of their situations which allowed them some flexibility and some of the men in my study retired early to become a caregiver. Thus, employed men may not be given opportunities to develop nurturing and empathic qualities due to societal expectations of career development along with family life and financial needs. Furthermore, the types of support
Gender role socialization may influence men to enact the caregiving role differently than women. McFarland and Sanders (1999) claimed men approach caregiving for people with AD “from a task perspective versus an emotional perspective” (p. 280) to protect them from the emotional pain of witnessing their loved one’s condition. Men may also approach caregiving with strong feelings of leadership, responsibility, and commitment (Mathew, Mattocks & Slatt, 1990). Belsky (1992) said that male caregivers are also more likely than female caregivers to delegate responsibility and call in formal sources of help. This is supported in a study by Barusch and Spaid (1989) whereby men were more likely than women to receive home-delivered meals, home nursing services, and home aide services. In my study I found that while most of the men did arrange and receive help eventually, some felt they “had to do it all” and many were initially reluctant to ask for
help. Coe and Neufeld (1999) found that opposing formal help occurred in the first of four caregiving phases for men caring for adults with a cognitive impairment and Parsons (1997) found that men only asked for formal help when they reached a crisis. My study adds some support to these findings in that as the men were more able to recognize their needs and, with repeated offers for help from family and health care providers, many men did open up to both formal and informal help. Conversely, some men had help in the early stages of caregiving and some declined help through their entire experience. In the popular book, Men are from Mars, Women are from Venus Gray (1992) offers an explanation for men’s reluctance to ask for help too soon:

A man looks for advice or help only after he has done what he can do alone. If he receives too much assistance or receives it too soon, he will lose his sense of power and strength.... In coping with problems, a man knows he has to first go a certain distance by himself, and then if he needs help he can ask for it without losing his strength, power, and dignity (p. 81).

Feeling they can do it all and delegating may be different male ways of caregiving and may be dependent on how men have reacted to previous life events. Belsky (1992) stated that “the way people react to this life event demonstrates continuity, not change, in gender behaviour: men respond to caregiving in a male way…” (p. 168). Thus, if the men had experienced delegation as part of their work life, this may seem a more natural way to enact caregiving. However, if they had worked independently, “doing it all” may then be a natural extension of how they had performed in the past. Other explanations for not asking for help may be that men view this as a sign of weakness or failure at caregiving (McFarland & Sanders, 1999), a dishonor in admitting a need for help and a desire for
privacy (Coe & Neufeld, 1999), and a feeling that families or health care providers may suggest alternate care arrangements for their loved one (Wallstein, 2000).

Divisions of labour influenced by gender role socialization may also explain the experience of men in caregiving roles. Male caregivers have been found to be more involved in independent/instrumental activities of daily living (IADL) (e.g., shopping, running errands, managing finances, household duties) than activities of daily living (ADL) (e.g., feeding, bathing, lifting, turning, and toileting) in such contexts as dementia care (Mathew, Mattocks, & Slatt, 1990), cancer care (Orsi, 1994), HIV related illness care (McCann & Wadsworth, 1992), and cardiac care (Young & Kahana, 1989). My study only partially supports this. Some of the men in my study did rely on family members and health care providers for the personal care of their loved one. Other men were willing to learn and perform these tasks with less reliance on others. The men who learned tasks of ADL appreciated the complexity and skill required in performing them and valued the guidance and expertise of others in assisting them to learn. The difference in whether men performed personal tasks or not seemed to be in their own comfort level and previous relationship with their loved one rather than kinship. For example, in my study no difference existed between sons and husbands in relation to providing personal care for their loved one. Some were comfortable with personal care (or with varying degrees of it) and some were not. The men were able to express their discomforts and the reasons for this. This finding differs from other studies where sons rather than husbands felt that providing personal care overstepped boundaries and went against relationship rules (Parsons, 1997) and felt uncomfortable with personal care tasks (Mcfarland & Sanders, 1999). As the requirement for help with personal care depends on the functionality of the
loved one, some men may not need to be involved in that aspect of ADL, as was the case with some of my study participants. However, dying people weaken as their illness progresses and, at some point, will require personal assistance. One man said his dying wife did all her own personal care until the last day or two and then his daughter, who was a nurse, did the care. A meta-analysis done by Miller and Cafasso (1992) found that in elder care, caregiving men were less likely than caregiving women to carry out personal care. One study examined helpful nursing behaviors in end-of-life care and found that men ranked patient independence and nursing services as high priorities for caregiving (Skorupka & Bonet, 1982), indicating perhaps that men may not wish to do personal care if possible. Studies of the frail elderly however suggest that if men learn personal care, they become more comfortable with it (Kaye & Applegate, 1990). Morano (1998) concurs that if men are taught personal care skills, they are both able and willing to perform them. However, in my study men indicated that creating boundaries around personal care was related more to a comfort level than to a skill level.

