THE IDEALIZATION OF DYING AT HOME:
THE SOCIAL CONTEXT OF HOME-BASED PALLIATIVE CAREGIVING

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ABSTRACT

THE IDEALIZATION OF DYING AT HOME:
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The impetus to provide home-based palliative care is growing in an effort to curtail health care costs and to provide a more therapeutic milieu for dying and death to occur. Despite an expanding body of research focusing on the provision of palliative care at home, there has been little attention given to the historical, social, economic, political, and ideological structures and processes that play a role in shaping family caregivers' experiences with providing home-based palliative care. This ethnographic study approached this problem by examining the social context of home-based palliative caregiving, with the overall purpose of uncovering how larger structures and processes influence family caregiver experiences with providing home-based palliative care. The investigator conducted 130 hours of field work in the homes of 13 palliative caregivers (and 12 patients), and interviewed 13 active caregivers, 47 previous caregivers, 28 health care providers, nine health care administrators, and one publicly known lobbyist for the assisted suicide movement.

Through this research, home-based palliative caregiving was revealed as more complicated than typically represented. Under ideal conditions, home-based palliative caregiving would result in life-enriching experiences, marked by negotiated decision making, careful consideration of caregivers' needs, respectful interactions with health care providers, and equitable access to health care. However, a number of factors stemming from idealized assumptions about dying at home and the contexts of health care provision resulted in some caregivers feeling "pressured" to provide home care, and consequently, left some of them feeling that their obligations

to care were exploited by the health care system. Recent shifts toward moving the provision of health care closer to home not only changed some of the caregivers in profound ways but also transformed the home setting into one that was infused with the influences of biomedicine. Long-standing philosophical divisions between mainstream medical practice and the ideals upheld by palliative care have inhibited the development of coordinated and consistent systems of palliative care that could ultimately benefit both patients at the end-of-life and their caregivers.

The findings of this study demonstrate a need to re-think the ways in which home care for the dying is conceptualized, pointing to a need to foster critical consciousness in order to explore how taken-for-granted assumptions influence and sometimes dominate the provision of health care at home. Such awareness will ultimately pave the way toward a health care system and society that genuinely respects and honours the obligations, choices, and needs of family members who provide palliative care at home.

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And, to my husband Doug -- You have been incredible and I would not, could not have done it without you. Your love, understanding, and support were of immeasurable sustenance to me.

DEDICATION

This work is dedicated to

My mother, Mary Milko (1931-1990) and my father, Clifford Milko

You have:
Inspired me with your strength and wisdom.
Given me the confidence to succeed.
Taught me about what is meaningful in life.

CHAPTER ONE:

INTRODUCTION

Situating the Study in a Historical Context

Dying at home is not a new phenomenon. For centuries, many cultures have supported the idea that people should remain at home while they are dying. The home was where family, friends, and neighbours congregated to take part in an inevitable and integral part of life (Thorpe, 1993). The shift from home-based to institutional-based care for the dying can be traced to 475 A.D. when Fabiola, a Roman matron, opened a place of refuge for the sick and the dying (Campbell, 1986). These early hospices, run mainly by Christian religious orders, proliferated in the Middle Ages (Manning, 1984). In the mid 1500's, however, the advent of widespread poverty and disease transformed societal attitudes, and those who were dying were often beaten and enslaved because of their illness (Stoddard, 1978). At the same time, the support of Christian religious orders was weakened by the Protestant reformation and this resulted in secular rulers or physician groups taking over many of the services offered by hospices (Phipps, 1988). Consequently, many hospices were closed and the dying were left, for the most part, ignored and unattended (Campbell).

In response to societal attitudes and the stigmatization of dying, the Sisters of Charity revived the European hospice tradition in the early 19th century, opening a 30 bed in-patient hospice unit (Campbell, 1986). Located in London, St. Joseph's Hospice worked in tandem with a long-standing tradition of home nursing care. Throughout the early 19th century, family members became formally recognized as

care providers and played a critical role in supporting those dying at home. Yet, despite changes in societal attitudes and a relative familiarity with dying and death, health care institutions gradually usurped the role of family members. These institutions became the socially accepted, and preferred, place to die (Aries, 1976; Thorpe, 1993).

Dramatic changes in attitudes to death and dying again took place in the mid-19th century. With the development of modern medicine, death was perceived as a failure by health care professionals and many began to view death as the enemy of life (Aries, 1976; Capra, 1982; Cowley, Young, & Raffin, 1992). Institutionalized death, which became the norm, was increasingly complex and highly dependent on medical technology in an effort to preserve life at all costs (Thorpe, 1993). Health care providers, in their devotion to curing, began to de-emphasize and dehumanize death (Campbell, 1986).

The Emergence of the Modern Hospice and Palliative Care Movement[1]

The emergence of the modern hospice movement has been linked to the inadequacy of Western medicine to face death and to care for the terminally ill (Dudgeon, 1992; James, 1992). In response, Dr. Cicely Saunders, the founder of the modern hospice movement, opened St. Christopher's Hospice in England in

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[1] The term palliative care was adopted in Canada in the early 1970s to delineate a program of care for the dying. Although the terms "hospice" and "palliative care" are used interchangeably throughout the world, palliative care is more commonly used within the Canadian context. Various definitions of palliative care exist and are used across Canada (e.g., Health Canada, 1989a; World Health Organization, 1990), although there is currently no national consensus on a definition. In 1993, the Canadian Palliative Care Association (CPCA) began a process to develop a national definition for palliative care along with standards of practice (CPCA & Ferris, 1998). For the purpose of this thesis, I have adopted the CPCA working definition (1995, Appendix A). This definition explicitly acknowledges both the patient and the family as the unit of care and is inclusive, covering all possible situations in which palliative care might apply.

1967. Following this, programs of care for the dying proliferated in England and, almost without exception, hospice care was provided in free-standing facilities with home care services playing a secondary, but supportive, role (Seale, 1998; Torrens, 1985).

Similar programs of care for the dying began to develop in Canada in the 1970s. In contrast to the United Kingdom's hospice model and home care models in the United States (U.S.), the foundation of the palliative care movement in Canada began within the acute care hospital setting (Ajemian, 1992). Few links to home care services were developed at that time, and death continued to be an institutionalized experience. Since the 1970s, there has been enormous growth in the number of hospital-based palliative care programs in Canada. The development of home care programs for the dying has gained momentum only in the past decade[2]. This shift from institutional care to home care has been advocated by policy makers and practitioners alike who maintain that people who are dying prefer to spend their final days at home, in familiar, comfortable surroundings, and prefer to be cared for by family members or those closest to them (Collett, 1999; Gilbar & Steiner, 1996; Gomas, 1993; Mann, Loesch, Shurpin, & Chalas, 1993; McWhinney & Stewart, 1994; National Forum on Health, 1997).

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[2] The development of home care programs for the dying has been linked to an underlying belief that the home setting promotes normalcy; where people with life-threatening illnesses and their family members can maintain freedom and control in their own environment (Davies, Reimer, Brown, & Martens, 1995; O'Henley, Curzio, & Hunt, 1997). Widespread criticisms of hospital-based care for the dying (Cowley, et al., 1992; Desbiens, Mueller-Rizner, Hamel, & Connors, 1998) have also contributed to the development of home care programs. Canadian researchers and leaders in palliative care suggest that there is also a perception that home care will result in considerable cost savings to the health care system (Chochinov & Kristjanson, 1998; Roe, 1992; Scott, 1992) although the existing evidence is inconclusive in this regard (Emanuel, 1996; Hughes, et al., 1997; Siu, 1997).

Background to the Problem

Family caregiving is a prominent issue in Canadian society (Aronson, 1998). Irrespective of whether a country has a universal, comprehensive health care system such as Canada's, estimates suggest that between 75% and 85% of all caregiving occurs in the home and is provided by unpaid family members (Kane, 1990). While Canadians have a long history of providing care and assistance to family members, the work of caregivers is not only unpaid, but also invisible (Canadian Coalition for Caregivers, 2000). Family caregiving[3], as an issue of concern, has gained attention in the last decade[4] as the Canadian health care system has struggled to meet the demands of an aging population and an increase in the prevalence of cancer, Acquired Immunodeficiency Syndrome (AIDS), and other life-threatening conditions (Mount, Scott, & Cohen, 1993)[5]. At the same time,

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[3] I use the term "family" quite broadly, taking direction from contemporary family theorists who maintain that "it is quite possible for people to have a family experience (including feelings of intimacy, connectedness, commitment, and so forth) with people who are not in one's actual family" (Hartrick & Lindsey, 1995, p. 154). Throughout this dissertation, I have used the term "caregiver" to refer to a person (i.e., family member) who is providing care at home and who is not a paid health care worker.

[4] Barris (1998) maintains that family caregiving is experiencing a "coming out" process. The burgeoning industry of services, books, and media attention imply that family caregiving is becoming a mainstream concern for Canadians (Bell, 1994; Chishom, 2000; Community Hospice Association of Ontario, 1994; Johnson, 1994; McIlroy & Picard, 1999; Picard, 1999; Tibbetts, 1997; Victoria AIDS Respite Care Society, 1995; Volkart, 1998). Internet web sites devoted to family caregiver issues are in place (see www.caregiver.com), online discussion forums have been initiated (see www.globeandmail.com), and a series of documentary films focusing on family caregiving and palliative care have been produced by the National Film Board of Canada (Curtis & Symansky, 1997; Curtis, 1999). Even June Callwood, a celebrated Canadian author and social activist hosted a weekly television series on family caregiving (McKay, 1998).

[5] In 1951, 7.8% of Canada's population was aged 65 and over (Anderson & Parent, 1999). By 1996, this percentage had increased to 12.2% of the total population, including 2.8% over the age of 80. Statistics Canada (1999) estimates that by the year 2016, the Canadian population will reach just over 37 million, up from 14 million reported in 1951. The percentage of those aged 65 and over will increase to almost 16% (5.9 million) and those aged 80 and over will comprise just over 4% of the total population (1.5 million). Along with Canada's aging population, new cases of cancer and other chronic, life-threatening illnesses are on the rise. The Canadian Cancer Society (2000) estimates that 132,100 new cases of cancer and 65,000 deaths from cancer will occur in Canada in 2000, with 82% of deaths occurring among those who are at least 60 years of age. In 1997, Statistics Canada

the reduction of health care budgets and the closure of hospital beds have placed increased pressure on community-based care. Canadians are becoming increasingly reliant on home care as more people die at home or spend a large portion of their illness in the home setting (Alcock, Danbrook, Walker, & Hunt, 1998; McWhinney & Stewart, 1994).

Calls to enhance home care services for the dying have been echoed across the country (e.g., Canadian Senate Subcommittee on End-of-Life Care, 2000; Expert Panel on Palliative Care to the Cancer 2000 Task Force - Home Care, 1991; Senate of Canada, 1995) and the federal government has voiced its support for expansion of these services (Chretien, 1997). At a national conference on home care, the federal Health Minister asserted that there is an urgent need to augment home care programs (McLean, 1998). Yet, Anderson and Parent (1999) argue that the social reality of home care in Canada is very different from the political rhetoric. Many claim that the health care system has been largely unresponsive to the needs of home-based family caregivers (Armstrong & Armstrong, 1996; Canadian Nurses Association, 1999; McIlroy & Picard, 1999).

According to a recent study conducted by the Queen's Health Policy Research Unit, the burdens associated with caregiving greatly exceed family members' capacity to cope (Anderson & Parent, 1999). Research focusing on home care for the dying suggests that there are physical, psychosocial, and financial risks to assuming the family caregiver role (Addington-Hall, MacDonald, Anderson, & Freeling, 1991; Davis, Cowley, & Ryland, 1996; Hinton, 1994a; Martens & Davies,

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(2000) reported 215,000 deaths, with 27.2% caused by cancer, 26.6% by heart disease and 46.2% by other diseases such as chronic illness, injuries/accidents, suicides, and AIDS.

1990; Muurinen, 1986; Rando, 1988; Steele & Fitch, 1996; Wodinsky, 1992). The social context of our modern society also produces unique challenges for families in palliative care. Migration of family members away from the home, smaller families, and changing household structures mean that there are fewer people to support those dying at home (Thorpe, 1993; Sankar, 1993; Shapiro, 1994). Changes to the dynamics and structure of the Canadian family do and will continue to have an impact on home care for the dying (Vanier Institute of the Family, 1997).

While the intent of palliative care is to support families with members in the terminal phase, recent media attention and debate focusing on euthanasia and end-of-life decision making also urge us to consider the implications of home-based palliative care and its influence on family members. Balfour Mount, dubbed the Canadian "father of palliative care" claims that the appeal of euthanasia and assisted suicide as a compassionate alternative to palliative care is unlikely to lessen due, in part, to increasing family caregiver burden (Kennedy, 2001, p. A2). Public calls for the decriminalization of euthanasia and assisted suicide bring forward questions of whether we, in health care, have created a social context that may overburden some patients and family members.

The impetus to provide home-based palliative care is growing in an effort to curtail health care costs and to provide a more therapeutic milieu for dying and death to occur (Seaton, 1991). An expanding body of research focusing on health service utilization, satisfaction with care, demographic characteristics, preferences for location of death, and on health care providers' perceptions of home care for the dying suggests that palliative care services provide specific benefits to family

members (Brown, Davies, & Martens, 1990; Cawley & Gerdts, 1988; Costantini, Camoirano, Madeddu, Bruzzi, Verganelli, & Henriquet, 1993; Devery, Lennie, & Cooney, 1999; Gilbar, 1996; Gomas, 1993; Keizer, Kozak, & Scott, 1992; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996; Kristjanson, Leis, Koop, Carriere, & Mueller, 1997; Lecouturier, Jacoby, Bradshaw, Lovel, & Eccles, 1999; Lewis, 1986; McWhinney & Stewart, 1994; Porta, Busquet, & Jariod, 1997; Sims, Radford, Doran, & Page, 1997). Yet, in studies that examine family caregiver experiences, there has been a tendency to focus on individual descriptions with little or no attention paid to the historical, social, economic, political, and ideological structures and processes that play a role in shaping the caregivers' experiences. Research focusing on the individual experience is important and has provided a foundation for the provision of comprehensive and family centered palliative care. But, attempts to explain and understand individual-level experiences in isolation of how they are constructed and influenced by health care relationships and encounters with the larger health care system, for example, are no longer sufficient to fully understand how family members experience and participate in the provision of palliative care at home. In light of this, the central problem addressed in this study was the interaction between family caregiver experiences, and the larger structures and processes that influence the home setting where palliative care is provided.

Purpose of the Study

The overall purpose of this study was to uncover how larger structures and processes influence family caregiver experiences with providing home-based palliative care. To address this problem, an ethnography, informed by critical

perspectives (Stewart, 1998; Thomas, 1993) was conducted. The study began by focusing on individual family caregiver experiences and then moved to focus on the social context in which this experience was shaped. My interest was to describe the experiences of family members, and to examine the dialectic between these experiences and the interactions with the larger health care system. It was anticipated that such a critical inquiry would provide a deeper understanding of the social context of home-based palliative caregiving and, thus, would provide the basis for health care decision-making and policy development in the area of home care for the dying.

The Research Questions

The overall research question guiding this study was: What is the experience of family members who provide palliative care at home and how does the social context influence these experiences? In order to conduct the multi-layered analysis required to understand the social context of home-based palliative caregiving, I required a framework by which to organize and conceptualize the various layers of investigation. Therefore, I began my study at a micro level, seeking to understand how family members came to the decision to provide care at home and how this decision influenced their lives. From there, I focused on meso-level influences, such as the community context in which home care was taking place. This emphasis allowed me to explore how the organization of health care and regional health care reforms had shaped individual caregiver experiences. In turn, my examination moved to a macro level with the goal of exploring how ideologies influence home-based palliative care and how the sociopolitical structures and processes inherent

within the Canadian health care system impact on family caregiving issues. My aim was to illustrate the interactions between the micro, meso, and macro levels of health care provision.

Definition of Terms

In order to clarify my key area of study, the following terms were defined:

<u>Social Context</u>: The social context is comprised of the interactions between various dimensions of the palliative home caregiving experience. These interactions include individual caregiver experiences, and how they are influenced and shaped by community health care practices and reforms, and the processes and structures within the larger health care system and society.

<u>The Dying Period</u>: The end of living with a life-threatening illness; when a person is expected to die within one to three months[6]. 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.

<u>Home</u>: 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 such as hot-plate hotels and shelters.

<u>Family Caregiver</u>: 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.

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[6] I used the expected time period of one to three months as a guideline for sampling caregivers. The rationale for this approach is fully explained in Chapter Three.

Organization of the Thesis

Having provided an introduction to the study in this first chapter, I now turn to a review of the literature, with particular attention to what is currently known about family members' experiences in providing palliative care at home. In Chapter Three, I detail both my theoretical positioning and the methodological approaches and decisions that I made throughout this study. Chapters Four, Five and Six outline the key findings of this research. Specifically, Chapter Four will highlight the individual experiences of family caregivers, describing how and why they came to make the decision to engage in home-based caregiving and how this decision had influenced their lives. In Chapter Five, I focus on the community context, examining how the organization of health care and regional health care reforms shaped caregiver experiences. Chapter Six extends the analysis by locating the home caregiving experience within the sociopolitical context. In Chapter Seven, I offer a discussion of key themes resulting from the study in an effort to extend our understanding of the social context of home-based palliative caregiving. Chapter Eight concludes the thesis with a presentation of key conclusions, and a discussion of further implications for practice, education, administration, research, and health policy development.

CHAPTER TWO:

REVIEW OF THE LITERATURE

It is increasingly evident that family members play an important role in the provision of home health care (Douglass, 1999). A recent survey found that more than one in eight Canadians over the age of 15, or about 2.8 million adult men and women, provided some sort of care in 1996 to people at home with chronic health conditions or life-threatening illnesses (Statistics Canada, 1997). In a study examining the status of home care in Canada, 78% of survey respondents identified family caregiving as an issue in their community (Anderson & Parent, 1999). Interest in the provision of home care for the dying has led to greater coverage of this topic by the popular media in Canada[7] and has, in part, led to the recommendation that home care become a nationally funded health service for all Canadians (National Forum on Health, 1997).

While it is clear that family caregiving and home care are both issues of concern for many Canadians, there has been little systematic examination of how the larger structures and processes within the health care system influence family members' experiences with home-based palliative care. The research problem directed me to explore a range of literature. In this chapter, I review both empirical and theoretical literature in order to provide an overview of what is known about home-based palliative care, the relationship between family caregiving and home-based palliative care, and the social context of this relationship. As a starting point, I focus on the possible consequences of caregiving on family members, paying

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[7] For example, see Daly, 1999; McIlroy and Picard, 1999; MacKinlay, 1996; Metella, 1998; Murphy, 1999; Paterson, 1999; Picard, 1999; Schaal, 1999; Ubelacker, 1998; Wigod, 1998.

particular attention to the physical, psychosocial, and economic burdens. The literature review moves to a theoretical discussion on the ethical implications of home care for the dying. Having established what is known about the burden of caregiving, I then review current epidemiologic and demographic trends in home-based palliative care and highlight research and review articles that detail the factors that influence the location of dying. Within this discussion, I offer a critique of the research that has focused on preferences for the location of death, and provide an overview of the theoretical arguments that support the idea that the home setting is the preferred place for palliative care to occur. Finally, I present further background information to provide context to this study, as I briefly examine some of the macro issues that influence the provision of palliative care in the home setting.

The Burden of Family Caregiving

There is a large and expanding body of research on family caregiving, particularly as it relates to seniors (Baumgarten, et al., 1992; Clarke, 1999; Harris, 1993; Hillman & Chappell, 2000; Lindgren, 1993; Parks & Pilisuk, 1991; Rabins, Fitting, Eastham, & Fetting, 1990; Schumacher, Stewart, & Archbold, 1998; Szabo & Strang, 1999; Wuest, Ericson, & Stern, 1994). A comprehensive review of the research literature on caregiving for the elderly exemplifies the adverse impact on both the physical and mental health of caregivers (Browning & Schwirian, 1994). While the difficult nature of caregiving in the senior population has been well established (Archbold, Stewart, Greenlick, & Harvath, 1990; Baumgarten, 1989; Boland & Sims, 1996; Cohen & Eisdorfer, 1988; Given, Collins, & Given, 1988; George & Gwyther, 1986; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit,

1986), studies focusing on caregiver experiences in palliative care are a more recent body of work. As with the senior population, this research attests to the burdens experienced by family members providing palliative care.

Physical, Psychosocial, and Financial Burdens

Much of the research to date suggests that family members are at serious risk for physical, psychosocial, and financial burdens as a result of caregiving at home (Blank, Clark, Longman, & Atwood, 1989; Brabant, 1994; Davies, Reimer, & Martens, 1994; Kristjanson & Ashcroft, 1994; Lewis, 1986; Lynam, 1995; Stajduhar & Davies, 1998a; Stetz & Hanson, 1992). Physical burdens have been attributed to the sheer magnitude of work required by family members. A descriptive study with 124 bereaved caregivers demonstrated that they provided, on average, 10.8 hours per day of direct care and 8.9 hours per day of companionship to their dying family member (Wyatt, Friedman, Given, & Given, 1999). Studies have shown that family members provide a range of services such as bathing, dressing, toileting, and feeding; household chores such as laundry and house cleaning; rudimentary medical care such as injections and medications; and, general supervision and coordination of care (Folkman, Chesney, Cooke, Boccellari, & Collette, 1994; Martens & Davies, 1990; Stajduhar, 1995; Stetz, 1987; Ward & Brown, 1994; Wrubel & Folkman, 1997). In a descriptive exploratory study examining the demands made on caregivers who were spouses of terminally ill cancer patients, Stetz found that 69% of family members found the physical demands of caregiving to be the most

difficult[8]. Indeed, managing the physical aspects of care has been found to be one of the most demanding tasks for palliative caregivers, marked by constant monitoring, vigilant assessment and management of symptoms, and relentless personal and nursing care (Folkman, Chesney, & Christopher-Richards, 1994; Holing, 1986; Martens & Davies; Powell-Cope, 1995; Stajduhar, 1995). Schachter (1992) maintains that caregivers frequently do not anticipate the day-to-day physical labours associated with caregiving and are unprepared for the demands placed on them.

While it is clear that the physical strains of home caregiving are substantial, they are often rivaled by psychosocial burdens (Neale, 1993). Studies report that family caregivers commonly express feelings of emptiness, fear, helplessness, anger, anxiety, and guilt in their caregiving roles (Atkins & Amenta, 1991; Brown & Powell-Cope, 1991; Goldberg, Wool, Glicksman, & Tull, 1985; Hileman & Lackey, 1990; Hull, 1990; Irvin, Bor, & Catalan, 1995; Jensen & Given, 1991; Kissane, Bloch, & McKenzie, 1997; Perry & Roades de Menses, 1989). Uncertainty about the timing of death and the way it might occur combined with difficulties with decision making are also commonly reported in research studies (Brown & Powell-Cope; Jensen & Given; Stajduhar & Davies, 1998a). Social burdens, including restrictions on time

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[8] In contrast to much of the research to date, Chan and Chang (1999), in a quantitative study examining tasks among family caregivers of cancer patients, found that 72% of caregivers *did not* have difficulty with physical caregiving tasks. This study was conducted with a small convenience sample of 29 Asian caregivers and the influences of cultural variations to caregiving expectations were not accounted for. However, as Tang (2000) argues, dying at home has distinct cultural meanings to people of Asian decent and their family members. Dying at home is viewed as a "glorious and fortunate way of death" (p. 368) whereas dying in hospital goes against many Asian customs. It would seem, then, that the physical tasks of caregiving might not be seen as burdensome by some members of Asian background, although I recognize that there would be significant variation depending on the Asian country or territory where palliative care was occurring.

and freedom, and disruption of personal routines and leisure activities have also been documented (Martens & Davies, 1990; Rose, 1998; Steele & Fitch, 1996). For example, Brown and Stetz (1999) conducted in-depth interviews with 26 people caring for an adult with either AIDS or cancer and found that many caregivers put their lives on hold and felt an overwhelming sense of being alone in their caregiving role.

Feelings of uncertainty, helplessness, anxiety, and fear have been attributed to relationship and role changes that occur in the family when a member becomes terminally ill (Kristjanson & Ashcroft, 1994; Lewis, 1986; Schachter & Holland, 1995). Caregivers are often confronted with perplexing and changing problems of identity in the course of caring for a dying family member (Davies, Chekryn-Reimer, & Martens, 1990; Hull, 1989). In a grounded theory study examining the impact on families having a member with advanced cancer, Davies and colleagues interviewed 66 family members, both individually and as a family unit, in order to determine how they managed the illness situation and the patient's care, and their perceptions of care at home and in hospital. Constant comparative analysis revealed that family functioning influences the palliative care experience and that many family members need to redefine or reconceptualize themselves to adjust to a new reality and to accommodate to the change in their loved one's health status. Although the study provides a detailed picture of how families function when a member has advanced cancer, it did not explicitly focus on how caregiving in the home setting had influenced family functioning.

The literature suggests that family caregivers also encounter financial hardships as a result of in-home caregiving. Studies have documented the subjective sense of economic burden and have found variations in the amount of burden reported. For example, one survey found that approximately 25% of all caregivers experienced financial difficulties (Davis, et al., 1996); another study reported 44.9% (Emanuel, Fairclough, Slutsman, & Emanuel, 2000); and another, 60% (Muurinen, 1986). Financial burden has been attributed to several factors. Caregiving can disrupt work performance resulting in missed time from work and unemployment (Addington-Hall, MacDonald, Anderson, & Freeling, 1991; Devery, Lennie, & Cooney, 1999; Muurinen; Sykes, Pearson, & Chell, 1992). The costs incurred by caregivers in the home setting can also be substantial (Armstrong & Armstrong, 1996; Fierlbeck, 1997). The cumulative effect of buying goods and services, including medications, equipment, and home care services, can drain family resources. This is the case even in Canada where government health plans ensure a basic level of coverage. Steele (1999) maintains that "people assume that all costs are covered by insurance. Most insurance plans, however, do not pay for incidental costs. The cumulative effect of these costs may take a toll on family caregivers" (p. 48-49). Studies have reported that families caring for a terminally ill member have had to spend their life savings, take out loans or mortgages, or obtain additional jobs to ease their financial burden (Emanuel, et al.). The U.S. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) reported that families of seriously ill patients experienced substantial

economic losses. In 20% of families, a family member had to stop working; 31% of families lost most of their savings (Covinsky, et al., 1994).

While there is little research that documents the actual costs incurred by family members providing at-home palliative care, the costs are believed to be significant. Some authors argue that the widespread and substantial move away from long stays in hospital facilities has had the effect of pushing sizeable costs onto family caregivers (Armstrong & Armstrong, 1996).[9] Others maintain that these costs can be so substantial that they limit the ability of family members to provide home care (Arno, Bonuck, & Padgug, 1995; Wodinsky, 1992). Lost opportunity costs, such as forsaking chances for employment outside of home, are rarely considered in determining the cost-effectiveness of home-based palliative care (Arras & Neveloff-Dubler, 1995; Whynes, 1997). Peters (1995) maintains that more often than not, Canadians choose family reliance over state intervention in the care of family members. At the same time, the National Forum on Health (1997) reports that Canadians are concerned about resource allocation decisions being made on this assumption without consideration given to caregiver compensation[10].

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[9] Armstrong and Armstrong argue that cost savings to the Canadian government arise because costs are transferred (i.e., they do not disappear) to individuals and family members. They state that "although there are differences among provinces in the provision of community services, none entirely cover all the required hours of care. Individuals and family members must make up the difference either by hiring home care services, usually from the private sector, or by doing all the care themselves" (1996, p.185).

[10] The CPCA and provincial hospice/palliative care associations are becoming active in the area of family caregiver protection (see www.cpca.net/fcp.htm). It is the position of CPCA that job protection and paid leave for a family member wishing to care for a dying loved one is a significant social policy issue facing Canadians. Most provinces provide little or no job protection for those taking leave to provide care and none provide income security. Income protection is within federal jurisdiction. Federal programs such as Employment Insurance and the Canada Pension Plan do not provide income security for caregivers. CPCA is now in the process of actively pursuing the issue of job protection and income security for family caregivers providing end-of-life care.

Health Outcomes

The physical, psychosocial, and economic demands of home-based caregiving have been linked to negative health outcomes for caregivers including chronic fatigue, depression, prolonged stress, physical exhaustion, sleeplessness, and burnout (Axelsson & Sjoden, 1998; Davis, et al., 1996; Hinton, 1994a; Hull, 1990; Jarrett, Payne, & Wiles, 1999; Schachter, 1992; Vachon, 1998; Wyatt, et al., 1999). A recent survey of 1,300 Canadians reported that over 60% of family members found caregiving difficult and that providing care to an ill person had a substantial impact on their own physical and mental well-being (Barris, 1998). Similarly, a British study investigating the effects of terminal illness on patients and their caregivers found that almost 50% of family members experienced ill health because of caregiving (Davis, et al.). In both of these studies, however, ill health was not well described.

In the U.S., family members providing end-of-life care have three times as many stress symptoms as the general population and take more prescription drugs to treat depression and stress (Mezey, Miller, & Nelson-Linton, 1999). In a longitudinal study assessing stress and coping in 253 caregivers of men with HIV/AIDS, caregiving partners were found to be at high risk for clinical depression resulting from the adjustments needed to cope with the ill person's unpredictable disease course (Folkman, Chesney, & Christopher-Richards, 1994). Studies conducted with spouses of terminally ill cancer patients also report that up to one third of caregivers have depressive symptoms as a result of caregiving

(Emanuel, et al., 2000; Greer, et al., 1986; Kissane, Block, Burns, McKenzie, & Posterino, 1994). In a large population-based study, Emanuel and colleagues conducted in-person survey interviews with 988 terminally ill patients and 893 caregivers in six randomly selected U.S. states to gain an understanding of the burdens associated with terminal illness. The caregiver survey contained 118 questions focusing on health status and symptoms, social supports, communication with health care providers, personal and spiritual meaning, care needs, end-of-life care plans, economic burdens, sociodemographic characteristics, euthanasia and assisted suicide, and interview-related stress. While the study report provides detailed findings on terminally ill patients, the authors did not provide detailed findings on caregiver experiences and did not define or systematically report on economic and "other" burdens associated with terminal illness. Nevertheless, some of the statistical analyses revealed caregivers were more likely to have depressive symptoms and to report that caregiving substantially interfered with their lives. The study also demonstrated that, as the disease progressed and the amount of care for the terminally ill person increased, the level of burden also increased. Similarly, Hinton (1994a) found that family caregivers suffered more emotional and physical distress as the disease progressed with 17% of caregivers being rated as seriously depressed and 14% very anxious.

Caregiving places considerable strain on family members regardless of the country in which it is occurring. Although the process of caregiving has been shown to have negative health outcomes, there is some evidence to suggest that caregivers neglect to seek medical attention or support for their health concerns

(Stetz & Hanson, 1992). Stetz and Hanson conducted a follow-up study with 31 bereaved spouses to determine if their perceptions of caregiving demands had changed over time. A mailed survey with seven open-ended questions was used to collect data and the responses were subjected to content analysis. Survey findings indicated that over half of all caregivers had suffered personal health problems and that they regretted not seeking help with caregiving. Research supports these findings and indicates that family members often think only of the needs of the dying person, at the expense of their own needs (Ryan, 1992; Skorupka & Bohnet, 1982). Some family members use avoidance as a coping mechanism to deal with the demands of caregiving. A phenomenological study with six home-based family caregivers found that avoidance was the predominant method used by family members to cope with the stresses of caregiving. These behaviors included not thinking about it, staying busy, deferring from asking questions about the dying process, and taking medications to relax (Brinson & Brunk, 2000). Even though this study provides some useful information on how family members cope with the stress of caregiving, the small sample size limits its generalizability.

It is only recently that researchers have begun to investigate the long-term effects on caregivers when they provide palliative care at home. Addington-Hall and Karlsen (2000) conducted a secondary analysis of data from a large retrospective population-based survey of a random sample of people who died in 20 English health districts. Caregiver respondents were asked about the extent to which they missed the deceased, whether they could look forward to things, whether they felt they had come to terms with the death, and how well they considered things to be

going for them. Using the General Health Questionnaire, a validated measure of psychological morbidity, the researchers found that 10 months after the death, bereaved caregivers of cancer patients who had died at home were found to have significantly higher levels of psychological distress than caregivers of patients who had died elsewhere. Caregivers were also more likely to report that they missed the deceased a great deal, and less likely to report that they could look forward to things, that they had come to terms with the death, or that things were going well for them. These findings, however, are preliminary and the authors caution that replication and longitudinal studies are required to explore the long-term effects of providing home-based palliative care on caregivers. These unexpected findings led the authors to conclude that palliative caregiving at home may provide benefits to dying patients but may cause considerable distress for caregivers. The study supports earlier conclusions reached by Hinton (1994b) who reported that bereaved caregivers often had serious misgivings about caring for their dying family member at home.

The literature presented on caregiver burden clearly indicates that there are significant risks to assuming the family caregiver role. However, with few exceptions, most studies focus on the description of tasks and do not fully explain the context of caregiver burden or provide detailed accounts of the actual causes of burden in palliative care. For the most part, burdens are mentioned almost in passing. Yet, without a broader understanding of the context of caregiver burden and those factors that might influence the home setting where palliative care is occurring, it is difficult to identify mechanisms that could meet the care needs of

home-based caregivers without imposing additional hardships on them. Further, most of the available research has been conducted in Britain, the U.S., or Australia. While these studies provide important information about family members' experiences, they may not be entirely applicable to the Canadian context because of differences in the organization of palliative care services.

Ethical Implications of Home Care for the Dying

The physical, psychosocial, and economic burdens associated with caregiving have prompted scholars to write about the ethical and moral problems associated with dying at home (Arras, 1995; Arras & Neveloff-Dubler, 1995; Coyle, 1997; Di Mola, 1997; Ruddick, 1995; Sankar, 1993). These writings have focused primarily on pointing out the possible implications of such care and have served to critique ideological perspectives that (sometimes) indiscriminately promote the "home death movement"[11]. While it is not my intent here to present all of the possible ethical and moral concerns in detail, I will highlight some of the predominant arguments that have arisen in the literature[12] as a way to provide further background and context to this study.

The Home as the Ideal Care Setting for Dying

The modern palliative care movement has strongly embraced the idea that the home setting represents the most appropriate place for dying and death to occur. In Canada, as in many Western countries, one of the primary goals of palliative care

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[11] I use the term "home death movement" here to exemplify the current push, both at a philosophical level and a more practice level (e.g., economics), to enable more dying people to remain at home.
[12] John D. Arras (1995), a professor in the philosophy department at the University of Virginia, has written an excellent book entitled Bringing the hospital home, which focuses explicitly on the ethical and social implications of high-tech home care. Many of the chapters offer comprehensive discussions about the ethical implications of home care for the dying.

is to support people to die in their own home (Fraser, 1990; Mor & Hiris, 1983; Ramsay, 1992). In an article entitled, *Enabling more dying people to remain at home*, Thorpe (1993) contends that, "when it comes to dying there is no place like home" (p. 915). Indeed, "in a view reflected in law, poetry, and cliches, home is commonly taken to be a refuge, castle, haven, or nest" (Ruddick, 1995, p. 167). It is argued that home is where people feel most comfortable. Home represents a place where we can be at ease, away from the pressures to conform to social norms. As Ruddick explains:

> For many people, home is where they feel most truly themselves, the very center of their lives, closest relationships, and most intense emotions. As such, home is their natural or, in Aristotelian terms, their "telic place" where mature selves are realized and revealed (p. 167).

Current conceptualizations of "home" provide an attractive alternative to institutional-based palliative care. Aries (1981) describes an institutionalized death as an unnatural experience: "the death of the patient in hospital, covered with tubes, is becoming a more popular image than the *transi* or skeleton of macabre rhetoric" (p. 614). These views have advanced the home death movement and have led some people to believe that the care provided at home (by family members) will be far superior to that of a depersonalized and paternalistic hospital setting (Coyle, 1997; Ruddick, 1995). However, when caregivers are led to believe that dying at home is a measure of success, and dying in hospital, a measure of failure, there is a risk that they will think they have failed their loved one when they cannot cope with the demands of home caregiving. Coyle argues that when patients and families are unsupported in the home setting, the dying period can seem unending. As such, "a rapid death becomes the hoped-for goal, while quality-of-life until death and the

ability to get pleasure from a moment or a day is lost. What could have been a life-fulfilling experience becomes instead a life-draining one" (p. 41). Sankar (1993) contends that our current impressions of dying at home are constructed upon romantic notions of the past where the dying were surrounded by loyal family members who had ample time to devote to caregiving. Sankar argues that technological and social changes, however, have influenced the dying at home experience and have resulted in outdated images. These images raise false expectations and inappropriate assumptions about what is involved in caregiving. Thus, despite all of the best of intentions, dying at home is not always ideal (Arras & Neveloff-Dubler, 1995).

Transformations of the Home

Ethicists argue that the home environment is often transformed when the provision of care is shifted from the institution to the home. Physical changes to the home in order to accommodate caregiving can transform what was once a restful and comforting environment into one that is confining and repugnant (Kapp, 1995; Ruddick, 1995). Collopy, Dubler, and Zuckerman (1990) claim that it is tempting to assume that the home provides families with greater control to self determine than do hospitals, but this is not always the case. Multiple care providers coming into the home and complicated technological mechanisms to support symptom management at home[13] can exert a significant cost in terms of important social values associated

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[13] These examples (i.e., multiplicity of health care personnel and complicated technological procedures) are used to illustrate how home life can be influenced when one makes a decision to provide at-home palliative care. I do, however, acknowledge that there may be other examples that could also influence home and family life.

with the home environment. Arras and Neveloff-Dubler (1995) question how

someone can truly be "at home" with the extension of health care provision into the

private sphere of patients and families. As they point out:

> Dying at home may be initially attractive in an abstract fashion to both
> patients and family members, but the reality is rarely benign. Agonal
> breathing, incontinence of urine and feces, and fear of impending death are
> facts about the dying process that have been largely hidden from Americans
> in an era when 80 percent of people die in hospitals and nursing homes (p.
> 3).

Some authors have expressed concern over the extension of medical care into the

home, warning that hypermedicalization[14] can seriously influence family systems

(Arras & Neveloff-Dubler; Di Mola, 1997). These authors also caution that the dying-

at-home experience has the potential to become bureaucratized[15], falling into all of

the medical trappings of a hospital-based system.

<u>Choice in Dying and in Caregiving</u>

Another ethical issue that arises is whether or not people truly have a choice;

choice for the patient in terms of where they die and choice for the family member in

terms of whether they become caregivers. In a theoretical paper, Dudgeon and

Kristjanson (1995) raise some key questions regarding the realization of one's

preference for dying at home. On the basis of findings from a study conducted by

McWhinney and colleagues (1995), the authors argue that the financial resources

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[14] "Hypermedicalization" is a term used to denote the extension of medical care into the private
sphere of family and friends (Arras & Neveloff-Dubler, 1995). In the mid-1970s social critic Ivan Illich
(1976) warned of the dangers of "social iatrogenesis" or an inability to cope with our surroundings
engendered in part by the medicalization of everyday life. More broadly, Sawicki (1991) explains that
the term "medicalization" usually "implies the negative phenomenon of reducing political, personal
and social issues to medical problems thereby giving scientific experts the power to 'solve' them
within the constraints of medical practice" (p. 119).

[15] James and Field (1992) offer a provocative discussion about the routinization and bureaucratization
of hospice and palliative care suggesting that the hospice movement may be in danger of being
unable to sustain its founding ideals.

required to support dying at home may influence whether or not people actually have a choice in where they die. Others suggest that having a choice in where one dies is more illusory than real. Arras and Neveloff-Dubler (1995) emphasize that there may not actually be a "choice" when considering care options. They suggest that there is no choice between an often highly regimented, rule-based institutional system versus the fragile, yet comfortable home environment. Patients and families invariably select the most appealing option (i.e., the home) because the alternative looks so bad.

Some authors have hypothesized that the choice to become a caregiver is often not a choice per se but, rather, an obligation particularly if the caregiver is a woman. With the exception of husbands caring for their terminally ill wives or an increasing number of gay men caring for their partners, numerous research studies support the belief that the majority of caregiving work is provided by women (Aronson, 1992; Bunting, 1992; Graham, 1985; Rutman, 1996; Wuest, 2000). Furthermore, notwithstanding the fact that many women value their caregiving roles and may come to regard them as opportunities for reciprocity and gratitude, ethicists have argued that "our rosy picture of 'home' is often parasitic on widespread but socially unjust roles for women caretakers" (Arras & Neveloff-Dubler, 1995, p. 8). Some women may have to forsake opportunities for professional or personal satisfaction outside of the home or abandon opportunities for employment in order to provide care in the home and may come to see their lives reduced to little more than a maid (Tedlock, 1995).

The ethical arguments presented here uncover some of the contextual issues that may influence the home caregiving experience. With few exceptions, these arguments have not been supported by research but have stayed within the realm of theoretical and philosophical discussion. Studies focusing on the contextual factors that may influence dying at home are noticeably absent in palliative care discourse and represent a knowledge gap in the area of home care for the dying. In other words, while the arguments provide context and substance to the discourse on home care for the dying, few scientific studies examine this topic.

Dying at Home

The ethical arguments, together with a review of the caregiver burden literature, depict a rather dismal existence for family members who provide palliative care at home. However, many research studies have documented the benefits to family members who are also caregivers. Current evidence verifies that some family members prefer home-based palliative care to care provided in an institution, particularly if adequate health services are in place to support them. In this section, I will review what is known about dying at home. To begin, I summarize the reasonably limited epidemiological data on dying in Canada. I then provide a synopsis of the demographic characteristics of those dying at home and highlight research and review articles that detail the factors that influence the location of dying. In concluding this section, I offer a critique of the research on preferences for location of death, including a review of why the home is often the preferred location for palliative care.

Dying in Canada

It is estimated that over 220,000 Canadians die each year (Senate of

Canada, 2000). Although some studies indicate that people generally prefer to die

at home, very little is known about where people actually die[16]. In an effort to

understand the epidemiology of dying in Canada, Heyland, Lavery, Tranmer, Shortt,

and Taylor (2000) conducted a cross-sectional analysis of death records in 1997.

The primary purpose of the study was to determine the proportion of all deaths in

Canada that occurred in hospitals. Data were obtained from provincial registries of

vital statistics and from the Canadian Institute for Health Information (CIHI).

Provincial death records were compared and then these data were aggregated to

determine the proportion of total deaths[17]. Of the 201,892 deaths that were reported

by the provincial registries in 1997, 73% occurred in a hospital. Hospital deaths for

each province were also reported with Quebec having the highest proportion[18] (87%)

and the Northwest Territories having the lowest (52%). The province of British

Columbia (B.C.) had a relatively high proportion of hospital deaths (78%) in

comparison to other provinces where the average was approximately 67%. The

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[16] Researchers in the U.S. and the United Kingdom (U.K.) have conducted epidemiological studies on this topic. Findings indicate that most Americans die in either hospitals or long-term care facilities, and studies from the U.K. show similar results (Sager, Easterling, Kindig, & Anderson, 1989; Seale & Cartwright, 1994). Studies focusing on where Canadians die are virtually non-existent in the literature, despite the relevance that this kind of information has for guiding palliative care practice, and for the development and evaluation of evolving health policy in this area.

[17] Each provincial government is required to maintain a registry of death statistics under the federal Vital Statistics Act. In most provinces, hospitals are included in recording location of death with the exception of Newfoundland and Manitoba where hospital-based deaths are not specified in their provincial totals. Therefore, data from Newfoundland and Manitoba were excluded from the analysis in the study (Heyland, et al., 2000). Moreover, hospitals do not include nursing homes, homes for the aged, or hospices, except in Quebec. Consequently, not all institution-based deaths are captured in the analysis, but only those related to acute care hospital deaths.

[18] The higher proportion of hospital deaths recorded in Quebec is due to the fact that the researchers were unable to disaggregate the data so that nursing homes, homes for the aged, or hospices were included in the overall provincial analysis.

study was descriptive in nature and the authors offered little explanation as to why the proportions might differ among provinces.

Heyland and colleagues (2000) theorize that health-system factors such as the availability of hospital and nursing home beds, and not patient preferences or patient characteristics, may be a strong determinant of the location of death,[19] although these factors were not examined in the study. Clearly, there is a need to gain a better understanding of why hospitals function as the major providers of end-of-life care in Canada. There is also a pressing need to determine the circumstances that may inhibit home-based palliative care. The researchers concluded by posing a number of questions that have not been examined within the Canadian context. They suggest that investigations are needed to understand the factors that influence the provision of home-based palliative care and to help explain why 73% of Canadians currently die in hospital.

I was unable to find any data that provide accurate estimates on the total number of Canadians who die at home. While death record data is available from provincial registries of vital statistics and from the CIHI, to my knowledge, they have not been subjected to any systematic analysis. Many palliative care programs across the country keep their own records that document location of death. However, they typically only capture this data on patients who are registered with the program. Some provincial home care programs or regional palliative care services keep this type of data, but this practice varies by province and the accuracy of such

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[19] A study reported on in the Medical Tribune, a medical news source for the New York Times Syndicate, also suggests that the location of death is more strongly influenced by the number of hospital beds in a community than by the patient's previously expressed wishes (Christensen, 1998).

information is dependent on how data systems are organized and how the data is entered.

Only a few Canadian studies could be found that document the proportion of people dying at home in their local health authorities. In 1992, Lubin conducted a retrospective study using the charts of 96 patients admitted to a palliative care service in B.C. These patients were followed until death and the location of death was recorded. Only five percent of patients in the study died in their own homes. Subsequent studies have shown that the number of people dying at home may be increasing. A retrospective chart review of patients referred to the palliative home care support team in London, Ontario showed that 28% of all patients on the program died at home (McWhinney, Bass, & Orr, 1995) and 68.3% of patients were able to die at home with support from a palliative care at-home team in Scarborough, Ontario (Gardner-Nix, et al., 1995). Variations in the number of people dying at home may be attributed to the type and level of health care services that are available in the particular community where palliative care is occurring. These variations were recently described from an international perspective (Grande, Addington-Hall, Todd, 1998). Despite this, Canadian researchers contend that local studies must be carried out to better understand the characteristics and circumstances that influence home care for the dying (Fainsinger, Demoissac, Cole, Mead-Wood, & Lee, 2000). In this way, solutions that account for the Canadian context can be derived in order to improve the care provided to patients and their family members in palliative care.

The Demography of Dying at Home

Many research studies that focus on the provision of palliative home care record demographic characteristics of patients to describe those people who are most likely to receive palliative care in the home setting or die at home[20]. Relatively few studies focus purely on sociodemographic characteristics but more frequently report on age, gender, diagnosis, and social class as part of a larger research project. I will not be providing a detailed analysis of what has been reported on within all of these studies but, rather, will offer a summary of what is known about the demography of dying at home.

Most studies have found that younger people die at home more frequently than the elderly[21] (Higginson, Astin, & Dolan, 1998; Hunt, Roder, & MacHarper, 1989; Karlsen & Addington-Hall, 1998; Moinpour & Polissar, 1989; Seale & Cartwright, 1994). However, multivariate analysis from a population-based study of 12,343 cancer deaths in Italy from 1986 to 1990 demonstrated that the probability of home death increased with advancing age (Costantini, et al., 1993). In contrast, a correlation study by Axelsson and Christensen (1996) found no effect of age on location of death, although the number of home deaths in their sample was small (n=24).

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[20] Several researchers have investigated place of death for both cancer and non-cancer patients and have reported on their demographic characteristics. Seale (1991b) notes that cancer patients differ from patients in other disease groupings: they tend to die younger and have more social supports; mental confusion and long term disability are less common; and, the incidence, duration, intensity, and type of symptoms follow a different trajectory. Christakis and Esarce (1996) report that those most likely to die at home have cancer. Because the demographic variables related to place of death might be different to those of the rest of the population, I have only reviewed literature pertaining to cancer patients.

[21] With few exceptions, age demarcations are not often reported in these studies. Thus, how the researchers define "younger" patients and the "elderly" is not always clear.

Some of the research literature suggests that males are more likely to receive palliative home care, or die at home than their female counterparts (Higginson, et al., 1998; Hunt, et al., 1989; Seale & Cartwright, 1994). Yet, other evidence indicates that a higher proportion of women die at home (Costantini, et al., 1993; Gilbar & Steiner, 1996). And like age, some studies suggest that gender is not significantly associated with dying at home (Axelsson & Christensen, 1996). In a comprehensive literature review investigating the relationship between patient characteristics and home deaths, Grande, et al. (1998) suggest that the variation in study findings related to age and gender are likely related to the cultural and family context in which patients live. These authors advise that further research is needed to better understand these contexts and how they may influence the provision of palliative care at home.

Studies with cancer patients suggest that the type of cancer is associated with whether or not the provision of palliative care or death occurs at home. Genitourinary and gastrointestinal cancers have been shown to be more strongly associated with dying at home (Costantini, et al, 1993; Johnson & Oliver, 1991; McCusker, 1983) than have haematological cancers, head and neck cancers, or lung cancers (Costantini, et al.; McCuster; Polissar, Severson, & Brown, 1987). These deviations have been attributed to the specific treatments and symptoms that result from different types of cancer. Axelsson and Christensen (1996) did not find that the place of dying was associated with a specific type of cancer diagnosis but, again, the sample size for home-based patients in this study was small and thus, the findings should be viewed with caution.

Studies investigating the relationship between socioeconomic status, education levels, and home-based palliative care have shown that cancer patients who have higher education or who live in higher socioeconomic neighborhoods are most likely to die at home (Costantini, et al, 1993; Gilbar & Steiner, 1996; Seale, Addington-Hall, & McCarthy, 1997). Contrariwise, data from a study analyzing the place of death for 820 cancer patients in a British health authority reported significant variations in the place of death according to social class (Sims, Radford, Doran, & Page, 1997). The study examined data that were categorized according to occupation and found that those in skilled and semi-skilled occupations were more likely to die at home than those in professional, managerial, and technical occupations. Even though these findings show that people with skilled and semi-skilled occupations are more likely to die at home, this group made up more than half of the sample population. Therefore, the authors' conclusion that people of lower socioeconomic status are more likely to die at home may have had more to do with the sample size of those employed in skilled and semi-skilled occupations than with providing an accurate representation of the entire sample. The authors' postulated that the variations in the place of death according to social class may be influenced by access to services and the availability of social support within different sections of the health authority.

Despite the fact that researchers report significant variations in age, gender, diagnoses, and socioeconomic status, this information helps to describe those people who are more likely to receive palliative care in the home setting. With few exceptions, studies on the demography of dying, however, do not account for

possible contextual factors that might influence why some patients receive home

palliative care over others. Most of the researchers theorize about what these

influences might be, but do not include these variables in their analyses. Some of

the work that has been done to delineate the factors influencing the location of dying

provides some context to the home-based palliative care experience.

Factors Influencing the Location of Dying

Regardless of where palliative care is provided, dying Canadians and their

family members have identified several outcomes that they associate with quality

end-of-life care: (a) adequate pain and symptom control; (b) avoiding inappropriate

prolongation of dying; (c) achieving a sense of control; (d) relieving the burden of

others; and, (e) strengthening relationships with loved ones (Singer, Martin, &

Kelner, 1999). Providing quality end-of-life care, particularly in the home setting, is a

challenging undertaking (Cantwell, Turco, Brenneis, Hanson, Neumann, & Bruera,

2000). A review of the literature suggests that there are a number of conditions that

need to be in place to effectively support dying at home. These include:

1. A desire on the part of the patient to be cared for at home (Beck-Friis &

   Strang, 1993; McCorkle, 1988; Stajduhar & Davies, 1998b);

2. A desire on the part of the caregiver to provide care at home (Beck-Friis &

   Strang; DeConno, et al., 1996);

3. The availability of skilled medical support on a 24-hour basis (Beck-Friis &

   Strang; DeConno, et al; McCorkle);

4. The availability of more than one caregiver, especially if the primary caregiver

   is elderly and the patient has been sick for several weeks or months (Beck-

Friis & Strang; Thorpe, 1993; Dudgeon & Kristjanson, 1995; Wilson, 2000); and,

5. Having the financial resources to allow caregiving to take place at home (Dudgeon & Kristjanson; Thorpe).

Based on these factors, a group of Canadian researchers conducted a prospective study to describe the relative role of these factors in predicting home death in a cohort of palliative care patients with advanced cancer (Cantwell, et al., 2000). The investigators developed a five-item questionnaire with sub-sections and pilot-tested it with 10 patients, making only minor revisions. Ninety questionnaires were administered by trained home care coordinators and a follow-up questionnaire was carried out to record place of death. Data were analyzed using multivariate techniques. The desire for a home death by both the patient and the caregiver, support of a family physician, and the presence of more than one caregiver were all found to be significantly associated with a home death. Logistic regression analysis identified the desire for a home death by both the patient and family caregiver as the main predictive factor for a home death. While the study signifies one of the first attempts to prospectively examine the factors that need to be in place for a successful home death, the authors acknowledge that there are some limitations. The questionnaire concepts were not well defined. Because of this, some of the caregivers that participated in the study were family members who visited the patient but who were not necessarily the primary care provider at home. Furthermore, some evidence suggests that patients and family caregivers change their minds about their desire for receiving palliative care at home or for a home death (Hinton,

1994a). Accordingly, making predictions based on a one-time response may not provide an entirely accurate picture of the factors that predict home death. Longitudinal studies are required, particularly with caregivers, to determine if their perspectives change over time.

Functional Status

Research reports have indicated that there are other circumstances that influence the ability to care for a dying person at home. In a grounded theory study of 23 families (71 family members), Davies and colleagues (1995) found that the patient's physical condition determined whether home-based caregiving was feasible. Findings suggest that family caregivers were concerned about their ability to manage bed-bound and/or incontinent patients. These findings are supported by research that confirms that patients are more likely to be admitted to, or maintained on, an acute care hospital ward if they have significant functional disability (Fainsinger, et al., 2000). An examination of the discharge characteristics of palliative care patients in an acute care hospital found that patients with better functional ability, as measured on the Karnofsky Performance Status Scale and the Palliative Performance Scale, were far more likely to return home than those with significant functional losses (Fainsinger, et al.). Similarly, a report by Karlsen and Addington-Hall (1998) on a survey of 229 cancer deaths in London, England concluded that high levels of dependence inhibited the likelihood of patients dying at home. A person's impaired functional status has also been linked to reduced quality of life in home hospice family caregivers (Weitzner, McMillan, & Jacobson, 1999).

Symptom Management

Managing pain and other symptoms, often with complicated technological devices, also produces considerable distress for family caregivers and can discourage home care for the dying (Davies, et al., 1995). Lubin's (1992) study, aimed at identifying some of the obstacles to home care, showed that pain, weakness, and shortness of breath were three of the top five reasons why people were admitted from home to hospital for palliative care. Beck-Friis and Strang (1993) also suggest that symptoms must be controlled in order for terminal home care to be satisfactorily achieved; however, this conclusion is not supported by their research findings. Participants in a study aimed at describing the components of a "good death" said that the proper management of pain and other symptoms was important (Steinhauser, Clipp, McNeilly, Christakis, McIntyre, & Tulsky, 2000). The study sample, however, was drawn primarily from in-patient settings and the findings derived mostly from health care providers' perspectives. In a comparative study examining perceptions of the good death, Payne, Langley-Evans, and Hillier (1996) discovered that patients and health care providers often differ in their conceptualizations of a good death. Therefore, study findings based on the perceptions of health care providers should be viewed with caution when applying them to patient and family situations.

Access to Palliative Care Services

Some studies also found that people who are more likely to spend their final days at home are supported by palliative care services (Brown, Davies, & Martens, 1990; Grande, et al., 1998). For example, Costantini, et al. (1993) found that the

proportion of cancer deaths at home were twice as frequent among users of palliative care home services (60.8%) than among nonusers (29.3%). Interviews with 80 caregivers following the death of a family member from cancer revealed that 90% of those dying at home had contact with home care nurses (HCNs) and 52% with palliative care specialist nurses (Addington-Hall, et al., 1991). Evaluative studies have also indicated that specialized home care services for the dying can promote home death. In an evaluation of a newly created community-based hospice rapid-response service, 82% of all referred patients were able to die at home (King, Mackenzie, Smith, & Clark, 2000). However, the study sample size was small (n=17) and no comparisons were provided. Therefore, it is difficult to ascertain whether this high proportion of home deaths was related to service implementation or other factors.

Bruera and associates (1999) conducted a retrospective study comparing the pattern of care and site of deaths before establishment of a regional palliative care program in Edmonton and during its second year of operation. Post hoc comparisons showed that significantly more cancer-related deaths occurred in acute care hospitals prior to program implementation (86% versus 49%). However, this does not mean that dying was occurring at home. On careful examination, study findings demonstrated that increased numbers of patients were dying in in-patient hospices and that the percentage of patients dying at home had increased only 10% after initiation of the regional palliative care program. Similarly, a randomized control trial was conducted in the U.K. to determine if "hospital at home"[22] facilitated dying at

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[22] In the U.K., hospital at home was a program set up with the aim of improving the provision of care for terminally ill patients (particularly at night) and to increase their choice of place of care. Hospital at

home (Grande, Todd, Barclay, & Farquhar, 1999). Patients were randomized to a control group (offering standard care) and to a hospital at home group. The study did not find that hospital at home significantly increased the number of people dying at home. The researchers suggest that this might be because the study was conducted in a locality with a good provision of standard community-based palliative care.

Hinton (1994a) conducted a prospective study to examine whether home care sufficiently addressed the comfort needs and adjustment of cancer patients and their caregiving relatives. A random sample of 77 adults and their relatives participated in the study with the ultimate aim of determining the success of home-based palliative care. Semi-structured interviews were administered with patients and relatives, each week over an eight-week period, and the Spritzer Quality of Life Index and several linear analogue scales were used to determine quality of life. Study findings indicated that community palliative care services can sufficiently meet the needs of patients and their caregiving relatives. However, they also suggest that perceptions about home care change over time as the patient's disease progresses. As patients become weaker and more debilitated, hospital care is favoured, particularly by family caregivers. The author concludes that, while home care services do much to enhance the comfort and adjustment of patients and their relatives, it should be complemented with inpatient care.

Hinton's (1994b) follow-up study, examining cancer patients who are admitted to a hospice unit from home, concludes with an interesting discussion about the

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home was available for terminal patients with any diagnosis whose prognosis was less than two weeks (Grande, et al., 1999).

feasibility of dying at home. The researcher asks whether there are practical limits to the amount of palliative care that can be provided in the home. These questions are raised because several caregivers in this study disclosed that they had considerable misgivings about home-based palliative care. Based on this research, the author argues that patients will likely continue to require inpatient care at several points throughout their disease trajectory unless full-time home nursing care is provided.

The studies presented here indicate that access to home-based palliative care services may be an important component of facilitating the dying-at-home experience but it is unclear whether they increase the proportion of people who are able to die at home. A systematic literature review that synthesized 83 research papers on patient and caregiver preference for, and satisfaction with, specialized models of palliative care revealed that patients and caregivers were more satisfied with all types of palliative care, regardless of where it occurred (e.g., hospice or home) (Wilkinson, et al., 1999). At the same time, the reviewers argued that the evidence is too patchy to determine whether any particular model of care is preferred over the other and whether this has any influence on the location of dying. Furthermore, with the exception of Hinton's work (1994a; 1994b), very few of the studies detailed here took into account how family situations or the context of dying at home might influence the location of dying. Clearly, further research is required in this area to determine those factors that might influence the provision of palliative care at home, and to better understand how access to palliative care services may or may not enhance the ability for people to die at home.