Although some IADL’s may seem non-gender specific (e.g., running errands), others (e.g., household duties) are often associated with the female role. When men take on caregiving they often assume household tasks which can add new and sometimes stressful demands on them (Hilton, Crawford, & Tarko, 2000; Stetz, 1987). In one study, male helpers were more likely to do shopping, financial management and heavy chores than cooking, laundry and routine household chores (Stoller, 1990). Stetz (1987) reported managing the household and finances as the second most frequent demand placed on caregivers. The men in my study were also frequently challenged to learn household tasks and some found this quite stressful when this had never been part of their role. Conversely,
some of the retired men had already been doing these tasks and did not find them a burden. As with personal care, when the men could not or did not take on these tasks, they found alternate ways of meeting these needs. Many of the men in my study talked about how family and health care providers regularly encouraged assistance. In accordance with the earlier discussion on when men ask for help, it appears that whether the help needed is for ADL's, IADL's or nursing tasks, men seem to need to reach this decision in their own time. Harris (1993) stated that men's control over the caregiving situation is a crucial coping strategy. Thus, it appears that when men do reach a decision of needing help, the availability and knowledge of how to access this help is critical.

A unique aspect of this study was that, throughout the course of their caregiving experience, the men were faced with the knowledge that their loved one was dying. Men who caregive at the end of life are grieving losses throughout their experience as their loved one's condition steadily declines. Studies of male caregivers in AD and in HIV/AIDS also found men experience many losses (McCann & Wadsworth, 1992; Parsons, 1997). Rando (1988) comments that anticipatory grief involves losses endured in the past, present and future and these losses affect the way people experience a terminal illness situation. Gender socialization may play a role in men's responses to grief situations (Levang, 1998; Martin & Doka, 2000). Martin and Doka claim "there are many different ways in which people experience, express, and adapt to grief" (p. 2). These authors and others (Strobe, 1998) assert that often women are more inclined to be intuitive or expressive grievers, whereas men tend to be instrumental grieverers. Instrumental grievers "are more likely to cognitively process or immerse themselves in activity" (Martin and Doka, p. 5) and less likely to express their emotions and seek help (McFarland & Sanders,
The men in my study were caring for a dying loved one and thus, were likely in anticipatory stages of grief. Although most of the men did not explicitly talk about loss and grief, some did recognize patterns in themselves that could be described as instrumental. Most of the men did not seek support for their grief and kept busy with the tasks of caregiving, household duties, and outside activities. McFarland and Sanders (1999) also found that men caring for people with AD “were careful not to let their feelings interfere with their caregiving responsibilities” (p. 280). Some of the men in my study talked about how being male led them to hold emotions inside and one man thought that this added to his suffering.

Levang (1998) says men may not have a language for expressing their grief nor the permission to articulate it in a way that is socially acceptable. Men are raised to be mute and not to express their emotional pain (Levang). This may explain why most of the men in my study chose neither to seek emotional support nor to talk about their grief, although many men displayed emotions such as anger, sadness, and despair and some became quite tearful at times while recalling their caregiving experience during the interviews. Only four of the thirteen men spoke about the formal support they received during or following the death. When talking about support, some men minimized their personal gain from individual or group counseling sessions. Instead, these men suggested their involvement was a way to help others experiencing similar situations. After their involvement, however, two of the men expressed surprise at how the group support had benefited them. Thus, if men are not socialized to be expressive in their grief and do not understand the various individual ways of grieving, they may set certain expectations for themselves that may not contribute to their mental health or adaptation to their loss. In addition, if men are
instrumental grievers, by delving into the tasks of caregiving and other activities, they may be dealing with grief issues in very useful ways and not have an awareness of that. This may explain why some men did not find formal grief support helpful.

**Major Challenges for Men who Provide Palliative Care at Home**

Besides the influences that gender role places on caregiving men, there were also many challenges in providing palliative care to their loved ones. Caring for someone who has been chronically ill for an extended period of time prior to becoming palliative may present unique challenges for men, including physical and emotional exhaustion. The toll that caregiving took on men sometimes included financial burdens. Finally, some of the situations the men faced in the course of caring for their loved one presented new and challenging experiences for these caregivers.

Palliative care is often provided at the end stages of a chronic illness. Many of the men in my study were caregivers for their chronically ill loved one for an extended period of time. Brown and Stetz (1999) found a psychological transition from chronic to dying stages in the examination of caregivers. Although a transition in caregiving was not specifically explored in my study, some men did provide care from chronic to palliative stages and did not seem to distinguish between these, even though some loved ones were diagnosed with a malignant disease in addition to their chronic illness. For example, one loved one with ALS also developed ovarian cancer and another loved one with a degenerative hip disorder and chronic lung disease also developed lung cancer. In these instances, the men seemed to continue their caregiving in much the same manner in their loved ones terminal stage as they had in the chronic stage, indicating that perhaps a clear delineation or transition in roles did not occur.
When care needs became greater and the men required more help, many men in my study enlisted health care providers and other family members to assist. However, some of the men were unable to enlist support they felt was helpful. The reasons for this were not explicitly clear but there may be some explanation for why this occurred. Situations where chronic illnesses become palliative may require more complex planning in determining appropriate supports. Often, time of death is difficult to predict in a chronic illness and may be another factor influencing the support caregivers need and planning for where the death will take place. Also, length of survival may be a determining factor in the caregiver’s ability to carry on in the role in a meaningful and satisfactory way. Buehler and Lee (1992) found that in rural situations when the dying trajectory and deterioration of the loved one was prolonged, caregiving became more difficult and under resourced. One study examined caregiving in general and found that vulnerable caregivers (defined as those having fair to poor health or a serious health condition) were providing higher intensity care (defined as more ADLs, more IADLs, and more hours of care) than nonvulnerable caregivers and that “reliance on informal caregivers without considering the caregiver’s ability to provide care can create a stressful and potentially unsafe environment for both the caregiver and the care recipient” (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002). Studies in dementia care, however suggest that with prolonged caregiving comes adjustment and settling into the role as men gain control of the situation, build routine into their lives, and find meaning in their experience (Harris, 1993). Of the men in my study who were in prolonged caregiving situations (months to years), some seemed to adjust to the role and others seemed to be more challenged as time went on. My findings may indicate that complex and prolonged caregiving situations could
situate men in a vulnerable state, making it difficult or impossible for them to continue caregiving and possibly contributing to emotional and physical exhaustion. As well, caregivers may not be able to articulate their needs (Conley & Burman, 1997) or be assessed for vulnerability (Schulz & Beach, 1999) and, therefore, may continue unsupported in their caregiving role. When these situations occurred in my study, the men seemed to feel powerless to change it, despite making efforts to communicate with health care providers. Complexity of care without the resources and supports for the caregiver may not only predispose the caregiver to increased stress (Perlin, Aneshensel, & Leblan, 1997) and deleterious effects in bereavement (Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997), but also may result in hospitalization of the care recipient (Brown, Davies, & Martins, 1990). Strained and vulnerable caregivers have also been shown to have higher mortality rates (Schulz & Beach, 1999).