The Nature of Support[23]

The nature of support provided to patients and family caregivers has also been found to be a factor that can influence the location of dying and the experience of family members providing end-of-life care at home. Many authors claim that having a team of skilled palliative care professionals can facilitate access to a range of services that are required to support home-based palliative care (Gomas, 1993; Mount, 1997; Roe, 1992). While these claims are not always supported by research findings, it is generally accepted that committed and skilled family physicians, HCNs, home support workers (HSWs), counsellors, and palliative care volunteers are essential to supporting family members (McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998; Moore, 1993; Wight, LeBlanc, & Aneshensel, 1995). Studies have found, for instance, that access to specialized nursing services can maintain dying people in their homes and significantly reduce psychological distress in caregivers (McCorkle, et al.). Maintaining contact, and providing explanations and support to caregivers, are reported to help as often as do physical treatments and practical nursing tasks in maintaining people at home (Hinton, 1996).

Although patients and family caregivers access support from a variety of sources, research has demonstrated that the nature of support received can be problematic and can seriously inhibit caregivers' abilities to provide care at home. In a grounded theory study of family members providing home care to people with AIDS, Stajduhar (1995) found that the nature of support received greatly influenced

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[23] Support is a concept that has been used loosely in health care literature to denote the existence, quantity, and type of interpersonal relationships (Norbeck, Lindsey, & Carrieri, 1981), the functional context of these relationships (Kahn, 1979), and the perceived quality of this support (Weiss, cited in Dimond & Jones, 1983). For my purposes here, I am using the term "support" in its broadest sense.

the caregiving experience. When caregivers received "good" support, they were better able to cope with their caregiving demands and feel a sense of personal worth in their role; they were able to carry on with their caregiving irrespective of the demands placed on them. But, when the nature of support provided by health care providers was unfavourable, caregivers felt isolated, angry, and disillusioned; they were more likely to have difficulties with caregiving at home. Similar studies have found that family members generate a passionate disrespect for the health care community when they are unsatisfied with the support they receive (Geis, Fuller, & Rush, 1986; Grief & Porembski, 1988). These unsupportive experiences have been linked to prolonged grief reactions following the death of a loved one (Broadhead, et al., 1983; Vachon, Sheldon, Lancee, Lyall, Rogers, & Freeman, 1982).

It is not only family caregivers who have spoken of the difficulties that result from a lack of good support. In a study investigating the attitudes of 151 physicians and nurses towards cancer patients dying at home, Porta, Busquet and Jariod (1997) discovered that despite high motivation, physicians and nurses reported widespread frustration with the quality of care provided to terminally ill cancer patients. While the majority of participants reported "the system" as the main cause of frustration, they indicated that there are few appropriately skilled health care professionals in palliative care to support patients and family caregivers. Other studies are just beginning to reveal that families may be reluctant to access formal community-based health care services, due in part to the unsupportive nature of the services (Davis, et al., 1996; Grande, Todd, Barclay, & Doyle, 1996). However,

none of these studies provides detailed explanations of the context that might lead to unfavorable support.

Family Caregiver Needs

Research studies, systematic literature reviews, and case reports on the needs of family caregivers -- particularly those that address patient and caregiver needs during the cancer illness experience -- are abundant (Hampe, 1975; Hileman & Lackey, 1990; Hinds, 1985; Meissner, Anderson, & Odenkirchen, 1990; Steele & Fitch, 1996; Wingate & Lackey, 1989; Wright & Dyck, 1984). Some studies focus on the needs of patients and their family members in hospital settings, whereas others are directed at determining home care needs. The literature in this area is extensive and, while it is not my intent here to review the plethora of needs-based studies, I will provide a short synthesis of the studies focused on home care needs[24].

Almost two decades ago, Grobe and colleagues (1982) concluded that family members might have more needs that those who are dying. Caregiver needs have tended to be categorized in the literature as physical, psychosocial, and informational (Edlund, 1995). In an early study centered on the needs of families who care for patients with cancer at home, Hinds (1985) found that as many as 31% of all caregivers had difficulties coping with physical care, especially giving treatments and managing symptoms such as nausea and pain. Five years later, Brown and her colleagues (1990) found similar results in a qualitative study with family members who revealed the need for support services, such as personal care,

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[24] It is important to understand the needs of home caregivers in palliative care. Studies have demonstrated that unmet caregiver needs might influence whether dying at home is a realistic option (Beck-Friis & Strang, 1993).

respite, and homemaking. These supports were especially important when there was only one caregiver in the home. Respondents emphasized the need for skilled health care providers to support symptom control and a need to learn practical caregiving skills. Later studies (e.g., Grande, et al., 1997; Silveira & Winstead-Fry, 1997; Steele & Fitch, 1996; Wyatt, et al., 1999) do not differ remarkably from these earlier findings, although Grande and colleagues found that the caregivers' need for assistance is sometimes in conflict with the patients' need to preserve independence. They recommended that caregivers' needs should be studied separately from patients' needs so that caregiver perspectives can be better understood with the aim of developing caregiver-focused interventions.

Home caregivers also have a number of psychosocial needs and some studies have found that they are more important than both physical and informational needs (Hileman & Lackey, 1990; Wingate & Lackey, 1989). Wright and Dyck (1984) reported that caregivers need encouragement and assurance that they are doing a good job keeping their loved one comfortable; for many, this is a top priority (Cherney, Coyle, & Foley, 1994; Ferrell, Ferrell, Rhiner, & Grant, 1991; McGinnis, 1986; Stajduhar, 1995). Lev (1991) maintains that unless the comfort needs of patients are managed, family members will often neglect their own concerns. Yet, in a descriptive study of 20 family members providing care at home to cancer patients, Steele and Fitch (1996) found that caregivers reported the need to have time away for oneself as one of their most frequent needs. Communicating with patients and having an awareness of the dying process has also been found to be important for caregivers (Seale, 1991a), as has the need to develop trusting and

cooperative relationships with home health care providers (Andershed & Ternestedt, 1998; Cherney, Coyle, & Foley, 1994; Kristjanson, 1989; Wright & Dyck).

The need for information is also an important component in facilitating the dying-at-home process. Lewandowski and Jones (1988) found that in the home setting, six of the 11 highest ranked nursing interventions involved nurses giving information to family members. Indeed, some studies have indicated that the more that family members understand the patient's care, the more satisfied they are with the care (Medigovich, Porock, Kirstjanson, & Smith, 1999). Conley and Burman (1997) conducted a qualitative study to determine the informational needs of home-based caregivers. Fourteen family members were interviewed and transcript data were subjected to constant comparative analysis. While the majority of caregivers indicated that they were satisfied with the information available to them, they often had difficulty in articulating what type of information was most needed. On careful examination, the researchers discovered that information on the disease process and on health care services that were available to them were most important in supporting home-based caregivers. Although caregivers in the study were vigilant about accessing information, the information was not always provided in a way that was most helpful. The authors recommended that written information must be reinforced with informal discussions. Steele and Fitch (1996) postulate that the complexity of health care systems may make it difficult for family caregivers to understand the services that are available, and suggest that information must be provided in a variety of ways to support them at home. Systems such as the U.S. Cancer Information Service have proved to be particularly helpful for caregivers,

although further research is required to determine the best ways to meet the informational needs of caregivers (Meissner, Anderson, & Odenkirchen, 1990).

Preferences for Place of Dying and Death

Dying at home is considered ideal when defining a good death (McNeil, 1998). In fact, with few exceptions, it is difficult to find any author who challenges this assumption. Some authors base their beliefs on their own personal experiences (Collett, 1997; Duda, 1987) while others draw on their professional knowledge of caring for patients with life-threatening illnesses (Bowling, 1983; Gomas, 1993; Moore, 1993; Thorpe, 1993). Health professionals who write about this topic invariably maintain that "death like birth, is a family affair" and should occur in the home, given that there is adequate support (Bowling, p. 158). Providing palliative care at home embraces what Gomas says "is most noble in medicine: sometimes curing, always relieving, supporting right to the end!" (p. 45).

Research reports suggest that, in general, people would prefer to die at home (Dunlop, Davies, & Hockley, 1989; Gilbar & Steiner, 1996; Townsend, et al., 1990), and this preference is often supported by physicians and nurses (Cartwright, 1991; McWhinney & Stewart, 1994; Seamark, et al., 1995). In one of the first studies that looked at patient preferences for location of dying, Dunlop and colleagues recorded the preferred place of death of 160 patients who were consecutively referred to a hospital palliative support team in the U.K. The information was recorded during routine interviews with patients when they were asked where they wanted to be cared for during the final stages of their illness. All of the interviews took place while patients were in hospital and did not include any in-depth discussion about the

reasons for patient preferences, but simply recorded the patient's response. Overall, 56% of the study participants expressed a preference for dying at home. However, the researchers were able only to record patient preference on 90 of the 160 participants. In addition, although they mention that family members were considered in the assessment, no details are provided about family perspectives.

In another prospective study of terminally ill cancer patients in the U.K., Townsend and others (1990) randomly sampled 84 patients to determine their preference for location of dying. A structured questionnaire was used and patients were asked where they would like to be if their disease progressed. Interviews took place more than once to assess changes in patient preferences. Of the 84 patients who were initially interviewed, 58% expressed a wish to be at home, 20% wished to be in hospital, 20% at a hospice, and 2% elsewhere. At the time of the final interview, 49% of patients wished to be at home and the remainder, either in hospital or hospice. The researchers also interviewed 30 caregivers three months after the death of their relative. Of the 11 whose relatives had died at home, seven were satisfied; three accepted the patient's wish to die at home although they thought they would have been better in hospital; and one would have preferred hospital but there had been no time to arrange for admission. Based on these findings, the researchers conclude that patients and their caregivers prefer palliative care to be provided at home. However, both this study and the study conducted by Dunlop and colleagues (1989) suffer from small sample sizes making it difficult to generalize patient preferences to other countries or patient populations.

Gilbar and Steiner's (1996) study of terminally ill cancer patients in Israel also concluded that the majority of patients (88.4%) preferred palliative care to be provided at home. Demographic, medical, and psychosocial variables gathered from 171 patient files were included in a multiple classification analysis. The data were collected throughout the period of illness and during interviews with family caregivers. The study reports on a number of factors that may influence the location of dying, factors which have been previously reviewed. While the study found that a large percentage of patients would prefer to remain at home for the last part of life, there were differences in patient and family preferences. Demographic variables were found to have the strongest association with patient preference, whereas family support systems were strongly associated with caregiver preference. Although no percentages were reported for caregiver preferences, when asked, they stated that they only wanted to fulfil the patient's wishes, even if these wishes did not always conform to their own. The researchers explain that these differences were likely due to the timing of the interviews and to the fact that patient preference data were collected by family caregivers who did the interviewing. The study report is somewhat confusing, however, as the conclusions reached by the researchers are not always supported by the data presented. Furthermore, having family members interview their dying relatives may have substantially biased the results and, thus, the results should be viewed cautiously.

Acknowledging that the family unit is affected by the need for palliative care in one family member, Brown, Davies, and Martens (1990) conducted a qualitative study to find out from both family members and patients with advanced cancer which

location of care (i.e., home or hospital) they preferred and why. This Canadian study focused on the preferred place of care rather than the preferred place of death. Content analysis of in-depth interviews with eight families (24 members) revealed that patients and their families preferred care at home over care in the hospital or care in an institution, such as a nursing home. Moore (1993) also suggests that patients and their family members preferred home care to care in an institution; however, her contention is not supported by research findings.

Other Canadian studies have focused on preferences for location of dying. McWhinney, Bass, and Orr (1995) conducted a retrospective case-control chart review on 150 patients referred to a home palliative care support program (75 patients who had died at home and 75 who had died in hospital). Of the 150 patient records that were reviewed, about 38% of patients expressed a strong preference for dying at home and 16% expressed a preference for dying at home conditional on the family's ability to cope. Conversely, an earlier study with 125 patients admitted to a palliative care unit pointed out that 90% of patients did not want to die at home (Bruera, Kuehn, Emery, MacMillan, & Hanson, 1990), citing a lack of family support and home care services. The patients in this study also had severe medical problems that were being treated in an acute care setting and this may have influenced their perspectives.

Although both of the preceding studies allude to the importance of the family's perspective, inclusion of family members' preferences were not included in these studies. However, as Keizer, Kozak, and Scott (1992) found, patients and their caregivers often vary in their preferences for location of palliative care. They

conducted a retrospective study involving 45 randomly selected family caregivers who were known to the regional palliative care unit in Ottawa. Caregivers were interviewed up to 12 months following the death of a loved one and were asked about preferences for location of dying. Unexpectedly, the large majority (80%) of caregivers believed that inpatient palliative care offered the best quality of life and death, even for those patients who had resisted admission to the palliative care setting. Only 16% reported that the home was the preferred location for palliative care to occur and four percent indicated acute care as the preferred location.

Many researchers and practitioners who write about the topic of home care for the dying state that most patients and their family members, if given a choice, would prefer that dying take place at home. These statements are surprising given that the research evidence in this area is both inconclusive and conflicting. Yet, many authors theorize or have found in research studies that there are specific benefits to patients and family members when palliative care is provided in the home setting. Most common is the belief that dying at home enhances the overall quality of life afforded the terminally ill and their family members (Roe, 1992). It is widely held, for example, that dying at home facilitates a sense of normalcy, providing comfort, security, intimacy, and familiarity to those coming to the end-of-life (Duda, 1987; Fraser, 1990). Research findings suggest that it promotes a sense of freedom and control that is not accorded in an institutional setting (Davies, et al., 1995). Being in the home environment also helps to sustain relationships with family and friends and contributes to reciprocity between the ill person and family members (Brown, et al., 1990).

Widespread criticisms of institutional-based care have also been linked to the belief that dying at home is preferable to dying in an institution. While attitudes toward death and dying among health care providers have changed considerably over the past 20 years, some authors contend that current hospital systems and those who work in them continue to value life above living productively (Cowley, et al., 1992; Gomas, 1993). As such, the predominant influence of biomedicine, with its focus on intervention and control of disease, has served to limit attention to the personal needs of the dying. Other less tangible needs (e.g., social, psychological, and spiritual) that are important to providing effective palliative care are often ignored in the hospital setting (Field & James, 1993). Even when attention to physical problems is required, the level of skill needed to control the symptoms associated with a terminal illness varies among general hospital staff (Ferrell, Eberts, McCaffery, & Grant, 1991; Hamilton & Edgar, 1992). Communication between disciplines and among patients, family members, and health care providers is also fraught with difficulties in the hospital system (Seale, 1991b). In a study of people dying from cancer and their family members, more than 50% of caregivers reported dissatisfaction with hospital care citing that health care providers were too busy to attend to the needs of the dying (Addington-Hall, Macdonald, Anderson, & Freeling, 1991). A comparative study of hospice and hospital care for people who die found that hospitals still have a long way to go in improving communications skills and the psychosocial climate, in spite of the provision of palliative care support teams in all of the hospitals in the study (Seale & Kelly, 1997). These difficulties

have led providers to advocate for better home care for the dying, as it may be better coordinated and inclusive of patients and family members (Moore, 1993).

There is little debate that dying at home can significantly contribute to the overall quality of life of patients and their family members. Although there are many good reasons why patients and their caregivers might prefer palliative care to occur at home, the research evidence suggests that this may not always be the case and that preferences can change over time. With few exceptions, the studies that have been presented on patient and family preferences suffer from methodological flaws or small sample sizes that make the findings difficult to generalize. Even then, these studies are often used as benchmarks for other authors who uphold and make assumptions that patients and families prefer palliative care to be provided in the home setting. Many of the studies that have been conducted focus primarily on patient preferences or do not detail family perspectives. Yet, as Dudgeon and Kristjanson (1995) argue, the family's perspective is clearly important given the interactive nature of decisions regarding place of palliative care. While a patient's preference for dying at home is undoubtedly important, this decision has implications for family members who will provide the majority of intense physical and emotional support. The assessment of preferences is not a simple matter. "Whose point of view should be included in the assessment? How should preferences by measured? When and how often should an assessment be conducted?" (Dudgeon & Kristjanson, p. 338). These questions point to the need for an in-depth investigation aimed at gaining a more complete picture of the home setting in which palliative care occurs. While ensuring patients' preferences and increasing the numbers of people

dying at home might be seen as a laudable aim, it is possible that this aim might be in conflict with another stated goal of palliative care: that of supporting families and improving bereavement outcomes for surviving family members (Addington-Hall & Karlsen, 2000).

Home-Based Palliative Care: Mapping Out the Macro Level Influences

By almost all indicators, the Canadian health care system functions impressively in relation to most western states (Evans, 1986). Yet, in Canada, there has been little move to implement the policy recommendations put forward in relation to home care in general, and palliative home care specifically (Scott, 1992). While a fundamental principle of palliative care is that the patient and family together comprise the unit of care (CPCA, 1995), the complexity of our health care system has greatly influenced and, at times, interfered with the ability to provide appropriate home-based palliative care (Scott; Stajduhar & Davies, 1998b; Wodinsky, 1992). One could argue that the issue of home-based palliative care is embedded within the larger contexts of Canadian health care reform, most notably the home care and self-care movements[25]. Indeed, in 1991, Anderson, Blue, and Lau argued that self-care was one of the most powerful ideologies underscoring the organization of health care delivery services, and this likely continues to be true today[26].

Provincial and federal governments expound the benefits of self-care and home care (Armstrong & Armstrong, 1996). This is often based on taken-for-granted

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[25] See Anderson (1990) for an excellent overview of the ideologies underpinning the home care and self-care movements.

[26] Policy advances are continuing to shift the context of care provision from hospital to ambulatory and community settings. Health care policy in Canada and B.C., for example, has established goals to increase self-care and to foster approaches that build upon principles of mutual aid and community support (Epp, 1986; Seaton, 1991).

assumptions that these movements are in the best interests of patients and family members, and are ultimately cost-effective[27] (Anderson, 1990; Fierlbeck, 1997). In writing about the status of home care for example, the Honourable Elizabeth Witmer (2000), Minister of Health and Long Term Care for the province of Ontario, stated that the increasing demands and pressures placed on the health care system are demands that can often best be met by delivering care in the home, both from an economic and humane point of view. Claims such as these, however, have been sharply challenged by researchers and health advocacy groups who claim that current home care proposals are aimed at off-loading responsibilities onto unpaid family members (Armstrong & Armstrong; Canadian Health Coalition, 1999). Bjorkman and Altenstetter (1997) suggest that one of the current aims of health care reform is to shift the burdens of health care financing from the public sector to private sources[28]. Rarely, however, are the outcomes of such actions considered. Furthermore, the factors involved in providing care in the home are frequently neglected when considering home care policy. In essence, the tension between what is occurring in health care reform, and what ought to be occurring, is what Storch (1996) calls a tension between the economics and ethics of care.

While I was unable to find any research that specifically addresses the influence that Canadian health care reforms have had on family caregivers providing palliative care, there are issues that should be considered in contexualizing the

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[27] The federal Liberal government has recognized the cost burden that home care may entail for family members who are caring for elderly or disabled loved ones by instituting a new caregiver tax credit. This tax credit came into effect in the 1998 fiscal year. The maximum personal amount of the claim is a $400 tax credit or a combined federal and provincial credit of about $600 per year for British Columbians.

[28] By this, I am referring to the shift in costs from the state to the individual or family and to the shift in public funds to the private for-profit system.

home care picture. One of the primary issues is the way in which home care is administered across the country. Currently, Canada has a patchwork of home care programs run by the provinces and territories. Typically, programs are community-based and administered by provincial health and/or social service departments or community/regional health boards. According to the Canadian Home Care Association (cited in Canadian Health Coalition, 1999), about 85% of home care is paid for by provincial governments with the remainder coming from user fees and third-party payers. As such, funding for home care takes up only a small part of Canada's overall health care budget.

Because financing for home health care is not an integral part of the Canadian Medicare system (i.e., not a part of the Canada Health Act), there are large variations in provincial home care programs. National standards for home care are nonexistent, meaning that the services provided, the methods of payment, and the criteria for eligibility vary widely from one jurisdiction to another and from one province to another. Consequently, home care plays a secondary and largely supportive role to the primary health care system. This model, however, has significant implications for families providing palliative care at home. As the provision of palliative care continues to expand to the home, there is no obligation on the part of the provinces to ensure that home health care services are provided in accordance with the principles of the Canada Health Act[29]. Armstrong and Armstrong (1996) argue that the provinces are more likely to respond to the lure of

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[29] I am implying here that the principles of the Canada Health Act (i.e., public administration, portability, accessibility, comprehensiveness, and universality), that are meant to ensure quality health care to all Canadians, are in jeopardy when programs such as home care are not part of a national health care strategy.

privatization to reduce fiscal responsibility. However, overlooking the potential

outcomes of privatization is dangerous (Baumgart, 1988). An extensive study of

Manitoba's home care program, for example, found that privatization resulted in

lower wages, increased staff turnover, and an inclination to reduce staff training in

order to maintain profit levels (Shapiro, 1996). These outcomes resulted in poorer

and sometimes detrimental quality of service to clients and their family members,

and did not produce substantial cost savings to the health care system.

Whether home care will result in substantial savings to the health care system

is a contentious issue (Arno, Bonuck, & Padgug, 1995; Whynes, 1997). Studies

conducted in the U.S. have demonstrated that home care leads to higher spending

and an over-reliance on family members (Weissert, 1991). A series of studies done

by Weissert and others has gained such credence in the U.S. that requests for home

care research proposals by the Robert Wood Johnson Foundation (1996) stated

that, "the old rationale that increasing home care benefits pays for itself by keeping

people out of nursing homes is no longer tenable, given research findings to the

contrary" (p. 4).

Canadian writers have begun to challenge the idea that home care is not

cost-effective, at least compared to care in a hospital or long-term care facility

(Hollander, 1994; Jacobs, Hall, Henderson, & Nichols, 1995; Saskatchewan Health

Services Utilization & Research Commission, 1998). A large scale, multi-phase

project examining the cost-effectiveness of home care in Canada is currently

underway to determine whether long-term-care substitution models[30] are cost-effective (Hollander, 1999). Preliminary findings have suggested that home care is a cost-effective alternative to long-term care, particularly for stable clients. However, as Hollander attests, "the issue of stability is important because it also reflects the converse, that home care may not be particularly cost-effective for those who change their type and level of care" (p. 104). According to the study's author, for those who are dying, home care may be more costly than care in an institutional setting.

Whynes (1997) suggests that the home care costs associated with palliative care are not usually accurate because a large part of the burden falls upon family caregivers whose efforts are not usually costed in a formal sense. Studies conducted both in Canada and in European cities that have shown that home care is cost-effective, have done so in part because the 'hotel' costs are borne, not by the institution, but by the patients themselves or by their family members (Ferris, et al., 1991; Beck-Friis, Norberg, & Strang, 1991). Even though Hollander's (1999) study demonstrated that home care costs for the dying may be higher than that of long-term care costs, his study did not account for costs incurred by family caregivers in palliative care.

In sum, it is unclear whether home care will result in substantial savings to the health care system and, overall, there is a lack of convincing scientific evidence to

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[30] In Canada, there are three major models of home care: (a) an acute-care substitution model, where home care meets the needs of people who would otherwise by cared for in acute care facilities; (b) a long-term care substitution model, where home care meets the needs of people who would otherwise require institutionalization; and, (c) the maintenance and preventative model, which serves people who are able to live at home, but who have functional deficits and may need support to continue to live independently.

suggest precisely when home care is cost-effective (Arno, Bonuck, & Padgug, 1995). Clearly further research is required in this area in order to make meaningful assessments of cost-effectiveness and the relative well being of patients who are hospitalized and those who are receiving home care.

Summary of the State of Knowledge

The shortcomings of our health care system in meeting the needs to support people dying at home have been echoed across the country (Dudgeon & Kristjanson, 1995; Johnson, 1995; Roe, 1992; Scott, 1992). However, it is only recently that there has been widespread public and government recognition of the important role that caregivers play in supporting home-based care for the dying. It is clear that a significant number of Canadians are actively engaged in providing care at home. The need for home care will increase substantially over the next several years as our health care system struggles to face demographic changes and demands resulting from a growing number of people with life-threatening illnesses who are in need of care.

While it is generally assumed that home-based palliative care is preferred, the research evidence does not always support this assumption. The research does suggest, however, that there are benefits to patients and their family members when palliative care is provided in the home setting. This research has greatly contributed to our understanding of the dying-at-home experience but, with few exceptions, this research provides only a cursory overview of the situation for family members when care is provided in the home setting. Most studies focus on death distribution patterns, service utilization, and demographic characteristics of home care patients.

In general, these studies have relied on quantitative measurements to explain patient and family experiences. However instructive, these studies neither provide the depth nor breadth of knowledge needed to fully understand the context of caregiving at home. It has been argued that the quantitative emphasis in the body of family caregiving research has constrained our understanding of the multiple ways in which the experience of family caregiving is important to family members (Kellett & Mannion, 1999).

I was able to find only one study, an ethnography, that involved observing patients and families in their natural settings (i.e., home), but this study focused on developing a conceptual framework for describing dying at home as a status passage and did not examine the family caregiving experience (Wilson, 1989). Indeed, there are very few studies that have focused exclusively on home care for the dying and much of the evidence that is available arises from studies done in the U.K., and to a lesser extent, the U.S. and Australia. Although there is a growing number of Canadian studies that have helped to "set the stage" for my current project, they also do not focus on some of the larger issues that may influence the caregiving experience at home. Most of the studies that have been done, regardless of the country of origin, have focused on individual experiences in isolation of the larger social contexts that may influence these experiences.

Although the research conducted to date provides an important beginning to understanding home-based palliative care, the dialectic between the social context of dying at home and family caregiving has failed to attract much analysis or systematic inquiry. Yet, palliative caregiving at home is a complex social

phenomenon that may improve life for many while, for others, may threaten to erode the conditions that tend to foster important social goods and opportunities. Indeed, the threat that such care poses to the conditions of a robust home life ought to inform how health care decisions and policies are made. Thus, this study was undertaken with the goals of enhancing our understanding of what Thorne (1993) calls the "grand and small pictures" of caregivers' experiences. Through the explorations that follow, I will endeavour to provide a contextualized portrait of the experiences of those who care for people who are dying at home.

CHAPTER THREE:

RESEARCH DESIGN AND IMPLEMENTATION

A survey of the empirical and theoretical literature directed me to explore a range of possible methodologies to address the research problem. One of my central concerns in conceptualizing this study was the lack of attention given to the broader social contexts in which home-based palliative care occurs. As previously mentioned, much of the current knowledge has described caregiver experiences in isolation of how they are shaped and influenced by larger social structures and processes. In this study, I wanted to situate caregiver experiences within a broader social context in order to gain a deeper understanding of the provision of palliative care in the home setting. My secondary aim was to move beyond individual descriptions in order to create understandings that might influence how health care decisions and policies are made in the area of home care for the dying. Addressing these aims meant that I required a methodology that would allow me to understand caregivers' experiences within the context of the whole. In other words, I needed a methodology that would direct me to probe the intersecting elements of the home experience in order to create a multi-layered account of the social context of dying at home in relation to home-based family caregiving. As such, I conducted an ethnography informed by critical perspectives.

In this chapter, I elaborate on the actual "steps" that I took in carrying out this research. I begin by exploring ethnographic and critical perspectives, explaining how I combined the two to provide theoretical and methodological guidance for the study. I then describe the more "practical" aspects of this project as I detail how

participants became involved in the study and how I negotiated entry into observation sites. I go on to present the ways in which I collected information as the study was implemented, commenting on interviewing, participant observation, writing field notes, and reviewing documents. The approach to data analysis is outlined and I conclude with a discussion of the strategies that I employed to enhance scientific integrity and maintain ethical standards.

The Intersection of Ethnographic and Critical Perspectives

Ethnographic Characteristics

Scrutinizing the ethnographic terrain quickly became perplexing as I endeavoured to wade through the sometimes ambiguous and paradoxical positions put forward by ethnographic scholars. At this time in history, ethnography is at a crossroads and, as Denzin (1997) argues, "it is no longer possible to take for granted what is meant by ethnography" (p. xiii). Ethnography has had a long and controversial tradition in the social sciences and has evolved over the past century as philosophies of science have developed and various disciplines have adopted and adapted ethnographic techniques (Hammersley & Atkinson, 1995). Founded on realist beliefs that offer authoritative accounts of the processes being examined (Malinowski, 1922/1961), ethnography has grown to include such diverse streams as ethnographic feminisms (Behar & Gordon, 1995; Cole & Phillips, 1996; Visweswaran 1994), autoethnography and ethnographic short stories (Ellis, 1995; Ellis & Bochner, 2000), ethnographic poetics (Marcus & Fischer, 1986), and performance texts (Richardson, 1993). Such developments arose from discontent with classic realist ethnographies. The classic tradition has been sharply criticized, mainly because it

continues to betray the influence of positivism and scientism, and claims to be value neutral (Anderson, 1989; Carspecken, 1996; Marcus, 1998; Quantz, 1992).

Given the various forms of ethnographic research, no universally adopted definition of ethnography exists (Boyle, 1994; Stewart, 1998; Wolcott, 1992; Wolcott, 1999). Some refer to ethnography as a philosophical paradigm requiring a total commitment to its tenets, whereas others define it as a method to be used when and where appropriate (Atkinson & Hammersley, 1994). At its core, however, ethnography is a theoretically-based methodology used for constructing knowledge aimed at the study of social contexts (Hammersley & Atkinson, 1995). Even so, this delineation was not particularly instructive in helping me to understand the "gist" of ethnography as a research methodology. Atkinson and Hammersley provided some guidance in this area by highlighting that ethnography has a number of the following features:

1. a strong emphasis on exploring the nature of particular social phenomena, rather than setting out to test hypotheses about them;

2. a tendency to work primarily with "unstructured" data, that is, data that have not been coded at the point of data collection in terms of a closed set of analytic categories;

3. investigation of a small number of cases, perhaps just one case, in detail; and

4. analysis of data that involves explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations, with quantification and statistical analysis playing a subordinate role at most (p. 248).