The men in my study also reflected on how caregiving either had or possibly could negatively impact their financial situations. Early retirement or a reduction of work influenced financial concerns as well as limitations of insurance coverage and unfairness of at-home care costs versus no costs in hospital. The men in my study were primarily middle classed professionals or retired and may be more advantaged financially than other caregivers. However, whether or not they actually suffered financial loss, they all recognized this to be a potential burden or barrier to providing at-home care. Many studies have shown the financial impact of caregiving to be a significant factor in at-home care. Studies have demonstrated, for example, that caregivers had to make significant adjustments to their employment and financial situations (Folkman, Chesney, & Christopher-Richards, 1994; Wyatt, Friedman, Given, & Given, 1999), seek alternate
methods of covering expenses (Stajduhar & Davies, 1998), and insurance (Enyert & Burman, 1999) had concerns about the day-to-day management of finances (Stetz, 1987), and even declared bankruptcy (Enyert & Burman, 1999) as a result of at-home caregiving.

Managing and controlling symptoms associated with end of life care also posed challenges for caregivers. Although the men in my study depended on others for help and advice, often they were left to make decisions on their own. Some of these times were especially frightening as the men were unsure of how to deal with situations they had never before experienced, such as changes in cognition, pain, and bowel regulation. These findings support the work of Stetz (1987) who found that caregiving demands included physical care, such as incontinence care, treatment regimes, such as medication administration, and illness related changes, such as pain. At times men felt disillusioned and that they could have done more, even reprimanding themselves for their lack of advocacy in some situations. Caregivers in a study by Folkman and colleagues (1994) also highlighted the responsibility of the advocacy role as their loved one’s condition changed. Men educated in the health care field seemed to have an advantage in communicating needs and advocating for their loved one and in making judgements about medications and symptom issues. However, even these men needed help and guidance at times and came to appreciate not only their own knowledge but also the expertise of others in the care of their loved one.

Participants in this study were also challenged by the complexity of nursing skills which oftentimes required instruction, guidance and practice. For example, men learned how to administer oral and injectable medications and some men found this skill challenging. McCann and Wadsworth (1992) also found giving injections to be stressful
for AIDS caregivers, despite having done this skill for long periods of time. When men lacked the skill and judgement required for these specialized tasks, they relied on health care providers and family/friends for advice and guidance. Unfortunately, there were times when advice was not helpful or came too late. These occurrences added stress to caregivers rather than supporting them in their role. While the palliative care literature generally discusses the helpful role of health care providers, there are also findings in the literature that suggest unsupportive behaviors. Some families may feel that the skill level of the helper does not meet their needs. For example, rural caregivers in one study were not provided with professional support for such skills as bladder catheterization, medical information, symptom management (Buehler & Lee, 1992). Hinton (1996) also reported some unsupportive behaviors, such as "inept" or lack of physician support and occasional "rough handling or unfortunate manner" by nurses (p. 132). Lack of communication between professionals and continuity of care was also identified as problematic by some caregivers (Jarrett, Payne, & Wiles, 1999).

**Men as Successful Palliative Caregivers**

Since men who are caregivers are often considered to be in a non-male role, some of the men in my study felt that had to prove they could do the caregiving well. While some men expressed the importance of proving it to themselves, others shared their success with family members and health care providers. Other researchers also report caregivers' pleasure and pride at feeling they had done a good job at caregiving (Grbich, Parker, & Mattocks, 2001). Some researchers have endeavored to develop instruments to measure how well caregiving is being done, both from a caregiver's perspective and from a professional's perspective (Schumacher, Stewart, & Archbold, 1998; Smith, 1999).
These quantitative measurement tools are based on concepts of doing caregiving well, including preparedness, mastery, self-efficacy, competence, and quality. Although these tools were not used in my study, there were, nevertheless, some indications of how caregivers in my study appraised their caregiving. Many, but not all of the men in my study initially did not feel fully prepared for caregiving. However, as the men became more involved in their caregiving, they developed strategies to ensure they could do the role to the best of their ability. At the time of the interviews most men felt some sense of mastery feeling positive about their ability to provide care. Self-efficacy was also evident as the men learned and managed IADL and ADL tasks and nursing skills and felt a sense of satisfaction as a result. As the men gained competence with these skills, they became more confident in their abilities. This finding is congruent with those of Orsi (1994) who found that as men learned tasks they became more confident in the care of their loved one. With time and practice some of the men also achieved a sense of competence, indicating they could provide better care than could be provided in a facility. Most men felt the quality of care they provided was superior to facility care. Quality of care can also be appraised by having the necessary skills, knowledge, and resources to provide care as well as establishing routines and life enriching activities that bring meaning or pleasure to the situation (Schumacher, Stewart, & Archbold). Harris (1993) found that men’s self-appraisal of doing a good job resulted from a structured regime and other coping strategies. Many of the men in my study developed competencies in caregiving tasks, established routines for themselves and their loved ones, and tried to enrich their lives through activities like social engagements.
Men's success at caregiving also involved other factors such as the help and support they received and respite time. Help and support came from both family members (informal system) and health care providers (formal system). One of the notable findings of this study was the extent to which men relied on family members, particularly nurses in their families, which I have referred to as 'family nurses' within this thesis. These family nurses were wives, sisters, daughters, or friends and had considerable influence on the men throughout their caregiving experience, from entering the role through to the death of the loved one. Although the support and help from caregiving families' informal systems have been well documented in the palliative literature (Davies, Chekryn Reimer, & Martens, 1994; Enyert & Burman, 1999; Hull, 1992; Silveira & Winstead-Fry, 1997), the gerontological literature (Barusuch & Spaid, 1989; Hibbard, Neufeld, & Harrison, 1996; Mathew, Mattocks, & Slatt, 1990; McFarland & Sanders, 1999; Parsons, 1997), and the AIDS literature (McCann & Wadsworth, 1992; Stajduhar & Davies, 1998), the family nurse's contribution is a unique finding and one that would warrant further exploration.

In addition to other family members' assistance to the caregiver, help may also have come from the dying person. Many of the dying wives in my study made an effort to help their caregiving husbands. These women continued to do their own personal care for as long as possible and tried to teach their husbands as much as they could about household tasks. Some of these women helped or did their own after death planning, such as funeral plans and writing their own obituary. Men found these activities to be helpful and seemed to be somewhat relieved of their burden of care. Schumacher, Dodd, and Paul (1993) found that the functionality of the patient was moderately related to caregiver strain, with higher functionality associated with less strain. Other studies have also found
that patients want to remain as independent as possible to enable them to remain home (Brown, Davies, & Martens, 1990) and to negate the need for outside help (Davies, Chekryn Reimer, & Martens, 1994). On one hand, independence is important to most people but in my study, men also recognized their dying wives independent activities to be helping them in their role as caregiver. This finding is also supported by the research done by Davies, Chekryn Reimer, and Martens (1990) and highlights the important contributions dying people may make to the caregiving experience.

Although men initially opposed formal help, when they did agree to it, they came to appreciate the contribution this made to their own success. Whether the help was for personal care, companionship, night sitting, or for specific treatments, the men realized help was crucial to sustain their ability to continue as the primary caregiver. This finding is supported by many other studies of family caregivers (Brown, Davies, & Martens, 1990; McCann & Wadsworth, 1992; Parsons, 1997; Payne, Smith, & Dean, 1999; Silveira & Winstead-Fry, 1997; Skorupka & Bohnet, 1982; Smeenk, de white, van Haastregt, Schipper, Biezemans, & Crebold, 1998; Stajduhar & Davies, 1998). Some of these studies also identify that, although the formal system of support is often helpful, there are times when improvements could be made in such areas as availability, competence, and sensitivity. Although most of the men in my study reported good and helpful relations with the formal support system, some also identified areas for improvement.

Taking time off was another strategy that helped men succeed in their caregiving role. Studies of caregivers have found respite a useful coping strategy (Chappell, Ried, & Dow, 2001; Grbich, Parker, & Mattocks, 2001; Harris, 1993; Hull, 1992; Meadows, Le Maréchal, & Catalán, 1999; Stajduhar & Davies, 1998; Strang, Koop, & Peden, 2002;
Strang & Haughey, 1999). Men in my study were creative in finding time for themselves. Sometimes they took longer breaks and left the place of care for several days. Other breaks, described as “creating rituals”, were shorter but equally as beneficial. For example, some men found that even momentary breaks, such energy work or naps, would improve their ability to carry on. This finding is supported by Chappell, Ried and Dow who found that caregivers of the elderly required respite in many ways, including longer breaks and stolen moments, where the caregiver was temporarily away. These researchers theorized respite as an outcome, rather than a service, with the goal of preventing over-stress and burnout. Strang, Koop, and Peden found the respite experience for caregivers of people with advanced cancer could be a physical break or a mental break from caregiving. For caregivers of persons with dementia respite has been found to be a cognitive experience of getting out of the caregiving world, whether for shorter times, to match caregivers daily routines, or for longer periods, to recuperate (Strang and Haughey). Hull (1992), in her study of hospice caregivers, found caregivers would create windows of time to help cope with the stresses of caregiving. My findings add support to this research, highlighting how men sometimes prefer shorter breaks than the longer periods away. Like Hull’s study, findings from this study suggest that caregiving men desire shorter breaks because they often feel they do not need longer breaks or feel they would be abandoning their loved one. Some study participants also refused facility respite because they felt they had to be present to ensure that good care was given to their loved one.