Certainly, many of these features characterize my current project in that I was exploring a social circumstance and working with unstructured data to interpret verbal descriptions and explanations. Yet, these features alone did not seem entirely different from other research methodologies in the qualitative domain[31]. I took further guidance from Stewart (1998) who proposes that ethnography has at least four widely accepted characteristics[32]. First, ethnography involves participation in the "everyday" setting to be studied. Therefore, immersion[33] in the

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[31] Grounded theory and ethnography, for example, share some commonalities. Agar (1986) claims that both use similar processes for generating understandings by comparing data and theory. Furthermore, "ethnographic theory is 'grounded', as ethnographers prioritize trying to think through observations in terms of their immanent context, before trying to construe the data in the light of existing theories" (Stewart, 1998, p. 9). Nevertheless, grounded theory and ethnography differ in at least three important ways. Unlike ethnography, the methodological procedures for grounded theory are documented in detail (for example, Chenitz & Swanson, 1986; Strauss & Corbin, 1990). Further, grounded theory does not require the same type of immersion in the field setting that ethnography does. As Strauss (1987) asserted, "one doesn't have to spend a lot of time and energy in the typical fieldworker's fashion, because theoretical sampling [for grounded theory] allows for more efficient, short-time observation and interviewing" (p. 275). This distinction lies in the claim that the *main* focus of grounded theorists is on the development of concepts for theory development rather than, in ethnography, where the focus is on the context of social situations (Stewart). Understanding this context requires immersion in the field setting. Finally, and in a similar vein, the "discovery" and modification of theory is the primary goal of grounded theory (Strauss). In ethnography, however,

> theory does not simply await refinement as analysts test concepts one by one against events in the social world ... rather, the ethnographer's assumptions, interests, and theoretical commitments enter into every phase of writing an ethnography and influence decisions that range from selecting which events to write about to those that entail emphasizing one member's perspective on an event over those of others. The process is thus one of reflexive or dialectical interplay between theory and data whereby theory enters in at every point, shaping not only analysis but how social events come to be perceived and written up as data in the first place (Emerson, Fretz, & Shaw, 1995, p. 167).

Theory matters in ethnography, then, but ethnography is not focused on theory or concepts as in grounded theory (Stewart).
[32] Stewart acknowledges that any attempt to define ethnography runs the risk of being essentialist as it is difficult to assign a particular study to a category or taxon. He also admits that more specialized forms of ethnography will have their own guiding elements. Nevertheless, I did find Stewart's articulation to be helpful in conceptualizing this study but came to see that ethnography may not be "defined" in the conventional sense but, rather, could be viewed as more of a mode of researching and presenting knowledge.
[33] While the aims of ethnographic fieldwork are similar for anthropologists and sociologists, Van Maanen (1988) asserts that they differ in their view of ethnographic field immersion. Ethnographies arising from the anthropological traditions typically go elsewhere to study culture. In contrast, ethnographies arising from sociological traditions usually stay "close to home" (p. 21) and the culture of interest is often familiar to the researcher. Based on Van Maanen's contention, I would see my work as aligned with sociological traditions in that I stayed within a locale that was known to me and

field through participant observation becomes a primary instrument (though not the only instrument) for data collection. Second, ethnography has a holistic mandate. As such, individual level experiences are understood as being a part of a larger whole and the range of attention to elements in the setting is comprehensive. In other words, the data obtained through ethnographic inquiry has "breadth" (Becker, 1996, p. 65). Third, ethnography involves providing a contextualized explanation for social events. Similar to the holistic nature of ethnography, Agar (1986) maintains that ethnographers seek to connect their observations to each other and then to a broader social context. Lastly, ethnography is concerned with describing, in a detailed way, the point of view of the main actors in a particular culture[34].

As I understand it then, operationalizing ethnography involves a period of immersion in the field setting in order to better understand the emic or "insider's" point of view (Spradley, 1979). Working from data in the form of observations, field notes, interviews, and other documents, such as policy statements and records (Germain, 1986; Morse & Field, 1995), the ethnographer seeks to understand a particular "culture" within a broader social context[35]. Typically, ethnography involves "thick description" whereby the analysis moves beyond simple descriptions to

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studied a culture that I was familiar with. Nonetheless, I acknowledge that I drew heavily from both traditions in seeking guidance for this study.

[34] In ethnography, culture can be used in the broadest sense (Morse & Field, 1995) from examining the beliefs of ethnic groups (for example, Lipson, 1991) to investigating beliefs and practices of particular communities, such as the operating room (for example, Fisher & Peterson, 1993) to inquiring about groups of individuals that share a common experience (for example, Haggstrom, Axelsson, & Norberg, 1994).

[35] I recognize that this might be construed as an oversimplified view of ethnography. I only use it heuristically to outline some of the main features of ethnography.

explain the meanings of behavior and the cultural context in which it occurs (Geertz, 1973). All of these features were included as a part of this study.

Critical Perspectives

While I found that literature about ethnography was helpful in conceptualizing this study, I came to realize that ethnography alone was insufficient to direct me to examine and critique how social and political structures and processes shape caregivers' experiences; it also did not provide the philosophical and theoretical guidance that I believe is important to the scientific process. Indeed, it is now widely held that the worldview or paradigm[36] that one brings to the research enterprise is an integral part of sound scientific inquiry. More specifically, a researcher's ontology, epistemology, and methodology influence all phases of the research process from conception to completion (Anderson, 1991). Denzin and Lincoln (1994) assert that ontology, epistemology, and methodology are interconnected elements, which not only influence the research process, but also reflect the encompassing personal biography of the researcher. As such, an understanding of the philosophical and theoretical base from which inquiry paradigms have arisen is central to engaging in thoughtful, reflective research.

Thinking through my own commitments to the research enterprise helped to clarify my philosophical and theoretical positioning. I found Guba and Lincoln's (1994) work to be particularly useful in making distinctions about the various inquiry paradigms. Guba and Lincoln use the term critical theory to denote a set of

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[36] For the purpose of this study, I understand a paradigm to be "a basic belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways" (Guba & Lincoln, p. 105).

alternative paradigms including feminisms[37]. Using ontologic, epistemologic, and

methodologic questions[38] to guide my thinking, I came to understand that critical

theoretical perspectives could provide direction for my methodology. Thus, the

study design that I employed is an ethnography informed by critical theoretical

perspectives[39]. Accordingly, I proceeded from a moderate realist position (the

ontological question), believing that reality is historically and socially created, and is

influenced by social, political, historical, economic, cultural, and gender values.

Thus, local meanings are embedded within larger societal meanings.

Epistemologically, I hold that knowledge is socially constituted, historically situated,

and valuationally based; it is intersubjective and transactional, and, therefore, both

the researcher and the researched shape what knowledge is constructed (Cook &

Fonow, 1990; Henderson, 1995; Rutledge-Shields & Dervin, 1993). Yet, I concur

with Reimer Kirkham (2000) in that I do not believe that "all knowledge is local or

subjective -- there are certain shared realities and common meanings that transcend

the individual and the context" (p. 86). Methodologically, I take a dialogic and

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[37] Approaches to ethnographic research informed by feminisms are concerned primarily with gender inequities and have both contributed to (Anderson, 1989) and been seen as contradictory to critical approaches (Stacey, 1988; Strathern, 1987). I have chosen to use Guba and Lincoln's (1994) conceptualization of critical theory as encompassing feminist perspectives as an overarching framework for discussion and understood that an ethnography informed by critical perspectives would allow me to conduct an in-depth analysis of the social context without diminishing or ignoring gender issues (Campbell & Bunting, 1991).

[38] The ontological questions (i.e., What is the nature of reality? What can be known about reality?), epistemological questions (i.e., What is the relationship between the knower and the would-be-knower? What can be known?), and methodological questions (i.e., How can the would-be-knower go about finding out whatever she/he believes to be know?), highlighted by Guba and Lincoln (1994), were particularly helpful in guiding me to articulate my theoretical positioning.

[39] I am deliberately making a distinction between critical ethnography and ethnography informed by critical theoretical perspectives. As I later argue, the emancipatory aims imbued in critical social theory are problematic for this project. Instead of aligning myself with the overt ideological goals of neo-Marxist critical ethnography or the critical social action projects advocated by some critical ethnographers (Carspecken, 1996; Lather, 1986), I chose to focus on the philosophical and theoretic directions that critical perspectives might offer for my current project.

dialectical approach in seeking what there is to be known. Thus, while I believe that relationships between the researcher and the researched are inevitably permeated with unequal power differentials, I believe that through the process of reflexivity, these differences can be minimized to create nonhierarchical, free, uncoerced, and undistorted communications between the researcher and researched.

Having articulated my critical "interpretive lens", I then considered those assumptions that underpin critical theoretical perspectives. This examination proved difficult as critical science has many forms (e.g., critical theory, critical social science, new paradigm research, praxis-oriented research, critical inquiry, emancipatory social theory, emancipatory research, and so on). I took direction from a number of sources to "piece together" those elements that were instructive for my intended purposes, although I did so with full awareness that some critical scholars might criticize this approach. Nevertheless, I chose these perspectives for what they offered, taking a pragmatic approach to decision making.

As previously mentioned, I wanted to situate caregiver experiences within a broader social context and move beyond individual description to develop knowledge with which to influence health care decision making and policy development in the area of home care for the dying. This meant that I would need to examine and critique some of the larger social, political, cultural, and historical structures and processes that shape caregivers' experiences. These aims imply that I am seeking not only to describe caregiver experiences, but also to develop knowledge to influence change[40]. Thomas (1993) maintains that ethnographers

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[40] Research informed by critical perspectives is more likely to be praxis-oriented (Lather, 1986,1991; Miller, 1997), aiming to uncover hegemonic and restrictive health care practices. Thus, individual

working within the critical paradigm study social structures and processes not only to

describe them, but also to critique and change them. As such, ethnography

informed by critical perspectives is "conventional" ethnography with a political

purpose (Thomas). Thus, the critical part of the ethnography pushes the analysis

beyond mere description of a particular experience, situation, or process to make

sense of it in relation to both the broader social and organizational context (Bent,

1993; Forester, 1993; Wells, 1997). Since one of my explicit intentions was to

create knowledge that may improve care for family members in the future, I believed

that using knowledge derived from this study may be able to correct inequities,

thereby contributing to the greater social good. As Rabinow and Sullivan (1987)

point out, "the great strength of ... critical theory has been continually to urge that

the human sciences cannot be detached from the greater problems of living" (p. 15).

Certainly, many nursing scholars have articulated the need for nursing science to be

directed at generating knowledge to meet its social and moral mandates

(Chopoorian, 1986; Moccia, 1988a; Starzomski & Rodney, 1997; Thorne, Canam,

Dahinten, Hall, Henderson, & Reimer Kirkham, 1998; Williams, 1991).

While I recognized the benefits of using critical theoretical perspectives to

guide my interpretations, I was concerned about the focus on oppression and the

emancipatory intents inherent in critical social orientations[41]. Although there is utility

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situations can be transcended to identify larger societal structures and ideologies that maintain ineffective and unequal health care practices. As such, a hallmark of ethnography informed by critical perspectives is its emphasis on developing knowledge for change (Carspecken, 1996).

[41] One of the overall goals of critical social theory is to liberate individuals from conscious and unconscious constraints by nullifying the effects of dogma and ideology (Allen, 1990; Brent, 1993; Wilson-Thomas, 1995). People's perceptions and experiences are thus freed or emancipated and they are able to see beyond the taken-for-granted realities that oppress them (Ray, 1992). As such, the focus of critical theory is to liberate people from unacknowledged circumstances of domination and to transform constraining conditions (Stevens, 1989). The emphasis is on eliminating false

to the emancipatory aims of critical social theory (see, for example, Brown, 2000; McCormick & Roussy, 1997; Thompson, 1987; Thorne, 1997), I was not intending to conduct a critical social action project nor was I intending to free individuals from oppressive conditions. A significant concern of mine regarded how oppression is defined and what constitutes an oppressive condition. If a goal of critical social theory is to enlighten agents about their oppression so that they can realize their own best interests, how do we best go about doing this in a way that is not paternalistic? Campbell and Bunting (1991) warn that, "the assumption can be made that agents (the oppressed) begin the process as less emancipated than the theorists" (p. 6) and suggest that this stance can result in a paternalistic position. The goal of enlightenment seemed antithetical to what I was attempting to achieve. That is, there are inherent dangers and implications in labeling people as "oppressed" since this label may influence how people are perceived and how others relate to them.

The notion of false consciousness was also problematic. While perhaps appealing from a theoretical perspective, false consciousness undermines subjective knowledge as valuable and legitimate (Brown, 2000). For example, do we support caregivers in their use of avoidance to cope with the demands of caregiving or do we characterize it as false consciousness? Characterizing this experience as false consciousness has the potential to minimize caregivers' experiences and dismiss their legitimate ways of coping. I concur with Brown who suggests that, "... nursing

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consciousness in order to redress power imbalances and end oppression (Freire, 1990). Emancipation is a central concept for critical theorists who argue that belief systems that are present and treated as facts by the ruling class, act as barriers to conscious action and freedom (Acker, Barry, & Esseveld, 1983; Schwandt, 1990).

science may benefit most from using false consciousness as a self-reflection strategy but refrain from applying the concept to individual patient-care situations" (p. 48).

In this study, I aimed to critique larger structures and processes in order to develop knowledge to influence change. However, I did not propose to emancipate family caregivers. The emancipatory aims imbued in critical social action approaches are problematic for family members in palliative care[42]. Family members are already overwhelmed in their caregiving roles. Engaging them in dialogue to "free them from oppression" would be inconsistent with the mandate of palliative care. Similarly, caregivers might be challenged to fully participate in the research process (a requirement for many critical social action projects) without adding to their already substantial burden of caregiving. As Thorne and Varcoe (1998) argue, "focusing emancipatory intent on the participants of the research itself rather than on the larger objective of the research ... fails to recognize the social inequities that might render full participation impossible..." (p. 488). Furthermore, overreliance on critical social theory may privilege the collective over the individual

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[42] Studies derived from critical social theory offer the possibility that participants will be emancipated. Emancipation may mean engaging with people in critical thought and analysis or enabling them to reflect on their situations and gain new meanings from their experiences. However, I thought that these aims presented difficulties for the population I was studying. While some might argue that the caregiving experience itself is oppressive, and that caregivers are in need of being "transformed" and emancipated, many caregivers have an intense emotional investment in the care of the dying. Engaging caregivers in a process to critically examine their position as a caregiver and the possible inequities that they may face or may have faced would inevitably bring forth painful issues that might be best left alone (at least from a research perspective). I was not prepared to instigate an expression of deeply embedded feelings with the participants in this study. This decision was informed by my extensive clinical experience in palliative care and supported by Opie (1992) who explains that "the tensions arising from the duality of positioning (willing/exploited) has to be simultaneously maintained so that women (and men) who derive significant positive affectional and personal meaning from their role are not defined as imbued with false consciousness" (p. 55).

(Brown, 2000) and can "permit representative appropriation of voice by more powerful members of a community over others in a misguided attempt to avoid researcher misuse of power" (Thorne & Varcoe, p. 488).

At the same time, I did not want to reject altogether the idea that emancipation could be a useful concept to direct my thinking. Therefore, instead of expecting change to occur based on the research process, I came to understand that emancipation could direct me to the possibilities of change (Lather, 1991). I saw these possibilities for change, however, at a systems level rather than at an individual one. I also came to believe that the knowledge developed through the interpretive process was emancipatory in itself (Thorne & Varcoe, 1998) as the knowledge derived from the study findings could be used to create an expanded repertoire of options for supporting caregivers.

In summary, ethnography informed by critical perspectives provided the substantive guidance for studying the social context of home-based palliative caregiving. This methodology directed me to:

1. Use a range of data collection strategies, including participant observations, interviewing, field notes, and a review of documents;

2. Situate caregivers' experiences within a broader context, taking into account how they were shaped by social, political, historical, economic, cultural, and gender values and contexts;

3. Intersubjectively construct knowledge with the main actors in the research process;

4. Engage in a reflexive process, always paying attention to the relationships between myself and the study participants[43];

5. Employ a critical stance in examining how larger structures and processes (inherent in the social context) influenced caregivers' experiences;

6. Explore the possibilities for change at a systems level and for formulating how the knowledge derived from this study could be used to influence health care decision making and policy development; and

7. Consider how the knowledge generated from nursing science could be used to meets its moral and social mandates.

On a final note, I believe that one of the major strengths of critical theoretical perspectives is in the ability for researchers to account for their biases through critical analysis. While many qualitative researchers endeavour to suspend or "bracket" their own experiences to enhance objectivity (Oiler, 1982; Omery, 1983), criticalists practice "strong objectivity" (Alcoff, 1991; Harding, 1991; Opie, 1992; Roman, 1993) by acknowledging their own experiences and locating themselves in

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[43] Oakley (1981) has argued that researching others makes those being studied the objects of study. Yet the dialogic and dialectical approach serves to reduce objectification by reflexively paying attention to power inequities between the researcher and the researched (Guba & Lincoln, 1994). I was aware that my location as a "researcher" doing a Ph.D. in palliative care might influence these relationships. However, I also shared many commonalities with the caregivers and health care providers in this study. With caregivers, I shared a common experience in having participated in caring for my mother who was dying at home. While I did not always openly share this experience, I was almost always asked by caregivers why I became interested in the area of home care for the dying. With health care providers, I shared many characteristics such as class, gender, and being a nurse who provides health care. Importantly, I shared a commitment to improving the quality of life for patients and families in palliative care. Although these commonalities helped to create a "common bond", I continued to be aware of the potential for power imbalances that might be oppressive. Along with keeping a reflexive journal throughout the study, I used a number of strategies to decrease power inequities, including seeking feedback on my field notes while doing observations in the home, talking about my evolving analysis with some caregivers and providers, and actively seeking critique on my ideas. Even so, I was constantly aware that the misuse of power was possible given that I retained control of the research process and its final product.

relation to the researched and the entire research process. I found this particularly useful because I knew coming into the study that I had biases that were shaped by my own life experiences and that would most certainly influence how I proceeded with the study. Rather than locating myself into any prescribed category, however, (e.g., as a white, middle-class woman), I used this opportunity to critically analyze my own assumptions and biases (Thorne & Varcoe, 1998).

I began this research having had the experience of participating in the care of my mother when she was dying at home. Our family experiences were marked by repressive relationships with health care providers, by careless attention to symptom management, and by complicated family dynamics. The combination of these issues resulted in the hospitalization of my mother, where she died in relative peace. In my clinical experiences in palliative care, I have witnessed similar family situations. Thus, I began this study needing to re-visit and confront my own anger at "the system". Although I previously went through a self-reflective process many years ago following the death of my mother, these critical reflections helped me to re-focus and think about how many families benefit from providing care at home. This became evident to me in my observations with family caregivers as I observed open expressions of love, gratitude, and commitment.

Even so, I realized that my experiences had, to a large degree, shaped the construction of this study in that I came to it believing that the idea of dying at home was in need of critique and further examination. I was also aware, like Opie (1992), that I might have a tendency to focus on the exploitative and oppressive nature of caregiving, disregarding the value that caregivers may place on their roles. Despite

my best intentions to be fully aware of my biases and assumptions, I did find, particularly during my initial interviews with caregivers, that I tended to pick up on the hardships of caregiving while minimizing the beneficial aspects of the role. I found in my observations that I began focusing on the messiness and clutter of hospital equipment and medical supplies in the home environment without embracing a broader angle of vision to see the possibilities that these tools might offer to family members. I was aware of my judgements and how they were based on my own conceptions of what a home environment should be.

I worked through these issues by engaging in reflexivity throughout the research process (facilitated by journalling) and by trying to understand the influences of my experiences rather than participating in futile attempts to eliminate them (Porter, 1993). As the study progressed, I began engaging with some of the participants in a process that would challenge my assumptions and biases. For example, in my interviews with health care providers, I used areas of potential controversy to challenge my interpretations. I asked some of the caregivers to comment on my beginning analyses and offer any divergent viewpoints[44]. At one point, I even found myself wanting to focus entirely on the positive aspects of caregiving at home! I came to learn that the practice of reflexivity is an iterative process that not only includes a thoughtful and critical examination of one's own

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[44] I was very careful about the extent and the ways in which I validated analytic themes with caregiver participants, recognizing the potential for ethical problems that could arise from explicitly confronting them with the evolving analysis. Based on my clinical experience, the population I was studying was a highly sensitive and vulnerable one. Caregivers in the midst of a home caregiving experience may or may not be in a position to actively reflect on their feelings about the phenomenon. I believe that pushing a reflection that may be premature would have been inappropriate and unethical. Further, some caregivers may not have been in positions to be able to tolerate comparisons with other families, for example, families in a more favorable situation than their own. For this reason, I was very selective in choosing caregivers with whom to discuss my evolving analysis.

biases and assumptions, but is also a "balancing act" of trying to mediate varying perspectives. Finally, I challenged my own biases by abandoning my initial inclinations to exclude family members whose caregiving experiences were distant (thinking that they may be unable to recall the details of their experience). Including these caregivers, however, proved to be important in the final analysis as they recounted, in detailed ways, the lasting effects that caregiving had on their lives.

Instituting the Study

Having laid out the methodology from which I proceeded, I now detail the more practical aspects of this study. As an overview, the primary sample was comprised of family members who were providing, or had provided, palliative care at home. Health care providers, health care administrators, and individuals who were publicly known lobbyists of the assisted suicide movement comprised the secondary sample. Data were collected from multiple sources using the ethnographic techniques of in-depth interviewing, participant observations, and a collection and review of relevant documents. Data collection began by interviewing and observing caregivers and proceeded to include interviews with health care providers and administrators. The collection of documents occurred simultaneously throughout the study. Thematic analysis of transcribed interviews, field notes, and documents were completed by the constant comparative method to create a composite description of the social context of home-based palliative caregiving.

Negotiating the Field

Negotiating Access and Entry

Access to the field involves a process of negotiation and renegotiation (Jorgensen, 1989). Many experts in qualitative research acknowledge that fieldwork, in any setting, is done in a number of stages and can be extremely time-consuming (Germain, 1986; Jorgenson; Lincoln & Guba, 1985; Morse & Field, 1995). Negotiating access for this study was a multi-layered process. As a first step, I contacted health care administrators and providers as I was seeking not only their support for and participation in the research, but also their assistance with recruitment of family caregivers. Accessing the field in this way was a relatively straightforward process. I had previously worked as a clinical nurse specialist in palliative care and, therefore, was well known in the palliative care community and had established relationships with both health care providers and administrators. In fact, I had begun negotiating the field long before implementation of this study when I had sought letters of support to attach to a funding grant proposal for it. As such, I began this study having already entered the field, with agencies and their staff being aware of the purposes of the study and the methods that I proposed.

After these initial contacts, I attained ethical approval from the University of British Columbia Ethical Review Committee and the Research Review and Ethical Approval Committee of the health region where the study was being conducted. I then began to recruit family caregivers and health care providers. Although I began this study by learning from family caregivers, recruitment of family members and providers occurred simultaneously. This was a pragmatic choice in that when I

spoke with providers about assisting with recruitment of caregivers, I also invited their participation. Invitations to participate were extended to health care providers at multidisciplinary staff meetings and through formal presentations. Using Bernard's (1994) recommendation, I provided written information about the study (see Appendix B) and asked those health care providers interested in participating to contact me. The only criterion for participation of health care providers in this study was that they be providing health care services to families that were, in turn, providing palliative care at home. In recruiting health care providers, I was especially sensitive to the possibility that they might feel obligated to participate because of their past association with me. Thus, I emphasized that I was seeking a voluntary sample and did not directly approach any health care providers to participate.

In my meetings with health care providers, I requested their support in recruiting family caregivers. I provided them with informational letters to give to caregivers that outlined the study purposes and that invited participation (see Appendix C). Family caregivers were invited to contact me directly if they were interested in participating. Criteria for participation in the study included:

1. being a caregiver who was actively involved in providing care to an adult[45] family member who was expected to die within approximately three months[46]; or

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[45] Because family members caring for children have unique and distinct experiences (Steele, 1999), they were not included in this study.

[46] I realized that I needed to place some parameters on participation. I was most interested in examining experiences in the "dying" period (see Chapter One for definition of terms). At the same time, I did not believe that it was morally neutral to recruit caregivers when their dying family members were so close to death that it would be inappropriate for me to "step in" and observe. I wanted the opportunity to establish relationships with family members and to observe them in their

2. being a caregiver who had previously provided palliative care to a dying family member at home[47]; and

3. being able and willing to articulate, in English, their caregiving experiences;

4. being over age 19 so that they could consent to participate; and

5. residing in the study region.

I again kept in mind that providers might feel obligated to help with recruitment, and emphasized that they were under no obligation to do so. I also stressed to health care providers that caregivers might feel obliged to participate because of their association with them. To some extent, I was reassured knowing that these practitioners were typically protective of families in palliative care and would be inclined to put the interests of their clients above the interests of the research. Nevertheless, I felt it important to stress the point as I aimed to avoid any approach that could be construed as coercing participation.

Having worked in home health care and in palliative care, I recognized the

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caregiving roles as the patient's disease progressed. Based on my clinical experience, I chose three months as an estimate, fully understanding that disease trajectories take their own shape and that caregiving could continue beyond three months or be completed within several days. I did not, however, explicitly state the three-month criteria in my letters of invitation to family caregivers as this may have precipitated some unwanted emotional reactions. Instead, I spoke with each caregiver on the telephone prior to meeting them and used the Palliative Performance Scale (Victoria Hospice Society, 1998), a tool used to aid in prognostication, to estimate the prognosis of the patient. Even so, prognostication is not an exact science and can only be used as a guide. While I used these tools to aid my decision making, I ultimately included all family members who were actively providing at-home palliative care, respecting the fact that they had taken the time and energy out of their already busy lives to contact me.

[47] I was deeply aware of and sensitive to the considerable burden experienced by many caregivers and realized that they may only want to participate in certain aspects of the study (e.g., participating in interviews only or observations only) or that I may have difficulties in finding active caregivers to participate. Family members with previous home caregiving experiences could offer unique perspectives, having had the time to reflect on their caregiving roles. As such, I invited previous caregivers to participate in this study. I considered placing a time limit on participation, only recruiting participants whose experiences were recent (i.e., within one year). I decided against this approach, though, as I felt that voluntary participation implied that caregivers had something important to share.

possibility that providers might be challenged to find the time in their busy work schedules to assist with recruitment. Therefore, I published an article in a local caregiver newsletter outlining the study and inviting participation. When my recruitment strategies met with only partial success, I consulted a communications specialist at the local hospice. Together, we constructed an "advertorial" and along with my picture (which the communications specialist suggested would help "put a face to a name"), it was published in the hospice newsletter, which was circulated in the Sunday edition of the regional newspaper. Within three days, I had telephone calls from over 50 caregivers who were interested in participating! I was then placed in the position of having more caregivers in the study than I had originally intended. After discussing this dilemma with my supervisors, I decided to invite participation from all caregivers who expressed interest[48].

While I had a growing number of caregiver participants, most were caregivers who had previously provided palliative care. Recruiting active caregivers and negotiating access and entry into the home setting to conduct observations was not as straightforward. While there are several examples of how nurse researchers have negotiated entry to conduct observations in field settings such as hospitals (for example, Reimer Kirkham, 2000; Rodney, 1997; Varcoe, 1997a), there is little written about how to recruit and negotiate entry when "the field" is the home setting.

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[48] Given the sensitive nature of this study, I felt that it was irresponsible and even unkind to invite family members to share deeply emotional experiences, only to then tell them that I "had enough" participants. I recognized that the study was getting much larger than I anticipated and that I would have to find creative ways to collect and work with the "mounds" of textual data that would result from data collection. I considered using focus groups as a strategy to reduce the workload associated with in-depth interviewing. I abandoned this approach, however, after consulting with several of the caregivers; they explained that they were uncomfortable participating in a group interview and talking about their experiences with "strangers".

Up to this point, I had recruited five family members to participate in observations but was unable to collect sufficient amounts of data since the patients had died relatively soon after I began my observations. To address this issue, I re-contacted some of the health care providers who had previously assisted with recruitment to remind them that I was continuing to invite participation from active caregivers. I also had another opportunity to publish an advertorial that specifically focused on recruiting family members who were currently providing palliative care at home. This article also served to update the community on the status of the study and to thank those who had already participated. These approaches facilitated participation of another eight active caregivers.

My approach to entering the field included a number of steps. Initially I talked with each caregiver on the telephone, providing a more detailed explanation of the study purposes and what might be involved. I introduced myself as a student researcher who was completing a Ph.D. in nursing and as a person who had an interest in palliative caregiving at home. After these discussions, I offered to mail caregivers more detailed information than what they had seen in the advertisements so that they could decide on whether they wanted to participate. All of the caregivers declined this offer, and instead, invited me to their homes to further discuss the study[49]. In my initial meetings with caregivers, I did not conduct any

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[49] I was surprised that caregivers were so willing to have me enter their homes having not met me. I realized that my position as a nurse and my association with agencies providing palliative care likely provided me with considerable advantages and facilitated my entry into the field setting. I was also aware that this privilege had the potential to raise difficulties if caregivers felt obligated to participate. Therefore, I paid special attention to ensuring that family members freely consented and that the extent of participation was negotiated and renegotiated each time I visited the home. My concerns were allayed somewhat when I later found out that some of the caregivers had "checked me out" with their home health care providers prior to contacting me.

observations, but explained the study further and invited caregivers (and patients, if they were able) to ask questions. I explained that they could participate in however they chose (e.g., interviews, observations, or both) or not participate at all. I understood that participation would include gaining consent from both family members and patients and, accordingly, I attempted to include patients in discussions as much as possible; however, only two patients were well enough to formally consent to participate. This initial meeting also gave me the opportunity to begin establishing trust and rapport with caregivers. I agree with Booth and Booth (1994) that establishing trust and gaining rapport is a two-way process, involving sharing personal information about myself when asked (e.g., sharing that I had been a family caregiver) and being respectful of caregivers (e.g., arriving for observations on time, returning phone calls, providing information when asked). After the initial visit, I arranged to observe at times that were convenient for caregivers. Prior to each visit, I called caregivers to ensure I would be welcomed. This process of negotiation and re-negotiation occurred throughout the entire project.