In summary, my study has contributed to current knowledge of male caregiving as well as presented new observations that can provide opportunities for further study. Clearly, the men in my study were influenced, to some degree, by gender role
socialization, specifically with age related role change, divisions of labour, and emotional functioning. Challenges included complexity of care and support, dealing with symptoms, doing nursing tasks, financial implications, and feeling unsupported. Success at caregiving was accomplished by men through strategies of care provision, having formal and informal help, including ‘family nurse’ support, and taking time off.
CHAPTER 6: SUMMARY, IMPLICATIONS, AND RECOMMENDATIONS

Summary of Study

The majority of caregivers are women, however, men also provide care in a variety of contexts. Studies of male caregiving have been done extensively in dementia care, specifically in Alzheimer’s Disease, AIDS care, and, to a lesser degree, in cancer care. This study focused on men who provide care to a dying loved one at home as there was a gap in the literature on this experience.

I chose to use a qualitative research method for my study, named Interpretive Description, as the experience had not previously been fully examined. This method provided structure to interpret, describe, and discuss the meaning of this experience for the men as well as to determine implications for nurses and other health care providers.

The sample of men in my study was taken from a larger study examining the social context of home-based palliative caregiving and, thus, was a secondary analysis of the original data. My close association with the principal investigator plus my role as a research assistant in the original study provided me with the confidence, support, and rigor needed for this secondary analysis.

Analysis of the data from these 13 male caregivers provided a rich description of their experience of caring for a dying loved one at home. Men entered the caregiving role in several ways: previous knowledge of caregiving, support for them as caregivers, a lack of other desirable options, and a strong sense of duty. As they became caregivers, the men developed strategies and ways of caring for their loved one, some of which were influenced by gender. “Giving care” involved becoming informed, learning and doing the required tasks, assembling needed equipment, dealing with challenges, and trying to
advocate for their dying loved one and themselves. Men also had to “take care” of themselves which involved getting help, setting boundaries, and taking time off. A few men were unable to take care and had less satisfactory experiences. Several outcomes were identified as a result of caregiving, including the rewards and toll of caregiving for men and outcomes for family members who were supporting the caregiver.

My preliminary findings contribute to current knowledge on men who are caregivers and especially to the gap identified in the palliative literature. Men who are caregivers of the dying seemed to be influenced by gender role socialization, particularly in role enactment, divisions of labour, and grieving congruent with other studies. The men were faced with challenges also experienced by men in other caregiving contexts and general caregiving experiences. Generally the men in my study found caregiving a rewarding experience and felt successful in their role. Although much of the experiences of the men have been found in other studies on both male caregiving and caregiving in general, my findings did reveal some uniquenesses, particularly with the involvement of the family nurse. As such, my study has identified implications for both nurses and other health care providers who are involved with at-home male caregivers of the dying.

Based on my study findings, the following conclusions are made:

1. Men’s entry into caregiving is influenced by at least four factors including previous knowledge of the role, support for them in the role, perceived insufficient options, and feeling a sense of duty to provide care;

2. Men want and need support in their palliative caregiving role, although they may show some initial reluctance to acknowledge and accept support;
3. Men can develop their palliative caregiving role by drawing on previous experiences and strengths;

4. Caregiving may present situations for men that challenge their ability to cope and derive satisfaction in the role;

5. Caregiving can take a financial, social, emotional, and physical toll on men;

6. Men require a variety of options for taking time off from caregiving;

7. Men need a variety of options for grief and emotional support;

8. Men can derive a sense of accomplishment from doing caregiving well.

Implications of Study

The provision of palliative care needs to be encompassed within the palliative care philosophy which indicates that care is best provided by a multidisciplinary team (Canadian Palliative Care Association, 1995). Thus, these implications are suggested for nurses and other health care providers and are discussed within the framework of four categories including clinical practice, education, policy/program development, and research.

Implications for Clinical Practice

Nurses and other health care providers involved with men who care for the dying at home can provide support in a number of ways. Approaching caregiving men in a non-judgmental and sensitive way and recognizing that each man's situation is unique will help set the context for a supportive and trusting relationship. This suggests that in order for nurses to build a trusting relationship, consistency with visiting nurses and other providers may be indicated. One strategy to support consistency of care would be the nurse case management model whereby a nurse takes responsibility for all aspects of
home care including nursing interventions, supervision of support staff, and financial and other assessments needed to support care at home. If consistent care was difficult to provide, another strategy may be to ensure all visiting nurses and other providers are knowledgeable and skilled in supporting end-of-life patient and family care. Once trust is established and caregivers feel they are supported, they may more readily ask and receive appropriate help and support.

Often men have strengths related to past life experiences that could be recognized and encouraged in the caregiving situation. Nurses and other providers can assess and identify areas where men can utilize their strengths in the caregiving role. For example, men frequently have experience with managing finances and this strength could be built on as caregiving impacts the financial realm. Recognizing that some men relate their caregiving role as a job is useful for nurses to consider. Since many jobs have routines, nurses could support men to structure caregiving in this way and provide helpful suggestions for men on how to establish routines in their caregiving role. Routines may also include built-in time off for the caregiver. Time off that has meaning and relevance for the caregiver can only be defined by each caregiver and nurses can support men by offering suggestions on taking time off, considering both mental and physical separation.

Men who provide care have a variety of coping strategies and ways of monitoring how well they are doing caregiving. While gender did influence men in a variety of ways, there were also variations in men’s caregiving ways. Each man’s experience must be explored individually, being careful not to make assumptions based on gender, to ensure that nurses and other providers can accurately assess needs and offer supports accordingly. Because caregiving is often viewed as a woman’s role, men may need extra
encouragement and praise for doing caregiving well. Nurses should discuss with men early in the experience how it is that they will monitor their caregiving and how the nurse can support this. Providers may have assumptions that men are willing and able to provide care at home. These assumptions may contribute to unsatisfactory experiences for men, as the support they need may not be forthcoming. Therefore, as early as possible, it is imperative that nurses discuss with men what their expectations of the role are and what supports they feel will be important to them. In this way, if the caregiving situation becomes too challenging and unsatisfying, men can feel supported in exploring other care options. Some men in this study felt they must provide care on their own and nurses can encourage men to try to let go of these expectations of themselves by emphasizing that caregivers frequently need help to succeed at the role. This discussion would need to be done in a sensitive way so as not to jeopardize the nurse-caregiver relationship and contribute to an even more unsatisfying situation.

Finally, since emotions such as grief are inherent in caregiving at the end of life, nurses can support men by providing an environment that encourages the expression of emotions in individual ways. Grieving is a personal experience and men may grieve and need support in different ways. Being sensitive to each man’s uniqueness and ensuring ample time for listening and encouraging in a non-judgmental way will promote a supportive environment. If men choose more formal ways of dealing with emotions, nurses can provide suggestions on available resources and services in the community.

**Implications for Education**

Caregiving may be a new experience for men requiring new knowledge and skills. Nurses and other providers can assess men’s learning needs as well as their readiness to
learn caregiving tasks. An assessment of learning needs could include the context of the situation, past experience of the caregiver, willingness to learn, sensitivity to men’s personal boundaries in the caregiving role, and the physical and emotional ability to take on the tasks. Nurses could also assess the learning styles of men to determine the best methods for delivering the new information. Individuals learn in different ways including written information, verbal instruction, hands-on demonstrations, and supervised practice until men become comfortable with the task. As well, men may require on-going support for tasks and skills, as their dying loved ones condition changes and caregiving demands change.

Nurses can assist men in learning tasks of ADL and IADL both formally and informally. Formal courses on caregiving could be provided in communities, such as within caregiver support networks and groups, and nurses may offer this information to caregivers if this is their preferred learning style. As well, nurses can teach caregiving men the basics of caregiving and more complex skills as demands present within their unique situations.

One skill that may be taught and supported by nurses is advocacy. Since nurses are knowledgeable about illnesses, health care systems, and community resources, they are positioned to teach advocacy skills to caregivers so they become comfortable and confident in advocating for the needs of their loved one and themselves. Teaching and encouraging the advocacy role of caregivers may serve to meet their needs in a more satisfying way, especially for caregiving men who are unfamiliar with these systems.
Implications for Policy/Program Development

This study and many others have demonstrated that at-home caregiving can financially strain families. There is some support that an option for paying family caregivers should be in place (Simon-Rusinowitz, Mahoney, & Benjamin, 1998). As the population ages and more people are cared for at home, policy makers and health authorities should carefully consider the option of fairly compensating caregivers, especially when the caregiving role impacts their employment. While some programs in British Columbia (BC), such as the Choice for Supports for Independent Living (CSIL), do provide younger disabled people the funding to pay their caregivers, there is a lack of programs of this nature for caregivers of the dying. Of the programs that are in place to assist in the care of dying loved ones at home, they often cover only a portion of the real costs to family caregivers, primarily for assistance not salary replacement. For example, caregivers are assessed and charged a per diem rate for home support workers to assist with the care to a maximum of 4 hours per day, as set by provincial policies. One program in BC for at-home palliative care, called the BC Palliative Benefits Program (Plan P), covers payment for medications, medical supplies, and equipment. These types of initiatives greatly enhance the support to caregivers by reducing the financial burden of care at home, however they are restrictive in eligibility criteria and type of resources covered. Furthermore, these programs are reliant on political influences and agendas which are uncertain and unreliable. Palliative care programs and health authorities could provide further support to caregivers by offering per diem waivers, extended hours of service, and more flexibility in supporting caregivers at home. Thus, health care
providers need to continue to advocate for policies and programs that offer tangible support to the caregivers of the dying.

Program development could also include formal support groups for men both during the caregiving experience and in bereavement. As men’s caregiving experiences may differ from women’s, male only groups may be more suitable than mixed gender groups and would offer another option of support for men during caregiving. As men may express their grief in different ways than women, a variety of options should be available for them in bereavement as well. Development of these types of programs needs to include the input of men who have had this experience to ensure men’s unique needs are met.