I began this study by observing and interviewing a core of five family members who were actively caregiving, and interviewing another fifteen who had previously provided care. Once I had developed an initial analytical framework, I extended the study to include another twenty caregivers and to include health care providers. These interviews and observations helped to extend the analysis and validate my evolving interpretations. Further purposive sampling involved recruitment of individuals who might be able to provide insight into the extralocal structures and processes that shaped caregivers' experiences (e.g., health care

administrators, policy makers, publicly known lobbyists of the assisted suicide movement). Formal letters of invitation to participate were mailed to these individuals (see Appendix D) and follow-up telephone calls were made to determine their interest in participation. The final phase included ongoing observations in the home environment and interviews with another twenty caregivers in order to further extend and validate my interpretations. In order to keep track of the various phases of fieldwork, I kept a fieldwork calendar of activities throughout the study (see Appendix E).

The Sample

Throughout this study, I sought caregiver participants who varied in age and gender, and who represented a range of caregiving experiences. Although the purposiveness (Morse, 1991a; Sandelowski, 1995) of the sample naturally unfolded (because of the number of caregivers who volunteered to participate), I monitored it closely to ensure that I was able to capture a sufficiently diverse sample. I originally intended to recruit caregivers who were providing palliative care in "non-traditional" home settings (e.g., hot plate hotels, rooming houses) but abandoned this idea when my sample size grew. I purposively sampled health care providers and administrators, thus seeking people from different disciplines and including those who represented a range of health care experiences.

The final sample consisted of 13 active caregivers, 47 previous caregivers, 12 patients[50], 28 health care providers, nine health care administrators, and one

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[50] Only two of the patients were able to actively participate; one in an in-depth interview with his wife, and the other, through informal conversations while I was conducting observations. I conducted observations in 12 homes, including one where a married couple was providing care to their dying

publicly known lobbyist for the assisted suicide movement, for a total sample of 110 participants. I collected demographic data on all of the participants, except the patients (see Appendix F for Demographic Collection Sheets). Caregiver demographics included age and gender, ethnicity, level of education, employment status at the time of caregiving, and the caregivers' relationship to the dying person. Information on the health care services that were accessed at the time of caregiving were included, along with diagnosis of the patient, status of residence at the time of caregiving, and average annual income at the time of caregiving. Previous caregivers were further asked where their family member had died and the number of years since caregiving had occurred. Caregivers were reminded that they could refuse to answer any questions[51]. A demographic profile of caregiver participants is provided in Table 1.

Demographic information was also collected on health care providers and administrators/lobbyists of the assisted suicide movement. Information on age, gender, level of education, employment status, and the years of experience in health care was obtained. The discipline of the health care provider was also noted. Table 2 provides a demographic profile of health care providers, administrators, and lobbyists of the assisted suicide movement[52].

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mother. This accounts for why there are 13 active caregiver participants but only 12 patient participants.

[51] I was cognizant that answering questions about financial status might be threatening to caregivers as this information is often used to determine the level of home support that they will be provided. Even though I reassured caregivers that this information would remain strictly confidential, there were some caregivers who declined to answer this question.

[52] I did not separate out lobbyists for the assisted suicide movement from the administrator sample as there was only one participant in this category and I wanted to ensure this person's anonymity.

Table 1

Demographic Profile of Caregiver Participants

Demographic Category	Demographic Information
Female	47
Male	13
Age	
25-35	4
36-45	10
46-55	12
56-65	17
66-75	12
76-85	4
> 85	1
Canadian-born	33
European-born	23
Not identified	4
Level of Education	
< High school	6
High school diploma	13
Diploma/Technical School	23
Undergraduate Degree	11
Graduate Degree	7
Employment Status	
Working full-time	13
Working part-time	2
On a leave of absence to caregive	4
Self-employed in the home	7
Unemployed	4
Retired	30
Relationship to the Dying Person	
Wife	20
Husband	9
Daughter	19
Son	3
Daughter-in-law	1
Partner	2
Mother	4
Sister	2

Table 1 (continued)

Demographic Profile of Caregiver Participants

Demographic Category	Demographic Information
Health Care Services Accessed[53]	
Community hospice program	49
Home nursing care	34
Home support	25
None	11
Diagnosis of the Patient	
Cancer	40
AIDS	3
End stage heart disease	11
ALS	3
Unrecorded	3
Status of Residence at Time of Caregiving	
Shared same household	42
Lived independently	8
Moved from permanent residence to caregive and shared same household	10
Annual Income at Time of Caregiving	
$0 - $20,000	6
$21,000 - $40,000	15
$41,000 - $60,000	18
$61,000 - $80,000	9
> $80,000	---
Not identified	12
Location of Death (n=47)	
Home	32
Hospice in-patient unit	9
Acute care hospital	4
Long-term care facility	2
Number of Years Since Caregiving Experience[54] (n = 47)	
< 1 year	6
1-3 years	21
4-10 years	16
11-20 years	1
> 20 years	3

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[53] The total number of health care services exceeds the total number of family caregivers because they often accessed more than one service at the same time.
[54] The number of years since caregiving is only recorded for the 47 previous caregivers that participated.

Table 2

Demographic Profile of Health Care Providers, Administrators, and Assisted Suicide Lobbyists

	Health Care Providers	**Administrator/Lobbyist**
Female	24	8
Male	4	2
Age		
< 24 years	---	---
25-35	1	---
36-45	16	6
46-55	7	4
56-65	3	---
> 66	1	---
Level of Education		
High school diploma	3	---
Diploma prepared	6	1
Undergraduate degree	12	1
Graduate degree	7	8
Employment Status		
Working full-time	18	8
Working part-time	9	2
On leave of absence	1	---
Years of Experience in Health Care		
1-5	5	---
6-10	5	2
11-20	10	---
> 20	8	8
Health Care Discipline[55]		
Home care nurse	10	---
Hospice nurse	3	---
Counsellor	3	---
Home support worker	7	---
Physician	3	---
Community Activist	2	---

Data Collection Techniques

In accordance with ethnographic methods, I conducted participant

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[55] I did not collect information on the discipline of administrators, as I wanted to protect their anonymity.

observations in the homes of palliative caregivers. In-depth interviews were done with caregivers, health care providers, administrators, and lobbyists for the assisted suicide movement. Three focus group interviews were also conducted with home health care providers. I strove to conduct observations and interviews in a reflexive manner, seeking to acknowledge the humanness of each participant while also listening in a reflective and analytic way (Alcoff, 1991; Oakley, 1981). Field notes became a primary source of data generation as I recorded my observations and reflected on the data constructed from the interviews. I supplemented observation, interview, and field note data by collecting and reviewing primary documents such as regional, provincial, and national policy statements, and reports and literature from the popular press pertaining to home-based palliative care.

Engaging in Participant Observation

Early philosophers, such as Aristotle, rooted their understandings of the world based on their own perceptions, visions, and direct experiences (Gaarder, 1996). In everyday life, members of society make observations of the everyday world. These observations often guide decision making, and help in interpreting and reacting to the world around us. It is argued that such "common sense" is fundamental to knowledge development (Johnson, 1975). As such, ethnographers have had an extensive history of using observational methods to answer questions about the nature of people, interaction, and society.

Observation is broadly defined as "gathering impressions of the surrounding world through all relevant faculties" (Adler & Adler, 1994, p. 378). Observational methods in qualitative research take many forms from complete participant to

complete observer roles (Gold, 1958). While a number of roles exist and have been reconceptualized since Gold's work, I undertook this study as an observer-as-participant, whereby my role was publicly acknowledged at the outset of, and throughout, the study (Germain, 1986), and through which I negotiated some limited work responsibilities with caregivers (e.g., house cleaning, preparing meals) (Emerson, et al., 1995; Morse & Field, 1995).

As previously mentioned, gaining entry and access to the field was a multi-layered and ongoing process as I negotiated and re-negotiated entry into twelve homes that served as the primary observation sites. I began my field work by conducting observations in the homes of five family caregivers over a three-month period and I then took two months off to reflect on what I had observed and what I had learned through the interviews. I re-entered the field for another five months and conducted observations in another eight homes in order to extend the analysis and validate my evolving interpretations. While I conducted participant observations in twelve different sites, I worked closely with a core group of seven caregivers. I did not enter the field with any preconceived idea of how often or for how long I would observe in each site. Instead, I negotiated the number of observation episodes and the amount of time I would spend in the home on each visit. Typically, I spent between three and four hours conducting observations; I found that I was too exhausted to stay any longer. I was also sensitive to the need for caregivers to have private time for themselves and with those they were caring for, even though they were often thankful and appreciative of my presence and my help. Observations occurred on weekdays when health care providers were more likely to visit, on

weekends, and during daytime and evening hours. The number of observation episodes numbered between three and ten, depending on the extent of my involvement. Some patients died soon after I became involved and others lived longer. All but one patient had died before I completed fieldwork. I completed approximately 100 hours of fieldwork as an observer-as-participant with the core group of seven caregivers and approximately 30 hours with the remaining six caregivers. The data generated from participant observations, along with interview data, was sufficient to meet the needs of data analysis.

My first observations were somewhat rudimentary as I sketched out the physical setting and recorded my initial impressions. Recording impressions provided a way to get started as I was initially quite anxious going into the field; not only because I had limited experience with using participant observation and was not entirely sure of what I was going to observe, but also because I was unsure of how family members would react to me being in their homes as a "researcher". As I later realized, these initial impressions provided me with some of my most important insights into the social context of home-based palliative caregiving.

Taking direction from Emerson and colleagues (1995), I proceeded to focus on key events or incidents that were occurring in the home. I was initially uncertain of what to observe and record in my "jottings" and, like most novice ethnographers, I attempted to observe and record everything! This quickly became overwhelming, particularly at times when a lot of activity was occurring. For example, it was not uncommon for two or three different health care providers to arrive at the home (all

at the same time) while I was observing[56]. Sometimes, the home setting was frenzied and imbued with distress when patient symptoms got "out of control" and required prompt intervention. At other times, the situations were so intimate, profound, and moving that I found it difficult to focus on what I was seeing. My personal and professional experiences sometimes coloured how I gave meaning to what I observed, and added a layer of complexity as I tried to cultivate understandings that were not judged by my own standards and values. Reflective journalling became an important tool for me as I tried to understand my own positioning in relationship to what I was seeing. Rather than attempting to be "objective" or place my own personal reactions aside, I recorded my reactions and then tried to "step back" and use these experiences to learn and to increase my sensitivity to what was being observed (Emerson, et al.). Nonetheless, I experienced ambiguity and challenge as I negotiated my emotions and recognized the centrality of reflexivity in the entire process of fieldwork.

As I became immersed in the field, my observations became more focused. Adler and Adler (1994) point out that participant observations typically begin with a general, unfocused, descriptive phase. Over time, however, the observations become more focused and move to a final phase where theoretical saturation

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[56] I had initially planned to "buddy" with health care providers during their home visits so that I could observe the interactions between caregivers and providers, and examine how community-based care services influenced the home setting. After there was little response to my initial attempts at recruitment, I approached the local hospice and invited participation from staff working with the community palliative crisis response team. Although many staff volunteered to participate, obtaining consent from family members who were in crises became problematic. I came to realize that caregivers may not be able to fully consent at the time of crisis and that asking them to do so may have placed undue pressure on them to participate. Therefore, I abandoned this idea. As it turned out, I had ample opportunity to observe these types of interactions as it was common for health care providers (e.g., HCNs, HSWs, and nurses and counsellors with the palliative response team) to arrive at the homes where I was conducting observations.

occurs. My primary goals were to a) observe family caregiving, b) understand the nature of caregivers' experiences, and c) understand how the context of the health care system influences these experiences. During my observations, I looked for variations in experiences in order to challenge, elaborate, or deepen my understanding of the events that were occurring. The actual "watching" of events unfolded in different ways. Unlike field studies with nurses where ethnographers do "buddy shifts" to observe patient care situations, for example, my observations were less obtrusive. For instance, sometimes (if it was appropriate) I helped with household chores, such as folding laundry or preparing a meal. At other times, I shared a pot of tea with caregivers as we engaged in informal conversations that had little to do with their caregiving. I did puzzles and played with grandchildren and I listened to the war stories of a dying patient. This approach was by design, as I did not think it appropriate to be "standing by watching" as caregivers went about their daily activities. I wanted to be useful and involved in what was "normal" family life. This decision was driven not so much because of my need to become an "insider" (Stewart, 1998), but rather, because it seemed the most natural and ethical approach.

Nevertheless, I was acutely aware that I was working with a highly vulnerable population and that an exploitative potential existed, especially as my relationships with some of the caregivers evolved. These relationships developed over time through informal conversations as I asked questions in order to clarify, validate, and extend my observations when it was appropriate to do so. Oftentimes, these conversations provided me with significant insights that I would not have realized

otherwise. Some of the conversations, though, were of a very personal nature and I had to continually negotiate consent with caregiver participants. There were times, for example, when caregivers shared very private stories with me that they asked not be part of the data. I respected these requests and assured them that I would not record anything with which they were uncomfortable.

Even with these guarantees of confidentiality, I began to see the "real" exploitative potential of research, particularly with women. My experiences were similar to Finch (1993) who explained that, "… the ease with which one can get women to talk in the interview situation depends not so much upon one's skills as an interviewer ... but upon one's identity as a woman" (p. 171). My identity as a woman and as a previous palliative caregiver unquestionably influenced my relationships with caregivers who often shared very private and intimate aspects of their lives. In return, they asked me to share personal stories about my experiences and myself. I took direction from Oakley (1981), who argues that the only morally defensible way to conduct research with women is to create non-hierarchical relationships in which the researcher is prepared to invest some of her own identity. While I shared information about myself when asked, I exercised judgement in these disclosures and I did not volunteer any personal information, keeping in mind that this might be unwelcomed or burdensome to some caregivers (Wolf, 1996).

There were other challenges that I faced and decisions that I had to make in the course of my fieldwork. I struggled to balance my student role as a researcher and my professional role as a nurse. At times, I found it difficult to "sit back and do nothing" (Field, 1991, p. 94) as I watched caregivers struggling to lift and transfer

patients, make occupied beds, and bathe unconscious patients. Although I had not planned to participate in patient care in a direct way, and had clarified this with caregivers at the onset of each field episode, I could not stand back and watch them struggle without at least offering to help in some way. The extent of my involvement was further challenged during one home visit when Henry[57] needed to have his subcutaneous infusion site changed[58]. The site was leaking and causing discomfort so Gwen, the caregiver, made a telephone call to the home care nurse. When the home care nurse did not respond, Gwen called the palliative response team (PRT)[59]. Cathy, the PRT nurse, called back but was unable to come to the home in time for Henry to receive his next dose of pain medication. This caused considerable distress for Gwen, who then told Cathy that I was in the home observing. Cathy asked to speak with me (as we had previously worked together) and suggested that perhaps I could change the injection site and give Henry his next dose of medication. This placed me squarely in a difficult position - demonstrating how clinical roles and ethnographic roles are explicitly intertwined (Lipson, 1991) - as I wanted to ensure Henry's comfort and ease Gwen's distress while needing to exercise some clear judgement about the extent of my involvement[60]. Thankfully,

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[57] All of the names that I use throughout this study are fictitious.

[58] Intermittent subcutaneous infusions are typically used to provide pain relief where rapid titration of a drug, such as morphine, is required or when a patient cannot ingest medications orally or tolerate the rectal route. By using a subcutaneous butterfly needle, it is possible to give intermittent injections without having to repeatedly puncture the patient. Generally, the butterfly needle is changed at least every seven days or more often if required.

[59] The palliative response team (PRT) is a community-based crisis response team. The team is on-call 24 hours a day and responds to crises or instances where family members are in need of support. The team covers a wide geographic boundary and is comprised of a nurse and counsellor, with physician backup as needed.

[60] This situation made me reflect on whether my interactions or observations with Henry and Gwen would have changed had I done the nursing procedure. It is possible that in subsequent visits, Henry and Gwen would have perceived me as a nurse coming into the home to provide care rather than as a researcher who was exploring home-based palliative caregiving. On the other hand, I think it is

Cathy was sensitive to my hesitation and understood that I was in a student role; she quickly arranged for the home care nurse to come and intervene.

Brannen (1988) and Edwards (1993) write about the emotional load that research relationships can place on researchers. Spending extended periods of time working intimately with family members who are providing palliative care can be an intense and emotionally draining experience. I was exhausted each time I left the field and found myself, like Kleinman and Copp (1993), thinking about my field experiences for several days afterwards. I did not anticipate the depth of emotional overload that I would feel even though I had worked in palliative care for many years and was mindful of the emotional aspects associated with the work. I drew on strategies that I have developed over the years to work with my emotions. Reflective journalling, talking with trusted colleagues, and taking time to do the things I enjoy served me well and allowed me to gain perspective prior to my next field visits.

The biggest challenge that I faced was withdrawing from the field. Having built up close relationships with many of the caregivers in the study, I found that leaving the field had to be approached with care and sensitivity. Many family members requested my presence at the funeral of their loved one and this was one way that I was able to gain some closure with family members. I agree, however, with Booth and Booth (1994) who suggest that it is unethical to pull out of the field abruptly just because the process of data gathering is complete. I came to see

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extremely difficult to explicitly differentiate these roles as, in some ways, I was already enacting my role as a nurse by assisting the caregivers with patient care. The relationships I developed because of this likely influenced the research process as the caregivers (and some patients) came to know me and "open up" to me in ways that they might not have had I "stood back" and observed.

withdrawing from the field as a process of mutual negotiation, taking my cue from caregivers and withdrawing from them when I sensed that they were ready. This time of negotiation provided me the opportunity to express my appreciation to family members for allowing me to take part in an emotional and intimate time. In order to show my appreciation, I gave each caregiver a small gift. I chose gifts based on what I had learned about the caregivers over the course of the study. For instance, one of the caregivers explained to me how she had always wanted to paint; she told me a story of how her husband had given her a paint set at a particularly difficult time in her life and how this had helped her to release some of her emotions. I gave this caregiver a small paint set as a token of my appreciation. Another caregiver and I had spent a lot of time snacking on licorice allsort candies and talking about the benefits of journalling. I gave this caregiver a personalized writing journal and licorice allsort candies. To others, I gave flowers and plants, or took them out for a meal. Each of these gifts was personalized with a card that expressed my deep gratitude for their participation.

Some of the relationships that I established throughout the course of this research continue today; not so much because I continue to withdraw from the field, but because I have developed friendships with some of the caregivers who participated. Hammersley and Atkinson (1995) contend that many ethnographers retain friendships and acquaintances from their fieldwork, and I agree with Booth and Booth (1994) who suggest that social researchers should be prepared to engage in extended relationships with vulnerable participants in order to minimize the risk of their field relationships becoming exploitative.

Writing Field Notes

I wrote field notes to generate data from my participant observations. Denzin (1989) suggests that observational notes include explicit descriptions about the people, interactions, and social organizations being observed. Such description includes detailing the visual images, sounds, smells, and gestures, movements, and facial expressions of those in the environment (Emerson, et al., 1995). As a novice ethnographer, I had little experience with writing field notes and was disheartened[61] to find, as Hammersley and Atkinson (1995) point out that,

> … anthropological fieldnotes have often been regarded as highly personal and private documents. Although fieldnotes are the basis of public-domain scholarship, their authors have rarely shared them with other scholars … in particular, fieldnotes seem to be treated as almost 'sacred' objects" (p. 176).

In preparing for my field work, I sought the advice of other ethnographers and eventually came to adopt a style for field note writing that was comfortable for me. I maintained four forms of field notes: (a) a small notebook for "jottings" in the field; (b) a field note journal; (c) a theoretical journal; and (d) a reflective journal. Each time I went into the field, I took my small notebook and made a habit of jotting. However, I felt uneasy as there was little opportunity to jot notes in the home without drawing undue attention to myself and there were many times where note taking would have been inappropriate. I got into the habit of carrying a tape recorder and when it was needed, I would audio tape my observations and impressions while I was driving home. I tried as much as possible to write up my "full" field notes immediately after leaving the field. My full field notes were computer generated and

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[61] I was disheartened in the sense that I was looking for a "recipe" for how to write field notes. Instead, I came to realize that writing field notes is a highly personal and individual experience. Perhaps this is why many ethnographers are reluctant to share their field notes.

had four columns. I wrote in the first column before entering the field as a way of situating myself, recording what I was thinking and how I was feeling that day. When I returned from the field, I recorded narrative descriptions of what I had observed in the second column, acknowledging that what I wrote was selective and based on my own interpretations of events. In the third column, I recorded what I was thinking and feeling in the situation; this became a place to practice reflexivity. Finally, I recorded analytic notes as a way to begin conceptualizing the data. I also used this column to highlight further questions that arose following my field visits. Taking Spradley's (1979) advice, I kept a theoretical journal with me throughout the study to track emerging ideas and questions and to record any new insights. I used this journal to create diagrams, to write theoretical memos, and to make connections between the literature and what I was observing. Ultimately, this journal served to help me appreciate and make sense of the multiple meanings of caregivers' experiences. Finally, I kept a reflective journal throughout the entire project. This journal often provided the means for me to "sort through" some of the emotions involved in fieldwork.

I found the process of field note writing to be labour intensive and more complex than what I had first anticipated. At the same time, I experienced a type of "catharsis" each time I wrote. I learned that developing well-crafted ethnographic descriptions is truly an "art". I agree with Emerson and colleagues (1995) that,

> Writing descriptive accounts of experiences and observations is not as straightforward and transparent a process as it might initially appear. For writing description is not merely a matter of accurately capturing as closely as possible observed reality, of "putting into words" overheard talk and witnessed activities. To view the writing of descriptions simply as a matter of producing texts that *correspond* accurately to what has been observed is to assume that

there is but one "best" description of any particular event. But, in fact, there is no one "natural" or "correct" way to write about what one observes. Rather, because descriptions involve issues of perception and interpretation, different descriptions of "the same" situations and events are possible (pp. 4-5).

Conducting Interviews

Interviewing is a predominant mode of data collection in qualitative research (Bernard, 1995; Fontana & Frey, 1994). Ethnographic interviews are now commonly understood as collaborative, communicative events that evolve and that occur in a context permeated by issues of power, emotionality, and interpersonal processes (Hammersley & Atkinson, 1995; Holstein & Gubrium, 1995; Kvale, 1996). As such, many scholars draw attention to the relational aspects of interviewing and highlight the intersubjective and transactional nature of knowledge development (Langellier & Hall, 1989; Oakley, 1981). In-depth, open-ended interviews were conducted in a reflexive manner with participants as a way to contextualize and augment data generated from my participant observations. Formal interviews[62] were conducted with 10 active caregivers, 47 previous caregivers, 25 health care providers[63], and 10 administrators. I also engaged in a number of informal interviews during the course of my fieldwork and used my field notes to record insights gained from these unstructured conversations.

I constructed interview guides for each participant group (see Appendix H), but remained flexible and open to exploring variations in participant experiences. Indeed, as Hammersley and Atkinson (1995) explain:

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[62] I was fortunate to obtain research funding for this project and was able to employ research assistants to help conduct some of the formal interviews and a typist to transcribe them. The research assistants only conducted interviews with previous caregivers and with health care providers; they did not conduct any participant observations. All of the individuals employed for this project signed an agreement of confidentiality (see Appendix G) prior to employment.

> Ethnographers do not usually decide beforehand the exact questions that they want to ask, and do not ask each interviewee exactly the same questions, though they will usually enter the interviews with a list of issues to be covered. Nor do they seek to establish a fixed sequence in which relevant topics are covered; they adopt a more flexible approach, allowing the discussion to flow in a way that seems natural (p. 152).

I used my initial interviews and observations to create a conceptual scheme and then began a second "round" of interviews and observations to validate and extend my understandings of the data. As the data analysis progressed, the nature of the interviews changed with the questions becoming more specific. This specificity assisted in gaining further information, testing preliminary findings, and looking for commonality and differences (May, 1991). I had planned to conduct more than one interview with several of the participants. However, I found that additional interviews were not required as I used the second round of interviews to clarify and validate previous interpretations. When I did require clarification or a situation arose in the interview from which I wanted to learn more, I conducted follow-up telephone interviews.

All of the interviews were audio taped except for interviews with four participants who were uncomfortable talking on tape. In these instances, I asked permission to take brief notes during the interview and later used them to write full field notes. The interviews lasted between one and three hours. All of the interviews with active caregivers and most of the interviews with previous caregivers occurred in their own homes. Some previous caregivers preferred to meet at my research office to be interviewed. This environment was somewhat more "sterile" but I respected their choice and attempted to make the setting as comfortable as

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[63] Of the 25 health care providers, 12 participated in focus group interviews.

possible (e.g., offering tea, getting comfortable chairs). All of the interviews with health care administrators took place in their work setting. Some health care providers were also interviewed in their work setting and some were interviewed in their own homes. All of the audio-taped interviews were transcribed verbatim. After each interview, a brief summary was written to emphasize initial impressions. These summaries often generated "rich" insights and were used to set the direction for exploring new ideas and themes. In order to demonstrate my appreciation to the participants, every participant was sent a personalized hand-written thank you card.

Focus group interviews (Kreuger, 1993; Morgan, 1988) were conducted with two groups of HCNs and with one group of HSWs. An interview guide similar to that used for the in-depth interviews was used by the facilitators (two per group, with one person as the lead and the other serving as note taker and assistant) to assist with the discussion. The focus group with HSWs occurred in a meeting room at a local health unit. Focus groups with HCNs took place in the home setting when nurses volunteered their homes for the group meeting. The interviews lasted approximately two hours and, with the participants' consent, were audio taped and later transcribed. Using the focus group interview technique was particularly helpful in stimulating group discussion and provided insights and generated data that were less accessible without the stimulus of a group discussion.

My approach to interviewing remained open throughout this study, even when the questions became more specific. This approach helped to maintain the flexibility that I was hoping to achieve and created opportunities for generating new insights. I came to see the interviews as a two-way process of collaborative "meaning making"

rather than a way to "get information", and concur with Ellis and Berger (in press) who explain that:

> The interviewing process becomes less a conduit of information from informants to researchers that represents how are things are, and more a sea swell of meaning making in which researchers connect their own experiences to those of others, and provide stories that open up conversations about how we live and cope (p. 8).

The risks inherent in conducting research on sensitive topics have been well documented (Cassell, 1978; Kaslow & Gurman, 1985; Kavanaugh & Ayres, 1998; LaRoss, Bennett, & Gelles, 1981). While many of the caregivers in this study commented on the therapeutic benefits of the interviews (Hutchinson, Wilson, & Wilson, 1994), I was continually aware that the interviews could bring forward strong emotional reactions[64]. Many times, caregivers cried as they shared their stories and talked about aspects of their caregiving experiences. Caregivers were always asked, with sensitivity, if they wanted to stop the interview. Mostly, caregivers wanted to continue but there were instances where I exercised judgement when I thought that the interview was becoming too overwhelming. Research on sensitive and emotional topics has raised questions about the boundaries between the researcher and the researched, and some scholars have considered how to react if the participant asks for help (Lieblich, 1996; Miller, 1996). While none of the caregivers in this study asked for assistance to work through their emotional upsets, I did carry a list of contact numbers with me to provide to

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[64] Because of the sensitive nature of the interviews, I chose to employ research assistants more for their background in palliative care than for their qualitative research experience. Having previously worked with these nurses, I knew that they displayed extreme tact and sensitivity in their relations with clients. Although employing individuals with little experience in conducting qualitative research interviews created much more work for me (e.g., training, providing ongoing feedback on interviews) I was more concerned about ensuring that the participants remained "emotionally safe".

participants if they asked. In particularly difficult interview situations, a telephone call to the participants was made a few days later to check up on them.

Although I entered this study having thought through many of the possible "ethical issues" that could arise, I did not consider the potential for harm to myself or members of the research team. I was only alerted to this potential midway through the study when I was arranging an interview with Brian, a caregiver who had previously provided palliative care to his wife who had died at home. In negotiating a location for the interview, Brian questioned whether my coming to his home might put me, "as a woman", in an awkward or unsafe situation since I had previously not met him. This conversation totally changed the way I conceptualized and approached the interviews; it made me more alert to the potential for harm and made me realize how easily I put trust in people. It also made me consider how having my picture in the newspaper advertisement might place me in a vulnerable position.

I discussed this issue at one of our research team meetings[65] and we devised a strategy to minimize potential dangers. For example, I had arranged an interview with Colin, who asked if I could come to his home in the evening as this was when his wife slept and when he would have more time to devote to the interview. I informed a team member of the date, time, and location of the interview and took a cellular telephone with me. I called my teammate prior to and after the interview to let her know that I was safe. However, I realized that even this strategy did not offer full protection from potential harm when I became uncomfortable in my

conversations with Colin and did not see a way of sensitively departing. After this incident, I considered having two people attend each interview but this was difficult to organize. I took some assurance in the strategy that we developed, and in the fact that I had previous experience with home visiting in my professional role and had dealt with similar situations in the past. However, I always kept the potential dangers in mind and did not go into any situations with which I was uncomfortable.