**Implications for Research**

My study has offered a preliminary exploration of men in a palliative caregiving role. As such, the findings suggest a variety of ways this experience can be more fully explored. Caregiving is often viewed as a woman’s role with an assumption that men lack understanding and knowledge of the role. In my study, some men indicated knowledge of the role as a result of being health care providers themselves. Other men endeavored to learn the role when they became caregivers. Research is needed on how well men are informed about caregiving and the impact of being more fully informed on their choice of becoming a caregiver. Questions concerning their knowledge of the role prior to entering caregiving could include: would men provide palliative care at home if they were fully informed about the role? Would men be more open to formal services if, after learning about the role, they felt they could not provide the needed care? Would having this knowledge lead men to refuse to become a caregiver and, thus, forgo the rewards of
caregiving? What would be the “right amount” of pre-caregiving knowledge for men to provide care at home to the dying? Exploring these questions further with men both in the role and contemplating the role would provide more depth to the current knowledge of male caregiving.

Further research could also examine men’s readiness to learn the tasks of caregiving. My findings suggest that there are a variety of indications of men’s readiness, including when they need to know the task, their own comfort level, the complexity of the task, and the support and resources needed to do the task. Studies examining men’s readiness to provide care in palliative situations would serve to provide nurses and others with information that would enable them to better support male caregivers.

Much research has been done in male caregiving in dementia care. Some of these studies could be replicated to include men in palliative caregiving situations. For example, my study indicated a strong commitment to the dying person and this was supported by research in other contexts (Enyert & Burman, 1999; Harris, 1993; McFarland & Sanders, 1999; Stoller, 1990). Further exploration of the commitment of men in long term relationships to provide care for a dying loved one would add to the palliative caregiving literature. Another area worthy of replication would be examining gender in the palliative caregiving situation, specifically if more men than women receive support and help in their role as palliative caregivers.

Some men in this study felt that caregiving enabled them to become more nurturing. Further exploration may illuminate how men perceive nurturing and the contexts they see as enabling the development of a nurturing role. An examination of men in perceived “nurturing” roles, such as fathers and male health care providers, and a
consideration of the barriers that men may face in developing nurturing could further our understanding of nurturing. This could provide further insight into understanding the concept and development of nurturing in men and may provide nurses and other health care providers with strategies to encourage this quality for men in a caregiving role.

Findings from this study also suggest the enactment of the caregiving role may be influenced by men’s’ previous work experiences. Further study is needed, however, to explore more fully how previous and/or current work roles may influence men’s ability to care. Some men in this study were accustomed to delegating tasks or felt strongly independent. It is not known, however, whether and how these qualities may influence the caregiving experience.

Men who provide care at home for a dying loved one often have a variety of supports in place. One of the salient findings in my study was the supportive role of the family nurse, yet it is unclear how caregivers perceive this role, how important it is to their caregiving, and how it influences men as caregivers. Comparative studies that examine caregiving families who do not have a family nurse with those who do could provide a better understanding of how this role supports caregiving men. Further studies could also examine whether a nurse advocate assigned to palliative families would be advantageous to their experience in general. As well, studying nurses (and other health care providers) on their perspective of how they support family caregivers would provide another avenue to explore this phenomenon.

Findings suggest that men may also receive support from the dying person. Research specifically examining the role that the dying themselves see in the support of the caregiver would add to this body of knowledge. In addition, researchers could
question whether dying people are more inclined to support a male caregiver than a female caregiver and a spouse caregiver more than a non-spouse caregiver. Further studies could determine whether the dying see their independence as protecting their caregiver or as a way to preserve their own dignity and self-respect. Examining caregiving situations as an interactive process between the caregiver and the care recipient, whereby a variety of factors may be influential to the success of caregiving, such as the illness trajectory, treatment regimes, personalities, and relationships, would also be worthy of further exploration.

Finally, more research on doing caregiving well is needed. While there are quantitative tools available for both caregivers and professionals to measure caregiving (Schumacher, Stewart, & Archbold, 1998; Smith, 1999), further studies are needed that can delineate variables aligned with palliative caregiving. This information would need to begin with qualitative research on the experiences of male and female palliative caregivers. Longitudinal studies that examine palliative caregiving from entering the role to the death of the loved one would provide rich descriptions of the continuum of the role. An examination of male caregiving over time would provide some insight into changes in role perception, specifically men’s adjustment to and level of satisfaction in the caregiving role. Caregivers could provide a description of how they view both doing caregiving well and not succeeding in the role, including factors that influence their experience. As well, providers could discuss their perspective of doing caregiving well. Comparing and contrasting providers’ and caregivers’ descriptions could provide information on the effectiveness of current services and suggest changes needed to support successful caregiving. In addition, studies that determined factors that could
predict caregivers who may need more support in “taking care” may be beneficial both to potential and current caregiving men and their providers.

**Recommendations**

My study provided further insight into the experience of palliative male caregiving. As such, I am presenting several recommendations, which may assist nurses, health care providers, and program administrators to more effectively support caregiving men. The first recommendations are directed towards improving at-home care and include:

1. Developing a nursing case management structure that would provide more consistent support in the home as well as enabling trust to build between caregivers and providers.
2. Ensuring all visiting nurses and other providers are skilled and knowledgeable in palliative care delivery including services and resources available;
3. Structuring a support system that can quickly and effectively respond to caregivers’ concerns;
4. Basing the hours of supportive care in the home on the dying person’s needs and caregiver capacity rather than a restrictive daily maximum;
5. Continuing to advocate for further financial support for at-home caregivers.

Since men often choose care at home due to a perceived lack of other options, my next recommendations would be to further enhance options for all palliative patients and their caregivers. This could be done by:

6. Improving long term facility care by educating staff in end-of-life issues and creating a culture of sensitivity and caring for patients and families;
7. Providing other options of formal care, such as shorter term care and respite care in a specialized palliative care setting staffed with providers knowledgeable in end-of-life care.

Men who provide are for the dying need grief and bereavement support and these needs may be unique to male caregivers. The following recommendations would support this need:

8. Ensuring nurses and other health care providers have the knowledge and skills to offer grief and bereavement support in all care settings;

9. Structuring individual and group support sessions based on men’s needs including group sessions for men only.

Conclusion

This study has provided an initial examination of the experience of men who provide at-home care for a dying loved one. Findings have been both congruent with other studies on male caregiving and have also raised new ideas. In addition, questions have been raised that would provide more in-depth knowledge on this topic. Implications and suggested recommendations may direct nurses and other providers to better support men in this role. As well, it is my hope that potential caregiving men and care recipients may benefit from knowledge gained from similar experiences of others.
REFERENCES


McCann, K., & Wadsworth, E. (1992). The role of informal carers in supporting gay men who have HIV related illness: What do they do and what are their needs? *AIDS Care, 4* (1), 25-34.


*CARING Magazine, 14* (4), 16-20.


*Gender issues across the life cycle* (pp. 107-123). New York: Springer Publishing Co.


APPENDIX A

ASSESSMENT TOOL
Assessment Tool

Criteria for Use in a Secondary Analysis of Qualitative Data


Criteria for determining general quality of primary study data set

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<th>Ready access to study documents/team</th>
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<td>Hard copies/disk of interviews</td>
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</tr>
<tr>
<td>Field Notes</td>
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<tr>
<td>Memos or interpretive notes</td>
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Criteria for determining fit of secondary research question

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Aggregate Impression

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APPENDIX B

ORIGINAL STUDY TRIGGER QUESTIONS
Interview Guide

Questions for Family Caregivers

• Tell me a little about how you came to be a caregiver.
• Tell me about what a typical day is (was) like for you.
• How did you come to make the decision to provide care at home?
• What are (were) the rewards in providing care at home? Can you give me an example(s)?
• What are (were) the challenges in providing care at home? What do you find most challenging? How do you manage these challenges? Can you tell me about an experience you had that was particularly challenging?
• How has your life changed as a result of caregiving at home? Can you give me an example(s)?
• What has been your experience with getting support from the health care system? What do (have) you found to be most helpful? What (do) have you found to be most difficult? Can you give me an example(s)?
• How can the services provided to patients and families in the home setting be improved in the future?
• Is there anything else that you would like to add that we haven't talked about?
APPENDIX C

DEMOGRAPHIC DATA COLLECTION FORM
Demographic Data Collection Form

ALL PARTICIPANTS

1. Age: ____

2. Gender: □ Female
   □ Male

3. Ethnicity: ____________________________

4. Religious Affiliation: __________________

5. Level of Education:
   □ Less than high school
   □ High school diploma
   □ Post secondary education
   □ Diploma
   □ Baccalaureate Prepared
   □ Masters
   □ Ph.D.
   □ Technical Program
   □ Other: ____________________________

Health Care Providers: Number of years of experience ____

6. Employment Status:
   □ Unemployed
   □ Unemployed but receiving income assist
   □ Self-employed
   □ Employed full-time
   □ Employed part-time
   □ Retired
   □ Other: ____________________________

Code Number: ____
□ Interview
□ Observation
□ FGI

Participant:
□ Family Caregiver
□ Health Care Provider
Type: ______________

□ Manager
□ Pol/Dec Maker
□ Assisted Suicide
□ Other: ______________

Referral Source:
□ VHS
□ Home Care Nurse
□ Physician
□ AVI; PWA; VARCS
□ Street Community
□ FCN
□ ALS Society
□ Home Support
□ Advertisements
□ Other: ______________

Notes:

Notes:
CAREGIVERS

1. Caregiver relationship to dying person:
   - □ Friend
   - □ Partner
   - □ Spouse
   - □ Parent
   - □ Mother
   - □ Father
   - □ Sibling
   - □ Sister
   - □ Brother
   - □ Adult Child
   - □ Daughter
   - □ Son
   - □ In-Law
   - □ Daughter
   - □ Son
   - Other: _____________________________________________

2. Location of death:
   - □ Loved one currently dying at home
   - □ Loved one has already died
   - Location: □ Home
   - □ Acute Care
   - □ LTC
   - □ Hospice
   - □ Other: _____________________________________________
   - Date/Year person died: ________________________________

3. Access to Health & Community Resources
   - □ Registered with VHS
   - □ Not registered with VHS
   - Access: □ Home Care
   - □ Home Support
   - □ PRT
   - Other: _____________________________________________

4. Diagnosis of dying loved one: ____________________________

5. Status of Residence:
   - □ Share the same household as dying loved one
   - □ Live independently
   - □ Reside in Victoria
   - □ Live outside Victoria but moved to caregive

6. Average Household Income Per Year (optional):
   - □ < $10,000
   - □ $10,000 - $20,000
   - □ $20,000 - $30,000
   - □ $30,000 - $40,000
   - □ $40,000 - $50,000
   - □ $50,000 - $60,000
   - □ $60,000 - $70,000
   - □ > $70,000
APPENDIX D

FAMILY CAREGIVERS CONSENT FORM