Collection of Documents

Ethnographers working within a critical paradigm often use existing texts to augment data generated from participant observations and interviews (Campbell & Bunting, 1991; Stewart, 1998). Such supplementary information contributes to evolving analytic frameworks (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997) and provides context to interview and observational data (Hammersley & Atkinson, 1995). I collected texts in the meso context (e.g., local news stories, regional policies, and reports) and in the macro context (e.g., provincial and national documents/policy statements, news clippings, magazine articles), focusing on compiling materials pertaining to home-based palliative care and caregiving issues. Acknowledging the enormity of information that could be collected, I limited the search to Canadian documents that had been written in the past ten years and sought information from specific sources[66]. The search was primarily conducted by accessing internet web sites and by contacting community-based organizations,

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[65] The research assistants and I met frequently during data collection to discuss issues that arose from our interviews. These meetings (often breakfast meetings at my home) became an important source of support for me throughout the study.

[66] For example, I searched for news stories from most of the major newspapers in each province and from both the National Post and the Globe and Mail. I searched popular news magazines and on-line web sites, and searched for provincial and national reports and policies on palliative care and on home care.

ministries of health, and research institutes, to see if they had produced any reports or policies that could be included in the review. By reviewing the reference lists of some of the more pertinent documents further sources were found.

"Making Meanings": Data Analysis

Despite the proliferation of qualitative research methodology texts detailing techniques for conducting a qualitative project, the actual process of data analysis remains poorly described (Morse, 1994). Yet, one of the most daunting challenges that face qualitative researchers is what to do with the data once it has been collected (Sandelowski, 1995a). Sandelowski (1995a) maintains that the analysis of qualitative data overlaps temporally and conceptually with data collection. In ethnography, analysis involves the concurrent process of developing categories and conceptual themes and discussing, verifying, and extending interpretations in an interactive fashion with the participants (Hammersley & Atkinson, 1995). As such, I conducted analysis concurrently with data collection.

Using the constant comparative method, analysis began immediately following the first interview and episode of participant observation. The analysis proceeded by first reading a "hard copy" of the interview and field note data to get a sense of the whole (Morse & Field, 1995; Hammersley & Atkinson, 1996; Sandelowski, 1995a). On my first "read" of the data, I listened to the interview tape and followed the transcript carefully, noting any subtle nuances or initial insights. Then, I read the transcript again, writing "margin notes" and comparing the interview and observation data where appropriate. The computer files containing the transcript data were then copied to the computer software package NVivo (Richards,

1999)[67]. These data were then coded in NVivo and analytic memos were written to highlight key categories and to identify areas that required further elaboration and clarification. I also read and re-read my field notes, coded them, and then included these coded sections in my coded computer files. Categories generated from the analysis were compared within and between transcript and field note data in order to clarify their meanings and explore their relationships.

The second group of interviews and observations was used to refine, modify, and reject or confirm the interpretations generated from the constant comparative process. I sought clarification by asking some of the participants to reflect on the categories and to evaluate their relevance. This kind of dialectical interaction between the data, the participants, and the researcher assists in raising new questions, gaining further information, testing preliminary categories, and looking for commonality and differences among the participants' stories (Lather, 1991). I used the strategies of memoing and diagramming (Morse & Field, 1995) throughout the data collection and analysis process as a further means to compare and verify my interpretations, and to provide a visual representation of my evolving analytic scheme. Moreover, meetings with the research assistants provided an opportunity for me to "interview the interviewees" and gain their perspectives on the knowledge generated from the data and my interpretations of it.

The various documents that I collected for this study were reviewed and then critically examined, paying particular attention to the language used and how

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[67] I was aware of the cautions associated with the use of qualitative computer software programs (Sandelowski, 1995b), but using NVivo helped immensely in managing the amount of data that I had collected. I used the program as a data management tool, and used it to code and retrieve data sections.

dominant ideologies were reproduced in the text (Fairclough, 1989; van Dijk, 1993).

A brief summary of each document was written, coded, and then these coded

sections were included in my computer generated data files. A critical analysis of

these texts contributed to the development of theoretical arguments and to my

analysis of the broader context of the study[68].

While the steps to data analysis are outlined sequentially, the analysis was an

iterative process and continued throughout the study as I wrote and rewrote, and

reconceptualized, my interpretations. For example, during my first round of analysis,

I used the code "entering the war zone" to depict caregivers' previous hospital

experiences as this data segment illustrates:

> When you're in there [the hospital], things kind of put you on edge and I didn't
> have 100% trust that my Mom was getting the care she should have been
> getting....That was the precursor to a lot of things and that's one of the
> reasons Mom didn't want to be in the hospital for too long....Because it was
> like, she wasn't being treated the way she should have been when she was
> dying....I felt when I went in there [the hospital], it was like I was entering a
> war zone.

"Being treated like a number" was another code that illustrated caregivers' previous

experiences with hospital care:

> I think the trouble with the hospital is that you're basically treated like a
> number. There is no personalized approach and you're just the next person
> in line to get whatever care has to be done that day. I mean, we all know that
> the hospital is short staffed and they [the nurses] don't have a lot of time but I
> mean, I guess that's one of the reasons why we thought it was better to have
> Dad at home. You're just treated like a number.

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[68] I had planned to use critical discourse analysis procedures as a means to examine the documents
collected. However, I became overwhelmed with the amount of data that I had from the interviews
and observations, and learning a new data analysis technique added further complexity to my study.
I decided to treat the data from the documents as collateral to my interview and observation data,
although I examined these texts through my critical interpretive lens.

As the analysis progressed, I collapsed these two codes into a broader category entitled "Institutionalized Health Care Practices". During this phase of analysis, I hypothesized that previous experiences with institutional care influenced caregivers' decisions to provide palliative care at home. My second round of interviews and observations confirmed this hypothesis and the category of Institutionalized Health Care Practices was then conceptualized as a factor influencing caregivers' decisions to provide home-based palliative care. This category was then subsumed under the broader theme entitled "Making the Decision" (see Chapter Four).

The analysis was multi-layered, taking into account the individual experiences of family caregivers and then extending the analysis to include how the organization of health care, health care reforms, and dominant ideologies influence these individual experiences. Comprehending, synthesizing, theorizing, and reconceptualizing the data generated from this study contributed to shaping the development of theoretical arguments that linked the themes and categories together and, thus, created a composite description and critical examination of the social context of home-based palliative caregiving.

Scientific Integrity

It is now widely recognized that the positivist traditions of reliability and validity cannot be applied when assessing research conducted in the qualitative paradigm. Strategies for ensuring the scientific integrity of qualitative research have been discussed and debated extensively (Anderson, 1989; Lather, 1991; Lincoln & Guba, 1985; Sandelowski, 1993; Wolcott, 1990) and there has been an unprecedented criticism of the standards by which social scientists use to evaluate

ethnographic interpretations (Altheide & Johnson, 1994). Stemming from the reflexive turn in ethnographic practice over the past two decades, considerable discussion about the "crisis of representation" and the "legitimation crisis" has made problematic two key assumptions of qualitative research: that qualitative researchers can no longer directly capture lived experiences; and that the criteria originally proposed for evaluating and interpreting qualitative research are no longer tenable (Denzin, 1997). Post-structural and critical social science critiques that challenge traditional post-positivist arguments concerning validity have led some scholars to recommend that a new set of criteria, to assess the scientific integrity of qualitative research, be constructed, specifically criteria divorced from positivist and post-positivist traditions (Ellis & Flaherty, 1992; Richardson, 1994). At a minimum, however, the ideas of reflexivity, triangulation, face validity, auditability, and generalizability appear to be major routes for assessing and evaluating research conducted in the critical paradigm (Lather, 1991; Lincoln & Guba, 1985).

Reflexivity

Reflexivity is one of the major routes to validity in ethnographies informed by critical perspectives. Some authors argue that reflexivity is not simply a luxury but a necessary means by which to achieve scientific quality (Lather, 1991; Lee & Ackerman, 1994; Wolcott, 1990). Reflexivity is defined as a "process in which an investigator seeks to understand how personal feelings and experiences may influence a study and then strives to integrate this understanding into the study" (Lamb & Huttlinger, 1989, p. 765). As such, reflexive research is imbued with a scrutinization of one's own positioning in relation to the research (Hall & Stevens,

1991). Reflexivity involves a dialectic process among "(a) the researcher's constructs, (b) the informant's commonsense constructs, (c) the research data, (d) the researcher's ideological biases, and (e) the structural and historical forces that informed the social constructions under study" (Anderson, 1991, p. 254). I "practiced" reflexivity throughout this study by dissecting my own assumptions and biases and examining them in relationship to my interpretations and decisions. For example, as previously mentioned, I entered this study believing that the idea of dying at home was in need of critique. Throughout the data collection and analysis process, I continually examined this assumption, trying to understand how my own experiences with being a caregiver might influence the ways in which I asked interview questions and interpreted the data. Reflective journalling, talking with colleagues, and writing field notes facilitated reflexivity.

Triangulation

According to Lather (1991), triangulation is critical in establishing data trustworthiness. While some authors advocate for and outline strategies to enhance methodological triangulation (Goodwin & Goodwin, 1984; Morgan, 1998; Morse, 1991b), others highlight the importance of "within-method" triangulation (Jick, 1979; Lather). Triangulation in this study was achieved by collecting data from different sources (e.g., family caregivers, health care providers, administrators, document review) and by using various data generating procedures (e.g., interviews, observations, field notes, diagrams, memos). I used triangulation as a way to expose differing viewpoints in the data when they existed and to look for congruence in the data.

Face Validity

Face validity speaks to whether research participants are represented in ways that they can recognize. In other words, is the data credible to and does it fit for the participants? Face validity[69] is operationalized by "recycling description, emerging analysis, and conclusions back through at least a subsample of respondents" (Lather, 1991, p. 67). In this study, I asked some of the participants to comment on my beginning analyses and to challenge my interpretations. I also used the second round of interviews to extend my analyses and establish data credibility. These "member checks" assisted in establishing the trustworthiness of the data. However, I recognize that there are inherent problems associated with member checking and that this strategy alone cannot fully establish data credibility. I agree with Lather who concludes that:

> Perhaps the best that can be suggested at this point is that, just as reliability is necessary but not sufficient to establish validity within positivism, building face validity into our new paradigm research should become a necessary but not sufficient approach to establishing data credibility (p. 68).

Data trustworthiness was further established by supporting my theoretical arguments with ethnographic data from this study and, as suggested by Morse and Field (1995), verifying some of these findings with existing bodies of literature.

Auditability

Creating an auditable research decision trail is the criterion proposed by Sandelowski (1986) for judging consistency in qualitative research. Hammersley

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[69] Lather (1991) has reformulated face validity to "'catalytic validity" or the degree to which the research process acts to re-orient, focus, or move participants to some action. Lather contends that catalytic validity has been achieved if respondents further self-understanding and ideally, self-determination, through their participation in the research. While I am drawn to the concept of catalytic validity, the emancipatory underpinnings behind this approach are problematic for this study.

(1997) argues that the research process can never be made fully explicit because the means for which data can be considered cannot be specified completely. Further, it is difficult to crystallize the research process because the process of analysis is a socially embedded, emergent process of learning characterized by non-linear cycles of comparisons between units of data and a range of other mental activities (Stewart, 1998).

While recognizing the challenges of crystallizing a decision trail, I have, in the process of writing, attempted to detail how the research process unfolded, how and why I made certain decisions, and how I approached data analysis. The practice of critical reflexivity that infused the entire research project assisted in delineating my decision trail. In order to facilitate further consistency, I used standardized information letters, consistent methods for data collection[70], and developed a coherent and consistent format for my field notes.

Generalizability

Generalizability has commonly been defined as the "extent to which research findings can be applied across, and are considered relevant to, different persons, settings, and times" (Johnson, 1997, p. 191). The concept itself has been contested within qualitative research circles as being an inadequate criterion upon which to

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[70] One of the challenges that I faced was in finding ways to promote consistency while working within a research team. Although I was the only individual conducting participant observations and interviews with active caregivers and administrators, the research assistants helped me in conducting interviews with previous caregivers and health care providers. While I am aware that having different people assist with data collection may have threatened consistency, regular meetings of the research team allowed us to discuss our approaches to data collection and ensure that we were being consistent with them. Further, all of the research assistants participated in a research training program prior to the study commencing so that they could learn about the approaches I was using for data collection.

evaluate research in the qualitative domain. Several scholars have argued that traditional notions of generalizability, founded upon positivist ideals, serve to decontextualize individual experiences (Donmoyer, 1990; Guba, 1981; Schofield, 1990). As such, the concept of generalizability has been reconsidered as a way to apply or transfer knowledge across settings, facilitated by what Geertz (1973) terms "thick description". According to Johnson, thick description aids generalizability in that it helps the reader judge whether findings in one study context fit similar contexts.

Although I have used the ethnographic data presented throughout the findings chapters to provide an in-depth description of family caregivers' experiences, some of the findings in this study were influenced by local history related to the development of home-based palliative care. While the organization of palliative care and home care share similarities across Canada, it must be acknowledged that local contexts have influenced the experiences of caregivers in this study. These local influences, therefore, must be considered when judging the extent to which caregivers' experiences are fully represented across settings. Furthermore, only English speaking persons were interviewed and observed in this study. Thus, the influence of cultural differences, which may influence how care is provided in the home setting, was not explored in this study. Supplemental data, such as provincial reports, national reports, and policy statements, assisted in enhancing generalizability and the testing and refining of study findings have contributed to theoretical generalizability (Morse & Field, 1995). Nonetheless, I fully

acknowledge that the ability to produce fully generalizable conclusions based on the data, is limited.

Ethical Considerations

Research on sensitive topics can pose a potential threat to those involved (Lee & Renzetti, 1990). The private and intimate nature of family life imposes unique constraints and raises distinctive ethical issues for investigators using qualitative methodologies (Larossa, Bennett, & Gelles, 1981). I anticipated that ethical issues might arise (as I have already discussed) and, thus, prior to beginning this study, I tried to clarify broad ethical principles that would guide my investigation and mediate relationships with the participants. I took guidance from the standard ethical principles of nonmaleficence, beneficence, autonomy, and justice (Arras & Steinbock, 1995). Layered onto this were feminist contentions that ethical relationships involve recognizing the interdependent, emotionally varied, and unequal relationships that imbue research and practice (Sherwin, 1992a). As a researcher informed by critical perspectives, I carried a heightened awareness of the potential for ethical issues to arise throughout the entire project.

I obtained ethical clearance for this study from the University of British Columbia, Behavioral Sciences Screening Committee and from the ethics committee of the health region where the study occurred. Informed consent was obtained prior to the initiation of data collection (see Appendix I for Consent Forms). There were a few incidents in which informed consent could not be obtained. For example, some patients were not well enough to provide consent to be observed. Thus, family members consented on their behalf. There were also times when I was observing in

the home and home health care providers would arrive. In those cases, I explained my presence, the overall purpose of the study, and told them that I would not take notes on my observations of them against their wishes. Most of the health care providers were supportive of the research and consented to be observed. For those who were uncomfortable, I did not include them in my observational notes.

While formal consent forms were signed prior to the first interviews and observations, I considered consent to be an ongoing process and continually negotiated and renegotiated consent with each participant, paying particular attention to any indications of hesitation from them (Merrill & Williams, 1994; Manhole, 1988; Ramous, 1989; Williams, 1995). Such "process consent" is considered particularly important in research projects where circumstances are likely to change and unexpected events are likely to occur (Munhall, 1988). The ongoing negotiation of consent was especially important in this study in order to minimize the obligation that some participants might have felt to participate because of their previous association with me in a professional capacity. I was also very aware that caregivers might feel burdened by my presence in their homes, and I made ongoing attempts to ensure that my presence was non-invasive and respectful as possible.

As well as obtaining written consent, I also provided every participant with verbal and written explanations of the research and what it entailed. I assured participants that their involvement was entirely voluntary and that they could withdraw from the study at any time, refuse to answer any questions, or terminate an interview or observation if they were uncomfortable. Confidentiality was assured by assigning a numerical code to each participant that was used on all materials

pertaining to them. All identifying information within the transcriptions of the interviews and field notes was altered to assure anonymity. Access to the data was limited to myself, my co-supervisors, the research assistants, and a transcriber. The audio tapes, field notes, and transcriptions were all kept in a locked filing cabinet and any documents that identified the participants were kept separate from the data. The data were not destroyed at the end of the project as I obtained consent from the participants to retain it for use by me, for other research purposes (e.g., to answer research questions that are beyond those specified in this study).

Summary

In this chapter, I have outlined the research methodology and the methods that I have employed to generate data. The strategies that I used to make meaning of the data have been highlighted, as have the ways in which I have attended to scientific integrity and ethics. I now turn to Chapters Four, Five, and Six where I present the findings of this research, providing a detailed description and critical analysis of the social context of home-based palliative caregiving.

CHAPTER FOUR:

DYING AT HOME: THE INDIVIDUAL CONTEXT

It is challenging to present qualitative data in a way that precisely represents the stories, lives, and experiences of those who participated in this study. Invariably, the narratives and texts are infused with meanings that are both complex and multi-layered. The experience of caring for the dying at home is not a simple or straightforward phenomenon but, rather, is an experience built and shaped by many intersecting factors. Caregiving does not occur in a vacuum but is influenced by many conditions including health care practices, the organization of health care systems, reforms in health care, societal values, and ideologies. Therefore, presenting a coherent story that highlights these influences and that also accounts for the diverse and sometimes contradictory perspectives of the participants is a challenging task. This particular representation attempts to bring clarity to the complex nature of family caregiving at home while, at the same time, illuminating the variations and contradictions that are expectedly present in the data.

While I began my study by seeking to understand the experiences of home-based family caregivers, I incorporated the perspectives of home health care providers to extend my conceptualizations. Such a focus helped to solidly root my interpretations in caregiver experiences while providing an opportunity to advance my initial understandings. These initial understandings then provided a platform from which to seek further understandings about the social context of home-based palliative caregiving.

I began this study by asking caregivers to talk about how they came to be caregivers. This beginning served as an entry point for developing my initial understandings. The findings presented in this chapter represent my interpretations of the participants' constructions of home-based palliative care. Specifically, I begin by discussing how caregivers came to make the decision to engage in home-based caregiving, highlighting those factors that influenced their decision-making. In the section entitled, living with the decision, I present a detailed portrayal of the provision of palliative care in the home and discuss how such care influences caregivers. Factors that influence caregivers to change the decision will also be described. The interpretations presented in this chapter provide the foundation for then exploring how larger structures and processes influence the palliative home caregiving experience (Chapters Five and Six).

Making the Decision

Initially, I was most interested in understanding how family members came to be home-based caregivers. In this section, I explore how decisions were made and how making a promise to provide care at home influenced caregivers' lives. I then describe those factors that shaped caregivers' decisions, explicating the themes of maintaining normalcy and previous experiences with institutionalized health care practices. I conclude this section by drawing attention to how caregivers often made decisions without knowing what lay ahead.

Variations in Decision Making

There was significant variability in how the caregivers who participated in this study made decisions about providing palliative care at home. The decision-making

process was unique for each individual and family situation, and was dependent on a myriad of factors: previous family relationships and coping skills; a willingness to discuss death and dying within the family; prior experience with organized health care; and so on. While each family situation was unique, there was some commonality in how caregivers constructed their decisions; they made snap decisions, indifferent decisions, and negotiated decisions.

Decision making has typically been understood as a process that involves consideration of the implications of a particular decision (Swigart, 1995). Studies examining the decision-making process of caregivers of the elderly indicate that caregivers often take many months to contemplate decisions regarding care provision for their family members (King, Collins, Given, & Vredevoogd, 1991; Wackerbath 1999). Rather than decision making being constructed as a contemplative process, however, many caregivers in this study made *snap decisions*, with little attention given to considering the implications. These caregivers said the decision was "something I hadn't really thought about, I just had to do it" and that dying at home was the "only way that we ever thought about the situation". Recognizing the imminence of death helped some caregivers make snap decisions, believing that an end was in sight and that their caregiving period would be short.

Contrary to the popular opinion that "families", if given a choice, prefer palliative care to occur at home (Bowling, 1983; Collett, 1997; Moore, 1993; Thorpe, 1993), caregivers in this study acknowledged[71] they sometimes felt they had little or

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[71] Most of the caregivers who spoke about their experiences with having little choice were previous caregivers. They told me that when they were actively caregiving, it would have been difficult for

no choice in making the decision. Rather, decisions were driven by the patient's[72] needs, with caregivers (and patients) giving little consideration to their own needs. The caregivers' and patients' wishes often did not coincide, resulting in *indifferent decisions*. When patients simply made the decision to stay at home without consulting their family caregivers, or when patients assumed that their family members would be able to care for them, indifferent decisions often resulted, as this wife of a dying patient indicated:

> He didn't even think about how this would all impact me. He just said, "You can do it, the girls will help you". I was saying to him that the girls have jobs and children and they can't always be around. It was really hard for me for awhile. I'd just go upstairs and cry. He was so stubborn. If he would have been more accepting of his disease it would have been easier for me but he just wouldn't have any of it. He just wanted to be here [at home] and that was that. It didn't matter that I wasn't sleeping or eating or anything. So I just became indifferent to the whole thing and did what I had to do.

According to health care providers who participated in this study, women[73] are most commonly placed in positions of making indifferent decisions. For example, when male patients failed to see the burdens associated with caregiving and considered only their own needs, their female family caregivers were more likely to make indifferent decisions. Indifferent decisions were indicative of a caregiving situation that was going to be difficult:

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them to reflect on whether or not they had choices because they had to maintain an attitude of optimism in their caregiving and felt guilty even thinking about themselves and their needs. I did not explore the "choice" issue with active caregivers unless they brought it forward and then proceeded carefully with these discussions.

[72] I am uncomfortable using the word "patient" to describe a person who is dying at home. This term is commonly reserved for people being cared for in an institutional setting and can serve to objectify people in their own home environments. I wanted to acknowledge that people who were dying at home were people first (as they are in institutional settings) and I did not want to contribute to a re-creation of the hospital at home (a theme that is explored later in this chapter). At the same time, referring to the "dying person" or the "family member who is dying" became somewhat redundant and confusing in this writing. Therefore, I have used the term "patient" when it seemed appropriate but am problematizing it here so that my sentiments are not linguistically buried.

What you find sometimes, particularly with older men is that they have no idea of how much strain it is on their wife. They just say, "Well you can manage". And the poor woman's just about on her knees and they just can't see it. Some people, when they are dying, are incredibly selfish. Everything rotates around them and they have no insight. That's when you know that it's probably going to be a difficult situation all around.

The providers confirmed that caregivers' decisions are often dependent on the preferences of the dying family member. In their desire to be supportive, they observed that caregivers reluctantly agree to provide care even when they lack confidence, are fearful that they will "do something wrong", or when they have little understanding of the responsibilities involved in caregiving. Yet, as this palliative care provider claimed, some caregivers are reluctant to disclose their ambivalence, thinking only of the needs of the dying person:

Most of the patients that I see want to stay at home. Probably some of the caregivers want them to as well but not necessarily because *they* want it. They'll often say, "Well my Dad really wants to stay here, but we don't know if we can take this". The client usually drives the decision, saying that they want to stay at home. Then I think the family tends to support that decision. But there is some ambivalence....They really don't want to talk about it.

The providers cited numerous instances where patient and family wishes did not coincide. In some cases, the providers stepped in to counsel against vulnerable caregivers taking on too much. At other times, the providers encouraged dying at home even when caregivers were reluctant. The providers suggested that caregivers' reluctance results from lack of awareness of available help. When aware, the providers observed that caregivers often reconsider their initial decisions:

Sometimes they've [caregivers] made a decision that they just couldn't possibly care for this person at home, that it would be just too big of a job. They don't see any alternatives. Then sometimes we arrive on the scene and show that things can be done, particularly for people at home, to make them

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[73] Other research has pointed to the gendered nature of caregiving (Aronson, 1992; Bunting, 1992; Rutman, 1996; Wuest, 2000).

> more comfortable and to make things work a lot better for them. Then they will go, "Oh yeah, I guess we can stay at home now and you're going to help us do that". So, a lot of people I find change their minds.

However, a few of the providers admitted to me after an interview that they were re-thinking their ideas about dying at home. One home care nurse questioned how her assumptions about home-based palliative care might inadvertently influence her approach with families. Having held strongly to the belief that dying at home had significant benefits for families, she later theorized that caregivers' reluctance might be a "sign of trying to exercise choice" (Field Notes, November 1999). She acknowledged that offering options for help was necessary but that this act could also place added pressure on caregivers, especially when they and the patient disagreed on the location for palliative care.

Like other study findings (Davies, et al., 1995), some caregivers in this study viewed the decision as an opportunity to reciprocate, indicating that their decision to provide care at home was a final act of love and reciprocity:

> It was an act of love and reciprocity. Whatever he wanted was what I was going to go for. That's all there was to it....If my Dad wanted to go into the hospital, I would have taken my Dad to the hospital. It's whatever he wanted. I was honouring his wishes, and there was no choice in that. I don't mean that begrudgingly. I was proud to look after him and care for him. It's the last thing I ever did for him.

While some of the caregivers made snap decisions and indifferent decisions, others negotiated the decision, engaging in open discussions with the patient. Both the caregivers and dying patients initiated such discussions when they were both aware of and open to talking about dying as previous research has found (Hinton, 1998) and as the following passage implies:

My Father wanted to talk to me about his going home. He asked me, "What do you think about me coming to your home?" I said, "We want to look after you at home" but he thought it would be too much work. I told him that we [the family] would all chip in but he was concerned that there was no room at my house and I said to him, "What do you mean there's no room, you can have a whole bedroom". But then he said, "Well what if I die in that bed, would it ruin the bed for you?" And I said, "No, in fact, it will endear the bed to me". But we went through this kind of negotiation all along the way. I was lucky that my Dad was so open about it.

Based on my observations and interviews with the caregivers and providers, families who negotiated decisions coped better with home caregiving than those who made snap decisions or indifferent decisions. The caregivers who made snap decisions typically did not consider the implications of their decisions and often felt overwhelmed by the responsibilities of caregiving, particularly when it became prolonged. The caregivers who made indifferent decisions, and who were unable to talk about their reluctance tended to minimize their needs, deferring to the needs of the patient. For some of the caregivers, temporarily placing their needs aside was a final gift -- something they would do again in similar circumstances. For other caregivers, however, lasting feelings of anger and resentment surfaced and coloured their bereavement; they were not sure they would ever engage in caregiving again. These caregivers did not feel that they had a choice and were more likely to be those who made promises that they were either unable to keep or were able to keep but with notable consequences.

Making Promises

Similar to findings in my masters' thesis (Stajduhar, 1995; Stajduhar & Davies, 1998a), the decision to provide palliative care at home was most commonly made in the form of a promise that the caregivers made to their family member. This

promise was often made out of a sense of duty or obligation. Such "loving

indebtedness"[74] stemmed from the caregiver's desire to respect the wishes of the

dying family member as this daughter suggested:

> For me it was just a promise I made. I don't want to say that it was a duty or an obligation but it was more like ... loving indebtedness. I just really wanted to be able to give him what he wanted. I respected that he didn't want to be in the hospital and I didn't even think about it.

One wife explained that her promise was tied to the commitment of her marital vows;

this provided her a sense of accomplishment and pride in knowing that she was able

to fulfill her vows:

> It was just a promise I made to him....I said to my husband, "I'll look after you". And that's what I did. To me that was what was ... it was part of our vows to one another. That was for better or for worse....I felt so good about it ... that I could do this for him and that I could actually do this. It was quite a sense of accomplishment.

The health care providers also described the accomplishment that caregivers felt in

their roles, highlighting that even while exhausted, many caregivers naturally cope

with the demands placed on them:

> When a person has made a promise and they've been able to hold to their promise, they feel some kind of accomplishment. They feel like a champion you know? They've fulfilled the promise and that really helps them feel good about themselves. However, it may have done a lot of damage to them in terms of them feeling completely exhausted. But people do cope because we provide them with a lot of support. It always amazes me to see how well people cope....There is an amazing number of people that do it really well naturally.

> Previous research indicates that family caregivers receive specific benefits

from caregiving (Brown, et al., 1990; Kinsella, et al., 2000; Higginson, et al., 1990).

Despite these benefits, the promise created a high degree of distress for many

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[74] Some of the caregivers were hesitant to label their caregiving as a duty or obligation. "Loving indebtedness" was a term used by one caregiver to characterize her reasons for caregiving.

caregivers in this study once they began to realize the impact of their decision. The caregivers who were challenged by the daily demands of their role, sometimes regretted the promises they had made, particularly when they were placed in positions of having to break their promises. As one wife caring for her husband with cancer explained, breaking the promise carried considerable consequences:

> That [promise] came back to haunt me in those last couple of weeks. I think he [the doctor] was trying to tell me something that I didn't really know and then when it got too much, at the very last minute, almost the last conversation I had with my husband was about trying to force him into palliative care. Trying to convince him that this was best. How do you think that made me feel? That was terrible. That was a guilt trip that you couldn't believe....That's the worst feeling, because you don't want to do it. Because, you have promised. You feel so guilty. You feel like a failure, as though you are letting this person down. You've had to renege on your promise to let him stay at home. It's awful. You're basically saying, "Sorry, I'm too weak, I'm giving up". And that's exactly how I felt.

Some of the caregivers did not deviate from their promises, even when the home caregiving situation became exhausting. I witnessed a caregiver struggle with the promises that she had made to her husband as recorded in my field notes:

> Margaret told me "It's just getting to be too much for me". While I was at their home today, five different providers showed up. It just seemed like there were people coming in and out and in and out -- just a constant stream of faces. Margaret said she is getting "Fed up with it all" and she is having difficulty coping with the constant demands. She said, "Wayne is expecting so much of me". Margaret wants to keep caring for Wayne but she said, "I'm coming to the end of my rope". I asked Margaret what she thought she might do and she said to me, "What can I do? There is no way I'm taking him back there" [the hospital]. Margaret is determined to keep Wayne at home, but she is visibly exhausted. She said to me, "I'm in this until the end, whatever it takes, I'm not going to go back on my word" (Field Notes, November 1999).

The home care providers disclosed that even in the most seemingly difficult circumstances, caregivers persevered to maintain their promises:

> There are families that try to make a situation that looks absolutely bloody unworkable into something that's going to work. When you look at the

situation you think, oh my God, how are they going to manage this dying at home thing? They're in a bachelor apartment and there's three of them with one sleeping on the couch, the other on the floor, and another on a bed in the corner. But again, it comes down to if it's something that people feel really strongly about and that's what they want, they'll find a way to make it happen.

The caregivers' determination to maintain their promises can provide opportunities for reciprocity and accomplishment, a finding that is well documented (Bowling, 1983; Beck-Friis, 1993; Brown, et al., 1990; Ramsay, 1992; Townsend, et al., 1990). However, when they could not maintain their promises, the caregivers felt guilty and a sense of failure. For this reason, caregivers were often determined to maintain their promises, even in situations that became disproportionately burdensome. Some home care providers explained that they would intervene with counsel when situations are becoming burdensome for caregivers. At the same time, I noted that some providers and administrators minimized the burdensome nature of caregiving, re-directing their interviews to focus on caregiver resiliency and the sense of achievement that can be accomplished through providing palliative care at home. Very few challenged the idea of home-based care for the dying; they maintained that caregivers cope well if adequately supported by the health care system. Some of the providers argued that caregivers do not make promises but, rather, make commitments to care. These discrepancies suggest that caregivers and health care providers may conceptualize and construct home-based caregiving in some fundamentally different ways.

Influencing Factors

Having described how the caregivers made their decisions, I now turn to an exploration of the factors that influenced their decisions to provide palliative home

care. The caregivers' decisions were influenced by two factors, regardless of the types of decisions they made (i.e., snap, indifferent, negotiated). The factors influencing caregivers' (and patients') decision making included a desire to maintain a "normal" life at home, surrounded by family and friends, and a desire to avoid the hospital because of their previous experiences with institutionalized health care practices.

Maintaining Normalcy

As demonstrated in other studies (Brown, et al., 1990; Martens & Davies, 1990), the desire to maintain a "normal life" influenced the decisions of many of the caregivers in this study. They welcomed participating in family events, being in familiar surroundings, and having control over their own environments. The caregivers believed the home provided opportunities for privacy where intimate exchanges occurred and where normal life was maintained. This interview segment with a dying man and his wife illuminates how family life can be maintained when palliative care is provided at home:

> R: Can you tell me a little bit about what being at home means to you?

> P: Well yeah. I don't want to go to any institutions. Hell with that. I want to stay home.

> R: Tell me about why that is.

> P: Well, Barb wouldn't be there and I've got two sons who I wouldn't see as often and I just like being here. I've got everything that I need here. What other reason could I give? There's no place like home I guess.

> C: Well, there is lots of good things about having him here. It's not all doom and gloom. Last year when he went through that bad patch, well it was pretty bad, sort of a toxic stupor. Whereas now, we can still laugh at some of the English comedies and watch a good play on TV and the little grandchildren are in and out.

P: Yeah, they're so great. They come to see me and climb right up here [on the bed] and tell me stories about school and stuff. I don't know, we just have a routine here. It just seems like the best place to be.

The perceived ability to control one's environment contributed to the caregivers' decisions to provide palliative care at home. Being able to determine meal times, rest times, and visiting times, for example, made the caregivers believe that they would feel more in control of a situation where they often felt "out of control and helpless to do anything". The caregivers also felt that providing care at home was more convenient and that by having the patient at home, they could capitalize on the precious time they had to share. As this husband who was caring for his wife explained:

> Going back and forth [for the caregiver] to the hospital in some cases is very inconvenient, especially if you don't have a car yourself and you have to bus it or it is a long distance. You know, you tend to think of those last few months as being quite precious. Your time and the patient's time is quite precious. So, you don't want to waste your time on a bus or in a car. So, it's really an ideal setting [the home] and provided there is good home care, it is certainly very feasible.

The provider participants agreed that families often seek control of the situation and that provision of care in the home environment provides a better opportunity to accomplish this:

> There is an element of control. When people are at home we teach family members to do everything and they're in charge of everything. We're not doing it for them basically. We tell them what to do and they do it. You know, here's the medications and stuff. Then they go into the hospital and the first thing that we do is we take the medications away from them....Now, I know that for some people, that's probably a relief. But for somebody like me, I would think, oh my god, I can't do what I need to do. It's all up to somebody else. I'll have to beg the nurse for an interim dose or whatever....So I think it's not only that people want to be at home for their space and their privacy, but because they also have some measure of control or they're delegating that control to their family member.

However, the fact that the provider states "we tell them what to do and they do it" also implies that caregivers may not have total control of their situations, even in their own homes (a theme I discuss later in this chapter and in Chapter Six). The preceding interview segment also suggests that the home setting affords greater control than that provided in an institutional setting. The caregivers' previous experience with institutionalized health care practices was the primary motivator for keeping the patient at home.

Institutionalized Health Care Practices[75]

During interviews and observations, caregiver participants frequently began by reflecting on their experiences with institutional care, most notably on when their family member was first diagnosed with a life-threatening illness. Initially, I was concerned that this line of discussion might not be the most instructive in helping me to understand the provision of palliative care at home. However, I quickly realized that discussions regarding the initial interactions with the health care system were integral to comprehending not only why the caregivers were determined to provide care at home, but also how their early experiences with the system shaped their decision-making process.

Previous experiences with institutional care[76] influenced the decisions of almost all of the caregivers. Notwithstanding occasional favourable feedback, the caregivers were mostly critical of institutional care. Based on their early hospital

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[75] Institutional health care practices are more fully explored in Chapters Five and Six. The discussion presented here is meant to demonstrate how previous experiences with institutional care influenced caregivers' decision-making.

[76] By the term "institutional care", I am referring to care provided in the acute care hospital sector as distinguished from patients' and caregivers' experiences with inpatient hospice or palliative care.

experiences, many patients communicated to their caregivers that "you must not ever take me back there". In turn, caregivers made promises, often without any knowledge of the caregiving process. The depersonalized, rule-based structure of the hospital system contributed to the caregivers' decision and to their likening the hospital to "entering the war zone".

The caregivers repeatedly told stories of the depersonalized and paternalistic nature of care provided in the hospital setting. Being treated "like a number" was a common experience for many of the caregivers and patients who hoped for individualized and personalized treatment. Some of the caregivers were humiliated by seeing their confused family members restrained and physically exposed on a hospital ward. Others found it difficult when their requests for help were ignored, especially in situations where patients were experiencing pain or other symptoms that required prompt management. Still others were flabbergasted at the paternalistic approaches of some hospital staff as this daughter reflected:

> I remember one morning that I went down and asked the staff, "Where's mom's food?" I went back a second time to ask and I suppose they thought I was being a nuisance. The doctor came storming out and he said, "What do you think this is, the Hilton?" After he left, Mom finally got a kind of bashed up banana. But he [the doctor] was ticked off. It was like he was saying, "How dare you". Like, "We're not here just to serve you". I mean, all we asked for was food.

The caregivers' negative experiences with institutional care reduced their confidence in hospital-based providers. These caregivers commonly used the war zone metaphor when placed in positions of having to "fight" for quality health care for the patient. One caregiver described fighting for adequate pain control for her dying mother and explained that, while her threats prompted swift reactions, the

experience made her behave in ways that were unsettling and prompted her to discharge her mother from the hospital against the advice of health care professionals:

> She [the nurse] told me she didn't have time. I told her, "The situation's gotten out of control, you're in charge, you're the one who's supposed to get it back into control so do it"....And she just said, "I don't have time". I said to her, "Well do you have time for when I call the ambulance to take her home? And I won't take her directly home. I'll stop at the news station". She went down the hall and got the needle and knocked my Mother out....I brought her home after that even though they told me that she would be dead in three days and that what I really needed was rest. They advised me not to, but what choice did I have? I don't really blame the nurses. They really didn't have time....But that's what it turned me into....I didn't even kill spiders but I had to fight every step of the way for her you know?....I didn't have a choice but to take her home.

Some of the caregivers were apprehensive at what being in the hospital represented. Almost all asserted they and their dying family members wanted to avoid technologically focused end-of-life care and were concerned that they may be subjected to unwanted interventions from health care providers if their care was provided in an institution. The following interview segment exposes how the caregivers constructed the power held by institutionalized systems and how they perceived the control that such institutions have over them:

> My decision didn't really have anything to do with our hospital experiences. Well, except for the fact that I had seen people in the hospital with IV's and things stuck in their arms and pipes in their mouth. I didn't want Mom to *have to have* that done to her and she didn't want that either.

Some of the caregivers had positive experiences with institutional care. They appreciated the help and advice received from nursing staff. They were thankful when nurses "went the extra mile" even when it went against hospital policy, as this interview segment implies:

> Suffice it to say that everything was put in place for us. Even the hospital was really supportive. Like, between you and me, they even gave us things, because when you're taking someone home you're faced with all of this and you don't know what you need. And they [the nurses] said, "Well we're not supposed to do this but here, take some of these pads and a urinal" and stuff like that. You know, and they asked if we had kids and could they go down to the Red Cross loan cupboard and so our kids chipped in. But, it was just advice like that that was really helpful.

At the same time, many of the caregivers acknowledged that nurses' workloads prevented them from providing quality health care. Therefore, these caregivers believed they could provide better care at home. One caregiver, who had previously been a registered nurse, reminisced about how the system used to be:

> The patient doesn't get the care they used to get. Maybe they're short staffed but in my opinion, a nurse is not like nurses in the olden days. They used to take care of patients. There were more nurses. Here, you ring a bell and wait until doomsday before you see somebody. The system is rotten. I can't blame the nurses....There is just not enough of them to go around. I mean, you can die in the hospital all right but I don't think it is very dignified. You are a number. So, needless to say, we didn't want that [dying in the hospital]. Oh God no. They would have to carry me out of this house feet-first.

Another caregiver, who was also a physician, speculated hospital staff lack sensitivity to the needs of families in palliative care because they only view the family through an institutional lens. However, as this participant suggested, institutional-based palliative care could be improved if hospital providers were given opportunities to better understand the home setting and the experiences of family caregivers:

> Working in the hospital, working in an institution, you don't have any perspective really, of the experience of the family. It's almost impossible to get that unless you work in a home care setting or do it yourself....There has to be an opportunity for hospital staff to be able to understand what we've been going through before we get there [the hospital].

The caregivers' decisions were also influenced by the hierarchical and rule-based structure of the hospital system. According to the caregivers, hospital systems do not allow for privacy or for creating environments that are conducive to healing. Rules governing hospital systems do not typically allow patients to self-determine. For example, hospital rules prevented patients from smoking, a habit many were unwilling to give up in the face of death. Other caregivers asserted the focus on cure and rehabilitation in the hospital placed unrealistic expectations on patients. The home setting allows families to "dance your dance rather than having to dance your dance according to the hospital's protocols and procedures". Social workers and nurses working with marginalized populations were particularly critical of hospital systems that are ill equipped to provide palliative care to patient populations that do not fit "mainstream" health care. As this outreach worker said:

> I think the hospital system would like to be able to pick and choose who its patients are. Our folks receive pretty shitty care at the hands of the helping professionals involved in the mainstream medical system which has not been sensitized to the issues about addiction. They may know the physiological stuff but they don't know the psychological stuff that really impacts how people look after themselves....So our folks end up not getting care....And when they're living in shelters, on the street, under bridges, in parks, on people's couches, or in transition houses, that is not stable housing for people. If you do not have those basic needs met, all the things we take for granted, your quality of life is in the toilet. So when people go into the hospital, it's sort of like a respite for them....But they want to be able to self-determine when they come and go and the hospital is pretty rigid about that kind of stuff. So we see people who have had addiction in their lives and who are dying but still have routines around their addiction....They need to be able to engage in the ritual of drug use and they are not allowed to do that in the hospital....So I know of people who have discharged themselves and later realize that they are really sick and they need to go back. So, they go back but their bed has been given away. Their possessions have been thrown in the trash. There is one woman I know who is in the end stages and she's being treated routinely with absolutely no dignity or respect. She's having to use so much of her life energy to advocate for the basic entitlements in the hospital, like having a bath....People see the addiction but don't see the

human being in that bed, suffering and terrified....They discharge themselves before they're okay because of the attitudes, because of lack of freedom, and because of their addiction needs. And, instead of working with people where they are at, and working out a way to meet those needs in a safe and humane way, we tend to punish people....Basically if you don't follow the rules, you don't get good health care....Even if you are at the end of your life.

The caregivers contrasted hospital systems and cancer clinics with inpatient hospice settings, indicating that hospice care may be better equipped to provide nurturing, personalized support that takes into account the individual needs of both patients and caregivers:

> When he was in the hospital and then when he went up to the Cancer Clinic he was just like another number. You know, in the Cancer Clinic, you sat on the couch, the nurse started your IV, gave you your chemo and then said, "See you in two weeks". There was no sort of nurturing support....Same as in the hospital. Whereas you would go to hospice and a counselor would meet you and people would ask you, "How's it going?" Not just with my Dad but with me. It was a totally different situation....It was a lot more open and there were fewer rules that you had to follow.

Even so, one caregiver, who was also a health care provider, revealed that the policies and procedures governing hospice care prevented her father from registering with the hospice program, even when she felt it was needed:

> C: We were at our wits' end and one of the options I explored with him [father-in-law] was hospice. A physician came to the house but because he [father-in-law] was still not accepting that he was dying, he wouldn't accept the criteria to be registered at hospice. So, we went it on our own basically.
>
> R: So the criteria you're referring to was ...
>
> C: Well, like the do not resuscitate order. Because he hadn't come to terms with things. He was still thinking, "Oh well, maybe if I do this alternative therapy, vitamins or whatever" it would help....Because you know for him, it was a short time and he hadn't come to terms with that. Ideally the principles [of palliative care] should kick in at diagnosis and help people along the path. But, it's like if you haven't reached the decision and accepted that you're dying, you can't get palliative care. That's the position we felt we were in ... So we weren't able to get hospice care because we didn't fit their criteria.

In the preceding example, the patient was unable to access hospice care because he had not come to terms with his dying and, therefore, would not sign a do not resuscitate order. However, the caregiver implied that access to services that apply the philosophies and principles of palliative care should be available early on in the disease trajectory so that patients and family members can have access to, and benefit from, the support programs available through hospice programs. Current models of care support the initiation of a continuum of palliative care beginning at diagnosis (CPCA, 1995; Health Canada, 1989a). Yet, findings from this study suggest that the policies governing some hospice programs may pose barriers for families wanting access to palliative care, especially when patients are first diagnosed and may not yet be ready to accept that they are dying.

Previous experiences with institutionalized health care practices played a major role in influencing many of the caregivers' decisions and made them determined to keep their promises. Even though initially reluctant to provide care, most of the caregivers believed they could provide a better quality of care in the home than professional providers could in the hospital. The caregivers' accounts stimulated thoughts about whether decisions to provide home care were made by default or based on a clear choice. When exploring this idea with the caregiver participants, some suggested they and their family members might have made different decisions if alternatives for care were flexible, personalized, and open to family involvement in care. However, in discussing this idea with provider participants, some were hesitant to accept my interpretations. They were concerned that conceptualizing caregivers' decisions as defaultive, and exposing that

caregivers and patients might choose alternative care settings, could potentially

detract from the important work done to build community-based palliative care

programs. They were also worried that an explicit focus on hospital systems might

result in resources being diverted from community-based palliative care to acute

care hospitals. Nevertheless, one palliative care provider admitted that better

hospital care would likely result in more patients and their family members deciding

to receive palliative care in institutional settings:

> R: So when families have had not so good experiences with hospital care, do you think their decisions become decisions by default?
>
> P: I wouldn't call it default. It's based on perhaps the reality of that system in which they live. That leads obviously to asking if the system should change. I certainly support that....Some of the elements of the evolution of palliative care have been expanding beyond just the death or terminal phase. It acknowledges that palliative care has a role earlier on in the disease. I think part of the motivation comes from that awareness that people do have bad experiences early in their disease as well as late....I think that if in a community you had excellent palliative care within an acute system, within a long-term care system, then probably the ability to make choices on other factors would come into play. If they [the patient] weren't so concerned about being stuck in a noisy 4-bed room or having very little attention to their symptoms....If they knew that it would be a better experience, probably a number of people would choose to die in hospital rather than at home. I think it comes back then to the individual characteristics of who the family providers are. It would broaden the range of clear choices for them. That doesn't detract though from the need for large attention for care in the home because irrespective of that, most people through a disease of two or three years duration, most of the time will be at home anyways. I wouldn't want to shift our resources to say, "Let's forget about the home and focus on the hospital".

Other researchers suggest the hospitalized experiences of the dying are

permeated by inadequate symptom control, poor communications, a lack of basic

nursing care, and staff not having enough time to attend to the needs of the dying

(Addington-Hall, et al., 1991; Hockley, Dunlop, & Davies, 1988; Mills, Davies, &

MacRae, 1994; Sudnow, 1967). Although these studies do not explicitly link hospital

experiences with caregivers' and patients' decisions, many authors hypothesize that there is a direct connection between the two (Bowling, 1983; Field & James, 1993; Roe, 1992) and this study supports those contentions. Previous research also points to the paternalistic care approaches found in hospital settings (Lynn, et al., 1997; Seale & Kelly, 1997). In this study, many of the caregivers perceived hospital systems to have "power over" them with little opportunity for self-determination. According to the providers, this is especially true for patient populations who are marginalized and who do not fit into mainstream health care practices. Previous research supports the finding that many people from marginalized groups experience difficulties with the provision of institutional care (Stajduhar, Poffenroth, & Wong, 2000). Findings from a large U.S. study demonstrate that hospital systems have a long way to go in providing quality palliative care to all dying patients and their families (SUPPORT Principal Investigators, 1995). Recognizing how caregivers and dying patients are influenced by early hospital experiences provides insight into how these experiences shape caregivers' and patients' perceptions of, and decisions about, future hospital care and home care. This finding points to the need for better communications and approaches throughout the illness trajectory so that caregivers and patients have a clear range of choices when deciding on where palliative care should occur.

Knowing What Lies Ahead

Some of the caregivers made decisions without giving much attention to the implications of those decisions. Many of the caregivers indicated they were unprepared for their caregiving roles, even though they were or had been previously

employed in professional caregiving roles or in health care. A few of the caregivers

mentioned that the media played a part in how dying and death were constructed at

home, perpetuating an often unrealistic and romanticized portrayal that led some of

the caregivers to make promises they later regretted. Both media and societal

influences led this thirty-six year old daughter to believe that dying at home would be

a peaceful experience, but she later discovered the implications of her uninformed

decision when she was caring for her dying father in his home:

> I had no idea. Because I've been watching too much TV....I'm appalled at the
> fantasy world that we see all around us, how unrealistically we view this kind
> of death. But I just had no idea what I was in for. Like I say, if I had known,
> maybe I wouldn't have been quite so forthcoming about making that
> promise....I mean it all sounds nice when we first talked about it like, "Oh yes,
> it would be nice to have him at home, that's so much better, so peaceful".
> Other people said to us, "Oh, it will be so much nicer if he is in his own bed".
> And I thought, yes it will. But it's like you're from the movies. And when it's
> really happening, you think, oh my God, this is horrendous. It's not at all what
> I expected.

Whether it is possible to fully prepare caregivers, and whether they desire this

preparation, varied among participants. Some of the caregivers said that advanced

preparation would have frightened them and prevented them from participating in an

event that generated considerable pride and accomplishment. Other caregiver

participants explained that even when information was provided to them, they were

unable to hear it or understand what the concept of dying at home would mean to

them. Still others wished they had been better prepared, recommending that

practical suggestions for and books about caregiving would have been helpful, as

would the opportunity to discuss the pros and cons of their decision with health care

providers early on, before they made promises. One caregiver described how

receiving information helped her to overcome her fears and participate in caregiving

at home:

> It was really my fear of dying, of watching a person die. I guess that
> precluded me from wanting her to be at home. Anyway, it took me about five
> seconds to realize that she wanted to die at home. I knew it, but I took that
> away from her by saying she'd go to the hospice. But when I realized that my
> fear was of her dying and it was explained to me how things would work, I
> had no difficulty in saying, "Hey, she should be at home".

Another caregiver, who was employed at the time of caregiving, believed it is

impossible to make fully informed choices and decisions without having adequate

information well in advance:

> I didn't really have the information that I needed at that time to make a
> decision….Because you're making a decision [about dying at home] that
> wasn't an informed choice….And by the time you have all the information and
> you realize that maybe that wasn't the best choice, it's too late….That's why I
> think the decision should be made and the information should be provided
> earlier.

Those provider participants with expertise in home care for the dying

emphasized that it is difficult to fully prepare caregivers and confirmed that many

caregivers are unaware of what they are getting into when they make their decision.

Caregiving at home involves periods of continual adjustment where support and

information is best provided at "transition" points. According to the providers, this

ensures that caregiving families receive the information they need when they need it.

Knowing exactly when to provide preparatory information, however, is not always

clear, as reflected in one provider's comments:

> In the beginning of the terminal phase, there's going to be a need for
> information about this to help them make a good decision about care at
> home….But many people aren't there. They're not. I can talk about it, but
> they don't hear it. It's an affront to them as well. It's not very respectable to
> go to a place that they're not ready to go to. Then they would say, "I don't
> want to talk to you again". So, at that point in time, you can't give them a lot

of information that's coming down the road in ten days. You need to kind of do it today and maybe in the near future, but you can't go too far in most cases. Sometimes you can, but in most cases you can't.

Determining when to impart information is difficult because each family has different needs and copes with information in different ways. This home care nurse stressed that "knowing" the patient and family assists her in deciding when to provide information. Even with this, she acknowledged that some information is not always provided when caregivers most need it:

> It's a really, really tough decision. They don't want all the information before they're ready to hear it and then you might miss it by a day. They'll say, "I wish you'd told me that yesterday". But you've got to figure out when they're ready to hear it because if they're not ready to hear it, several things can happen. Either it goes in one ear and out the other or they get a bit panicky and they get scared....But if you go along with them as things progress and try to anticipate as each day goes by, you can give them little bits of information. And sometimes I just stick things in the front of the chart and tell them, "It's there if you want to read it". And most people will read it....But if you give them information beforehand, it's not good....You have to know them really well and be able to decide when it's most appropriate.

The importance of knowing the patient and family was a sentiment echoed by another provider who tries to be fully engaged with people in her work. She does not attempt to distance herself but, rather, seeks the connection and the sameness between herself and the person she is helping, a process she calls "joining". For this provider, joining means letting go of control and not imposing personal values. Providers are thus freed to let the family direct care and they simply move to the rhythm of the family, anticipating their needs at transition points.

The information needs of patients and family members, particularly during the cancer experience, is the focus of much research (Hileman & Lackey, 1990; Hinds, 1985; Skorupka & Bohnet, 1982; Steele & Fitch, 1996). The knowledge and skills

required to participate in palliative caregiving at home has also been described (Schachter, 1992). Family education for home care has been associated with positive outcomes for both patients and caregivers (Archbold, Stewart, Greenlick, & Harvath, 1992). Some authors indicate that the decision to provide palliative care at home involves determining whether patients and family caregivers understand the obligations that home care will entail (Schachter & Holland, 1995). However, the findings from this study demonstrated that the caregivers often made their decisions with little understanding or knowledge of what lies ahead. There is a paucity of knowledge highlighting how to best prepare caregivers for their roles in palliative home care and for guiding health care providers in knowing when to most appropriately provide this information. As shown in this study, the caregiver participants often differed in the ways in which they desired to be prepared, implying that flexible approaches are needed when working with caregivers. Findings also suggest that "knowing" and "joining" with the family are important components in deciding when to impart information at transition times. Davies and Oberle (1990) similarly found nurses who connect with patients and caregivers enter into their experience and are better able to anticipate family needs. Nevertheless, further research is required to determine the most appropriate strategies to work with caregivers as they adjust to new realities and make decisions to provide palliative care at home.

In this section, I provided interpretations of how the caregivers constructed their decisions. In some cases, the caregivers made decisions quickly and without much thought, while others negotiated decisions with the ill family member. Many of

the caregivers reluctantly made decisions, basing them on the wishes of the patient, often at their own expense. Some of the caregivers felt they had little choice because of their reluctance to break promises or because they believed they could provide better care than provided in the hospital. Making promises to provide care at home was often viewed as a final gift leading to pride and accomplishment. However, for many of the caregivers, this decision carried considerable consequences, especially when unprepared for the caregiving role. This final quote from a hospice counsellor summarizes the experience for caregivers who decide to engage in providing palliative care at home, illustrating the simultaneous positions that caregivers often occupy:

> Sometimes you see that people say, "Well, I can do this, I owe this to him or her". But they have no concept of what is involved. Then all of a sudden they hit a wall and then say, "I can't do this anymore". Then it's crisis management....They start to see themselves as being between a rock and a hard spot. If their family member had asked to be kept at home but they know they're reaching the end of their rope and they don't see that they have any choices or the choices they have aren't good, well, it's just not a choice. You care for someone else because you love them and that is the only thing you are going to do, whether it burns you out completely or not....On the other hand, there are so many really, really good stories where it all works out. But, it's always hard. The situation is never an easy one.

Living With the Decision

Having established how the caregivers made their decisions, I now move to a portrayal of the provision of palliative care in the home setting, discussing how such care influenced the caregivers' lives. For some of the caregivers, living with the decision was life-enriching while, for others, it was life-draining. Contrary to the home being constructed as an environment for privacy and healing, and representing a place where we can be at ease and away from the pressures of

everyday life, this study demonstrated that a re-creation of the hospital at home was a more typical experience. Because care provision in the home often models what occurs in hospital, many of the caregivers reinvented themselves as they took on roles that eroded their core identities as mothers, fathers, wives, husbands, sons, and daughters. These changes in the home environment, and in themselves, led some caregivers (and patients) to conceptualize dying and death as a hoped-for opportunity, wishing that death would soon happen. Other caregivers and patients in this study seriously contemplated euthanasia and assisted suicide as they tried to cope with the increasing demands placed on them.

Constructing Caregiving as a Life-Enriching Experience

Similar to other study findings (Davies, et al., 1995; Hadwiger & Hadwiger, 1999; Stajduhar, 1995), some of the caregiver participants constructed the provision of palliative care at home as life-enriching. These caregivers tended to be those who negotiated decisions or who maintained their commitments and promises. Whereas some of the caregivers indicated their caregiving was a final gift, others said it was they who were provided with a gift:

> She gave me the gift of understanding, that will be her gift to me [when she dies]. Her presence in our home has gifted me with patience which she has in abundance and I have not. I've learned the value of silence. And I'm a talker....But I've come around to understanding now.

One benefit of providing palliative care at home is that it gave some of the caregivers opportunities to spend quality time with the patient. As other research has shown (Brown & Powell-Cope, 1993; Davies, et al., 1995), such cherished moments allowed the caregivers to learn about themselves and their loved ones in new ways. Home caregiving also facilitated the re-establishment of estranged

relationships. One daughter had not regularly spoken with her father for many years. When her father was diagnosed with a terminal illness, it allowed her to "put aside what had went on in the past" to re-create a relationship prior to his death. Likewise, a husband and his wife previously had a troubled marriage. When his wife became terminally ill, he was able to express his love and it taught him how to live each day for the moment. The ability to mend helped some of the caregivers to accept their impending loss, work through their grief, and realize that life was short as this daughter explained:

> I would have had a lot harder time letting her go and accepting that she was gone if I hadn't had that time with her. Not just the caregiving, but the grieving process. It's not something that you would ever want to go through but it's still one of the most life-affirming things that I've ever been through. It gives you a perspective that life does go by and time does go by and you're not here indefinitely. That's something over the years since Mom's been gone, I tend to slip back into the daily rut and worry and what not. Then I give myself a shake and remember what the intensity was like at that point. So it still definitely has an effect on my life.

The experience made some of the caregivers examine their own beliefs and how they had previously lived their lives:

> R: So it [caregiving] helped you examine our own beliefs.
>
> C: Yes, definitely. I never would have gone on the spur of the moment on that trip with friends but I thought, "What the heck. What am I waiting for? Life is here so go for it"....You tend to take more chances too, as far as what my caregiving and losing my Mom gave to me. That would be one thing too. You can play it safe but you don't want to lie on your deathbed saying, "I wish I'd done this or done that".

Being at home provided some of the caregivers with opportunities to make plans so they were not placed in positions of having to second guess the wishes of the patient. Having the patient at home allows time to overcome reluctance to having discussions that were sometimes difficult. One wife, caring for her husband with

cancer, explained that having him at home allowed time for her and her teenage daughters to discuss difficult issues:

> It was easier for me I think because it [being at home] gave you more than ample opportunity to discuss anything. I mean, we even discussed where my husband might like his ashes. I didn't particularly want to raise the subject but I thought if he has some particular desire, I want to know that now and not try to second guess. So it made life easier after he died because I knew those kinds of things …. It made it easier for the girls to know what was going to happen and to be involved with those kinds of discussions.

Like studies examining caregivers' experiences with chronic illness (Aronson, 1992; Brown, 1992; Parks & Pilisuk, 1991), caregivers in this study commonly expressed feelings of guilt: guilt that they were not providing adequate care; guilt that they could do no more; and guilt at recognizing the need to care for themselves. Similar to what Payne and colleagues (1999) found, some of the caregivers' guilt was allayed when they were able to provide care at home, maintaining it made them feel "we were doing all we could". Some of these caregivers theorized that providing home care allowed them to gradually work through their guilt and to view dying at home as a healing experience:

> The process was positive to the end because we felt really glad we were not left out….We were able to work things through as they happened and we didn't have this great burden of guilt. That's the major thing that people have to cope with afterwards and have so much trouble coping with. The sense of loss is not so great because we don't have that great ball of guilt over us … We had a period of time when we were cognizant of the fact that we knew what was happening and we were able to work through it gradually at the time. And the fact that we were doing something positive at that time helped us as well….It was healing in itself.

Such positive experiences were expressed by those caregivers who approached caregiving with an "attitude of gratitude":

> If I dwell on the negative then I use up all of my emotional energy in a very negative way. Instead, I try to focus on what are the good things that are

happening each day and to develop a sense of gratitude. An attitude of gratitude. So that even though all of this is going on, we can still each day say, "Wasn't it great we heard from so and so today?" Or, "We got a card from so and so today". Or, "Isn't it a beautiful day outside and we had such a nice walk". So we are focusing on the positive things that are happening.

My observations provided me with some of the most poignant illustrations of how caregiving can be life-enriching. During my field visits, I was witness to intimate exchanges and profound expressions of love and gratitude. Perhaps one of the most touching experiences came when I observed Jessie, who was with her husband Matt, when he died:

> As Matt took his last breath, Jessie looked at me and asked, "Is he gone?" and I slowly nodded my head, indicating that Matt had died. Matt has just taken his last breath. Jessie tells me that she wanted it this way. She wanted Matt to be surrounded by people who loved him. Kim, Jessie's daughter is also in the small, rather crowded bedroom. Tears are slowly running down her face as she gently stroked her Mother's arm. Jessie rose off the bed where she has been sitting with Matt all afternoon and she held Kim in a tender embrace. Tears were streaming down both of their tired and worn faces as they look on at Matt. Jessie said to me, "This is exactly how he would have wanted it to be". She looked at Kim and then me and said, "I want to lie by him now". As Jessie laid her weary body down on the bed, she rested her head on his chest and then looked up at Matt and stroked his brow, telling him "You are in a good place now". Tears are flowing down my face as Kim and I walk out of the bedroom, hand in hand, to give Jessie some time alone with Matt (Field Notes, October 1999).

The caregivers who constructed their experiences as life-enriching were typically those who felt prepared, were able to anticipate and "move with the rhythm" of the patient, had previously shared a good relationship with the patient, were supported by providers, had adequate support from the home care system, and had the time and financial resources to commit to caregiving. These factors are well documented in previous research, highlighting the conditions needed to effectively

support caregivers providing palliative care at home (Beck-Friis & Strang, 1993; Davies, et al., 1994; DeConno, et al., 1996; Hinton, 1994a).

Constructing Caregiving as a Life-Draining Experience

There were very few instances of caregiving situations that were unequivocally life-enriching. Most caregiving was also challenging and life-draining for the caregivers. Despite the resources for support provided by health care agencies, the caregivers who participated in this study often suffered during their experiences. The caregivers who constructed experiences as life-draining were typically those who made indifferent decisions or who could not maintain their commitments and promises. Even where there were stated benefits to providing care at home, caregiving was described as exhausting, difficult to recover from, and requiring financial and self sacrifices. Caregiving also produced "nightmarish" memories, as these caregivers watched the decline of their dying family member and then re-lived these experiences.

Self Sacrifices

Providing palliative care at home resulted in most of the caregivers having to sacrifice their own needs to meet the needs of the patient, regardless of how they conceptualized their experiences (i.e., as life-enriching or life-draining). The providers indicated that self sacrifices might provide caregivers with opportunities to demonstrate their commitment and to strengthen themselves and their bonds with the patient; the caregiver participants did not always construct sacrifices in such a positive light. Many of the caregivers suffered, but did not realize the toll of caregiving until they were able to refocus on themselves:

When you're a caregiver, you put yourself at the bottom of the list. He came first, the kids were there you know, your other household duties. So, I knew I was working my body to the ultimate. Getting up early, getting to bed late, and then having a restless sleep with him. So, I knew I wasn't doing myself any favours but because I could keep doing it, and doing it, I did it....I didn't realize until after he died....I looked at myself in the mirror and I had lost a lot of weight and I just really noticed it all of a sudden. I thought, "I just have to cover my neck up". There was nothing there, there was just sinew there.

Some of the caregivers were hesitant to speak of the importance of meeting their own needs. Others were more forthcoming, describing how they felt "tied down" and "closed in". Some felt envious at how others were able to carry on with their lives while they were "stuck" at home. The envy and resentment that some of the caregivers felt stemmed from not having choices in their lives as this wife, who cared for her terminally ill husband, explained:

> C: I do feel really tied down....Like sometimes I wish I was on another planet. But I am tied down. There's no question about it....My girlfriend called to say that they just got back from a month away and I said, "Oh, isn't that lovely".
>
> R: Do you ever feel envious about that?
>
> C: Oh, absolutely. Absolutely. It's not that I would go away, but it's just that she has the choice and I haven't got a choice. Not having the option really bothers me more than the fact that I'm not exercising it.

Resentment also arose when caregiving became unexpectedly prolonged, resulting in the caregivers sacrificing their own needs for extended periods. In these situations, caregivers constructed caregiving as a "job" rather than a commitment:

> Everything started being closed in. I started feeling closed in and weighted down. I don't know what the criteria is for somebody looking after somebody else when you start feeling resentful....But I didn't know it would last this long....But I just did the job I had to do. It's your lot in life and I damn well did it. I mean, I certainly wouldn't give up my life with him. It's just to say that I didn't have a life for three or four years.

The caregivers knew at some level they were sacrificing their own needs, but were so engrossed with caregiving that they were unable to see that they, too, were in need of help. As this daughter caring for her dying father explained:

> I wasn't looking at what was going on for me with any degree of intellectual view. I wasn't taking that view at all. I was strictly feeling what I was feeling and I wasn't the least bit analytical. It took someone from the outside to say, "Whoa, stop the train here"....You don't know. But, this is no fun! It's not sexy and if you're in the glue, you're often so fried that you don't have the where-with-all to go looking for resources for you. You spend all your time trying to find resources for the person you're caring for.

Being "stuck" at home and having little choice made the caregivers feel isolated from the outside world, even when they had professional support or support from family and friends. The caregivers' "worlds had changed completely"; they had to give up many activities they enjoyed because they felt solely responsible for care. Even the most taken-for-granted contacts, such as telephone calls or letters from friends became special events. However, many initial supports evaporated when caregiving became prolonged:

> Caregiving for my Mom and Dad was over a long period of time. It's amazing. You have your friends and you have your supports but I had been totally consumed in that whole time. I mean, it started off at the beginning where the friends would be driving up with the casseroles and that sort of stuff but that dried up a long time ago. And I had become so isolated. So totally isolated and insular.

Generally, the caregivers appreciated the support received from home health care providers. However, some of the caregivers felt that providers sometimes minimized their sacrifices: "If I hear one more person saying how great this is [caregiving at home] and how wonderful I am to do it, I'm going to scream" (Field Notes, May, 2000). Sometimes, the provider participants assumed caregivers' needs ought to take second place to the primary needs of the patient:

> We had one lady who didn't want her husband at home because the hospital [equipment] didn't match her décor. When the guy's sister eventually volunteered to help out, she [the wife] reluctantly took him home in a hospital bed and like with a child, she had spread a huge plastic sheet over her carpet around the bed so there would be no chance of anything soiling her carpet. So, you get the sense that she really was more concerned about her home than she was about her husband. I mean, this kind of situation happens and you pull your hair out and you think, "Why did this guy choose this wife" because when the chips are down, they're not on their side.

These attitudes were uncommon. Most providers in this study recognized and understood the sacrifices and burdens of caregivers. Interestingly though, the providers were much more likely than the caregiver participants to point out the beneficial aspects of making sacrifices, as this physician commented:

> The fact that it is a burden is not necessarily a bad thing. Where a burden becomes excessive, prolonged, without relief, or misguided, then I think it's a difficult thing. The fact that people get tired, that fact that it is hard, in and of itself may not be a bad thing, because later they look back and can say, "We did it. It was hard but we were able to support that". Yes, it is a burden, but that can strengthen people. So, the distinction is where a burden is becoming disintegrating to that individual as opposed to a good element of being family and sharing difficult times. So when it's a disproportionate burden. That is where it is really difficult.

Financial Sacrifices

Financial consequences accompanied the decision to provide palliative care at home. Regardless of the public health care services that were available to the caregivers, the costs of caregiving could be substantial. Some of the caregivers left their place of employment to engage in caregiving, resulting in lost wages. Others hired private help to provide care and assistance with household tasks because the public system did not allow for adequate coverage. Some of the caregivers did not have health insurance plans that covered all prescription medication costs and the out-of-pocket expenses for non-prescription drugs were daunting. In addition, many

of the caregivers took on added personal costs such as nutrition supplements and wound care supplies. Some of these caregivers "downsized" their lives, leaving them with few resources to enjoy things that were taken-for-granted as Kevin explained:

> It's been a financially draining experience. In terms of coffers, the cookie jar is pretty empty and it's been very difficult to believe....If you don't have a financial plan in place or $800,000 in savings, you're out of luck. That's a financial hardship....We've downsized. We don't go out. We don't spend any money. I don't buy clothes. I don't have a car. I can't afford Christmas presents. But certainly, it's been about spending it all on health remedies to get her where she is.

Kevin's promise to care for his wife prompted him to quit his job. Although he was able to maintain the household on a small amount of money he acquired through selling some of his possessions and by renting out a room in his home, he did not always have sufficient funds to cover basic living costs. Kevin was angry at institutional structures and the lack of understanding from the people who worked for them:

> This major bank who makes $300 million dollars a quarter was virtually playing God with me when they said that I didn't have enough money in the bank account to cover the overdraft....I had this lady on the phone saying to me, "You don't have enough money in your bank account to cover this cheque, what you are going to do about it?" I felt like saying, "I've spent all my life savings to come this far to save my wife"....Instead, it was like financial abuse over the phone. Incredible. Financial threatening....And of course, the major suppliers of utilities have done the same things. I get threatening letters....You know, "If you don't have the money by Wednesday we're going to shut your hydro off". So, I've virtually had all these threats ... And neither of them bothered to ask me or even inquire why I was behind on my payments....They could ask me why. Is that too much to ask? Or perhaps their computers are not programmed to ask me questions but just programmed to tell me I'm overdue and that they're going to shut me down in three days. That's where it hurts.

Provider participants confirmed that providing palliative care at home can be "financially crippling", especially for younger families who lack the financial reserves of some older people. The providers said some caregivers lost their homes because they could not make mortgage payments or were forced to hospitalize the patient because they could not afford to care for them at home. A home care nurse explained the financial sacrifices made by some families, implying the provision of palliative care at home is not an option for all people:

> If you are under 65 in this province, don't plan to die here. It's not a good idea. If you've got extended benefits from work, depending on what the ceiling is on them, how long they last, that might cover your drug costs. Probably it won't. It will for a short time. You have to quit work because you're too sick to work. Maybe your partner has to quit work to look after you. You may end up on welfare. And then if you're on welfare, all the over-the-counter medications are not covered. And people go through a fair amount of Gravol and Colace and vitamins and numerous things….The house has a second mortgage on it and the kids' university costs have been spent and there you are. And for many people, it's not just the cost of dying, it's the cost to the family once that person's gone.

Seeing caregivers struggle with their financial burdens led some of the providers to "go against the rules". Going against the rules occurred when the providers felt what they were expected to do conflicted with their own values and beliefs. As such, some of the providers were forced to keep their activities secret. This excerpt shows how one HCN constructed the payment for services provided in the home, illustrating an underground system for payment and demonstrating how the providers hold strong allegiance to publicly funded health care:

> If we catheterize a patient, we're supposed to tell them to order the catheter and replace ours. I've never done that. *Don't tell anyone*. But you know, that's the kind of stuff we're expected to do and that just boggles my mind. I cannot do that. You know, "Cough up ten dollars now because I put the catheter in".

Some of the caregivers in this study became disillusioned with a health care system they believed was set up to support them. Fran, a middle-aged homemaker caring for her husband, indicated that throughout her caregiving, she believed she was contributing to reducing the burden on the system because home care could realize substantive cost-savings to the system. However, as she became embroiled in caregiving, she realized that while there might be possible savings to the system, these cost-savings were at her expense:

> The idea that it's cheaper for patients to be at home than in a hospital is only true for the provincial finances, not for the home finances. It costs far more to keep somebody at home if it's the patient [or the family] doing the paying. But it's only cheaper for the government. It's not cheaper for the individual....I learned that lesson the hard way....There wasn't much [money] left when it was over and I still have to live. Now I'm faced with wondering how I'm going to survive.

When another caregiver sought publicly funded health care services, she felt punished for having been financially responsible. She had difficulty understanding why the system was not more flexible in providing financial support, was frustrated that "the system" minimized her contributions, and upset that she had to forgo her primary source of income to care for her husband with little acknowledgment from the system:

> The thing that I find very frustrating is that I have to pay my premiums into health care but then they want to turn around and come out and do an evaluation on me in terms of how much money I have. Now, we have lived, I won't say frugal but we have lived carefully with our lifestyle. We have not spent a lot of money travelling or going to casinos or doing cruises three times a year or whatever. So, we do have this certain level of living because of that. But somebody else who has turned around and done all that but has no money, they are now eligible to get more home care and at a lower cost whereas I am going to have to pay an awful lot of money for it. So, you're kind of punished for being responsible. And so, it's a real catch 22 and I can get really worked up about that. On the other hand, I think why doesn't the system say to me, "Look, you're doing all of the health care for your husband.

You are providing for all of his needs. Now, we understand you can't keep up your yard so we're prepared to give you some money to help you do that" ... But there is nothing like that. I mean, I have lost 80% of my own income because I am looking after him but there is no acknowledgement made of that.

Lasting Memories

Providing palliative care at home produced memories that sometimes haunted caregiver participants and complicated their bereavement. Watching the decline of their loved one was one of the most difficult experiences these caregivers faced. Even years after the death, some of the caregivers continued to relive the experience. Some caregivers, faced with reliving these moments, sold their homes in order to move on with their lives. Others stayed in their homes but renovated them or moved their bedrooms because they could not sleep in the room where their spouse had died. Others had recurrent nightmares and were afraid to sleep. Marie had so much trouble watching her father's decline that she was unable to be with him when he died, realizing the lasting effects this would have on her:

> I was standing there and tears were running down my face and I just thought, I can't stay here. I can't see him like this....It just killed me. Dad was a very proud man and he had false teeth. And at the end, he had his teeth out. You know, your face kind of sinks in and I knew I didn't want to see him like that....I knew that that would be the only thing I'd think about over the years, so I left.

The provider participants maintained that caregivers who relive the dying and death experience often have difficulties in coming to terms with the death. As such, bereavement is prolonged, complicated, and inhibits moving forward. This hospice counsellor theorized that caregivers who experience lasting memories that complicate their grief are those who made promises rather than engaging in a mutually negotiated decision:

I've seen people in bereavement where the struggle for them is their memory of the last day, the last few weeks. Their memory and their view of that isn't around, we were at home, the family could all be there and that kind of stuff. It was all about the dying in the bedroom....And people can have a difficult time moving away from that. They can't remember the good times in their life, just the dying part with the symptoms and being in the bedroom. I think it complicates their grief. From my experiences, people are able to move through that, but it took a while. It took longer than they thought and it's pretty scary because a number of weeks or months after the death, they are still thinking, "Well am I going to spend the rest of my life remembering what that was like?" And not focus on, "What am I going to do now with the rest of my life?" You know, they just focus on, "This is what is in my day dreams and this is what is in my night dreams". And I don't think that happens so much in families where they went into the idea of care at home with a really wise decision of what they were getting into, and it was a mutual decision rather than something that they promised.

Other researchers have documented the physical, psychosocial, and financial sacrifices made by home-based caregivers (Axelsson & Sjoden, 1998; Davis, et al., 1996; Emanuel, et al., 2000; Hinton, 1994a; Hull, 1990; Rose, 1998; Steele & Fitch, 1996; Stajduhar, 1995) and, like this study, other researchers have highlighted how caregivers often neglect their health needs (Ryan, 1992; Stetz & Hanson, 1992; Ward-Griffin & McKeever, 2000). Interestingly, the providers in this study tended to view dying at home more positively than did many caregivers. Some of the caregivers suggested that the overly optimistic attitudes of providers were sometimes not helpful because they minimized caregivers' experiences. This finding highlights the possibility that providers, in their efforts to help and support caregivers, may in fact be contributing (in subtle and not-so-subtle ways) to pressures that some caregivers feel to maintain their dying family members at home.

Re-creating the Hospital at Home

With few exceptions, most of what is written about the provision of palliative care at home focuses on the benefits of the home setting as the primary location of

care. However, I observed how the home is often transformed in the course of palliative caregiving. Once a restful and peaceful environment, the home is often re-created when palliative care is provided, taking on many of the characteristics of an institution. Dining rooms and living rooms, once used for social gatherings, become hospital rooms, filled with equipment and nursing supplies. The refrigerator becomes a receptacle for medications along with a place to store nourishment for the family. And, the telephone, once used for social interaction, becomes a mechanism used for organizing and coordinating health care. Maintaining privacy, intimacy, and self-determination, hallmarks of a "normal" home life, were eroded as the home was invaded with multiple care providers, all seeking to offer support and guidance in their own unique ways. Caregiver participants often reinvented themselves to become nurses as they tried to keep up with the pace of caregiving, engaging in shift work and personal care. And like patients and caregivers in institutional settings, caregivers who participated in this study were sometimes neglected or abandoned by the health care system and its providers, leading them conceptualize death as a hoped for opportunity.

The Physical Space

The home is in a well-established older neighbourhood with giant oak trees dotting the streets. Nourished perennial gardens surround the home, smelling sweetly of spring blooms. As I walk up to the front door, I am greeted by the barking of the family dog that sniffs me and wags his tail enthusiastically. Louise, a grey-haired, heavyset woman greets me, smiling warmly as I enter the home. I am immediately affronted by the sour smell of urine and try not to wince as I walk in the door. The living room furniture is pushed aside to make room for Chuck's bed. Chuck is laying in a hospital bed against the wall in the living room. His commode seat is open and filled with dark yellow urine. Louise apologizes and rushes to the bathroom with the commode container in hand. The living room is cluttered with magazines and two tables beside Chuck's bed serve as trays for medications, paperwork,

water, and juice. Another table holds a wash basin and dirty wash cloths that will soon be added to the mound of laundry sitting on the living room floor. A check-list of tasks for HSWs is taped to the wall, outlining explicit directions for Chuck's physical care. Chuck asks me if I would give him a drink as he reaches for the floor-to-ceiling pole installed beside his bed and points to where I can find some bendable drinking straws. Louise returns to the living room and offers me a cup of tea (Field Notes, March 2000).

These field notes exemplify how the physical living space in one home was transformed and re-created as a hospital setting. In the homes of other participants who were actually caregiving, "hospital rooms" were set up in bedrooms, isolated from the interactions of family life. Living rooms and dining rooms also served as a primary site of care. Caregiving sites were determined by the amount of space in the home; when bedrooms were too small to accommodate hospital equipment, living rooms and dining rooms were rearranged. In other instances, the caregivers wanted their dying family member at the center of family life and, thus, used family living space as the site of care. In one instance, an attached garage was renovated and set up with all of the equipment and supplies.

Physical transformations in the home seemed to go unnoticed by some of the caregivers. However, others noticed changes, particularly when incidents occurred that reminded them that they were providing palliative care. For example, one caregiver scrubbed the carpet at four o'clock in the morning because her husband's catheter had leaked urine on the floor. Subsequent incidents prompted her to replace the bedroom carpet with linoleum, which "created a somewhat sterile environment but it worked". Providing care at home was much like, "transferring one hospital room to another hospital room [at home]". Some of the caregivers even labeled household rooms as "hospital rooms". Given the transformative effects of

illness and medical equipment, it was not likely that a person's home, so

transformed, remained the familiar, secure, or welcome place it may once have been

as this son described when he explained his mother's reaction to providing care at

home:

> We transformed the upstairs dining room into a hospital room....All the equipment we needed was there....But when people would come out, my Mom always said, "Let's get the house back to normal". I think it was more Mom's feeling that she wanted everything back to normal. Everything had been in such turmoil for a while. Sort of upside down. Not her house any more....There was a lot of confusion around the house, you know, clutter. People coming in, dropping stuff off, wanting to put stuff in the fridge....And I had moved the dining room table right outside the dining area and it was covered with charts and paperwork and medication bottles and that sort of thing.

Some provider participants mentioned, almost in passing, that changes to the

home environment were sometimes needed to accommodate caregiving. However,

this was not a major theme in their interviews. I asked one provider directly about

the transformations to the home to which she replied "it's not really a big deal, it

usually just involves adjusting stuff". However, this interview excerpt demonstrates

that adjustments to the home can be significant and can mean giving up things that

have been meaningful and important:

> We got a hospital bed with the sides and a commode. That was a nightmare that day because Mother's bedroom suite was bought in the 1940's....It was really special to her. It was the bed that her and dad shared. And, the fellows couldn't get it apart because where the pieces of the bed go together, I guess the glue was old or something. It ended up, here's poor Mom on the couch in her front room with this hellish racket going on, while they had to take a hammer and just smash her bed apart to get it out of there to put in the hospital bed.

The equipment and supplies brought into the home by the providers also carried

meaning. For example, nurses commonly carry supply bags with them when they

enter the home. But even this traditional nurses' activity held symbolic meaning for some of the caregiver participants:

> R: You've mentioned the black suitcase about three times and I'm just curious to know what that's about or what it represented.
>
> C: I think what it was, like I knew when I saw that, that the crisis response team was there and it would be worse. It would be at the inside of the door....At one point it was even left there....My brother and I hated that....It was always right by the front door so everyday I would go up and I'd walk in the door and then I'd open the door and then I'd see the suitcase. And then I'd think, "Oh my God, he's worse. Why are they here? What are they going to do to him?" Because even though intelligently, from an adult perspective, they're there to give prescribed medications so that he's not going to be in pain, from a child's perspective I thought, "What are you doing to my Dad?" So immediately, you walk in and there's sort of an aversion.

The preceding excerpt also exposes that caregivers may not perceive themselves as having power or control in the home setting (i.e., "what are they going to do to him?") but rather, may see providers as holding the power and control[77].

Home Invasions

Enduring the invasions of privacy resulting from the numbers of providers coming through the home was a major problem for the caregivers in this study. Privacy, an important social value held in Western culture (Magnusson & Lutzen, 1999), was often eroded in the course of caregiving. Although maintaining privacy was one of the factors influencing the decision to provide palliative care at home (because of the perceived lack of privacy afforded in the hospital), "home invasions" were a common occurrence for these caregiving families. The caregivers struggled to adjust to the sheer numbers of providers coming into their homes, encountering sometimes over fifteen different providers in a one-week period. Much like hospital

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[77] The issue of power and control is further explored in Chapter Six in the section Biomedical Imperative.

personnel moving in and out of hospital rooms, the home constituted a place for

constant activity. Home visits from health care personnel, deliveries of medical

equipment, "on-site" pharmacy services, and emergency services were all provided

at home with little attention given to the implications of transferring public services

into the private sphere of the home. Unlike the hospital where certain activities are

largely invisible, moving such medical services into the home made visible the

functional aspects of institutional life:

> There is a downside to having someone dying at home as opposed to having
> them [in hospital]. When you think of all those people coming on the ward in
> the course of the day, it's discreet isn't it? There's always somebody coming
> onto the ward, with some function or another. Well, if you are in the home, it's
> the same process, except that they're coming in and out of your front door as
> opposed to coming out of the ward. On a ward, you don't see these people
> all the time. Most of them just go to the desk and leave. But, if it's your front
> door, of course, you do see them.

Although it was assumed that the provision of palliative care at home would

create opportunities for privacy and intimacy, the home became a site of "continuous

traffic", with providers revolving in and out of the front door on any given day. Thus,

instead of the home being constructed a place for privacy and intimacy, the

extension of care provision into the home diminished the privacy and intimacy that

the caregivers in this study were hoping to achieve by deciding to care for the patient

at home. As this daughter who cared for her dying mother explained:

> If there had been one person it would have been fine and quiet. But the
> home support worker would arrive to wash him and get him up for breakfast,
> which took a while. And, it wasn't long after then, the hospice people would
> come. They would be around. And then, maybe in the afternoon, somebody
> would interview me from home care. And it just wasn't like being in your own
> home. Lots of times I couldn't do things I wanted....It was dreadful because it
> kind of diminished the intimacy and privacy that we wanted.

The invasion of public service into the home consumed the lives of many of the caregivers and of those receiving palliative care, and eroded the time that families had to spend together. The caregivers, wanting to spend time with their family members, were often "pushed aside" so that providers could "accomplish their goals" while in the home. The lack of coordination between service agencies and service providers contributed to home invasions, leading to a chaotic home environment:

> The other thing that was really horrible when she [Mother] was at home was with all these people coming in. Nurses, people in the administrative program, HSWs. It was just a barrage of visitors constantly, all through the day. She was exhausted and we couldn't get in to see her half the time because she was busy with a nurse or somebody else. It just wasn't ever coordinated and I got the impression that it was convenient for them but not for us. It was absolutely like an invasion of our home. There were so many people in the house, it was chaos.

The provider participants were very aware of the problems resulting from the numbers of people moving through the home. They admitted that coordinating care at home was problematic and the lack of coordination contributes to difficulties in achieving continuity of care[78]. The lack of continuity often compels caregivers to terminate their relationships with providers (particularly HSWs[79]) because the work involved in constantly explaining their needs becomes overwhelming. The providers indicated that continuity could be established by having only one or two workers involved, suggesting that when this happens, the experience of providing palliative care at home can be rewarding:

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[78] Continuity of Care is a theme I further develop in Chapter Five.

[79] One of the central problems with home support is, like hospital workers, most HSWs are unionized employees. Therefore, union scheduling and seniority rules take precedence over maintaining a consistent worker in the home. This is another example of how the hospital is re-created when palliative care is provided in the home setting.

> The big problem is continuity, or lack of. I think families that have one or two HSWs that they get to know that are good, it's a good experience. The family that has a different person come in every single day, nine times out of ten, I've had that family say to me, "Stop this, get them out, there is no point". Because they end up spending more time explaining to that new home support worker what they need done....So if you can have one person that they happen to get along with, that knows what to do rather than having to be told every hour, those [experiences] work out extremely well.

Nevertheless, an assumption often operates alongside the provision of palliative care in the home setting. While the home is usually assumed to provide privacy, and is constructed as the location where families have control over their own environments, this was sometimes not the case. During my field visits, I observed times when care providers walked into homes unannounced, sometimes without knocking on the door. Others did not remove their shoes or acknowledge the caregiver. Instead, they proceeded to the task at hand. Although many providers told me that they considered themselves to be "guests" in the home, my observations revealed that sometimes the providers had more control over the home than did the caregiver, illustrating how control-based structures[80], most often associated with institutional care, can be re-created in the home:

> Tammy [the home support worker] waltzed into the home, seemingly unaware that Sarah [the caregiver] and I existed. She went about setting up the wash basin, telling (not asking) Sarah that "I'm going to wash him now". Sarah explained to Tammy that Justin [the patient] had an exhausting night and was too tired to have a bath. Tammy said, "Well, I can't stay long so I'm just going to do it while I'm here". Sarah nodded in agreement although she later told me, "It doesn't matter what I say, she just does what she wants to do. There's not really anything I can do about it. I need the help" (Field Notes, April, 2000).

Even though many of the providers thought of themselves as guests while in the home, some of the caregivers and patients did not hold the same view. Instead,

they conceptualized health care personnel as "strangers[81]", arriving at their doorsteps to provide care that was of a highly personal and intimate nature. The provider participants often assumed that they would be welcomed into the home because of their status as legitimate providers of health care. However, the caregivers and patients were not always so open and trusting, especially when providers constantly changed. The following interview segment suggests providers may unquestionably assume their positions in the home, but these assumptions are not always appreciated by caregivers:

> They [HSWs] came in, I don't know how many times. We maybe had three of them. One of them helped me give him a bath, one of them changed the bed while I rolled him back and forth, and the third one came in that day and said, "I'm going to give him a bath". But one of the things they [the agency] said to me was that when home support people come in, they like you to leave. They want you to go out for a walk or go for a drive. How can you do that? How can you possibly go out the door and leave your husband with a total stranger while they do who knows what to him?

Many of the caregivers and patients established trusting relationships with their providers; others had experiences that left them guarded. Some of the providers were unprepared to deal with the emotions associated with providing palliative care; others seemed incompetent. However, as this caregiver suggested, it was the invasion of her own personal space that was most disturbing and left her wary of the people coming into her home:

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[80] I expand on this idea further in Chapter Six, where I describe how paternalistic practices in the home shape caregivers' experiences.

[81] The term "stranger" was most commonly used by caregivers when referring to HSWs. Registered nurses, physicians, and counsellors, who also frequented the home, were not generally referred to in this manner. While it was not entirely clear why this differentiation existed, it is possible that caregivers' constructions of home support and the sometimes negative experiences that they had with this system and with its providers, may have influenced the words they used to describe HSWs. Issues pertaining to home support are more fully explored in Chapter Five, where I discuss the rationalization of health care services and in Chapter Six, where I consider paternalistic practices.

> The first time we had one [home support worker], I guess what it boiled down to was that she had lost her mother and she had done home care for her and I guess it was just too soon, this was her first terminal case after that and I think it was just too hard on her....So, we had another one come in but I guess after she bathed him, she didn't know what to do. There were other people [health care providers] here and we were trying to be both places and then we didn't know where she [HSW] had disappeared to. So the door was closed in my bedroom and my daughter looked in there. She'd [HSW] picked up one of my books I was reading on my nightstand and she was sitting there reading it. It was a personal book you know, about meditations and things. It was out of line to pick it up and look at it. What if I had letters or anything personal and private in it? It was in my bedroom you know. That really bothered me.

Invasions of privacy were difficult for all of the caregivers who participated in this study. At the same time, they acknowledged that without the help provided to them, they could not have maintained their promises. As one caregiver said, "I felt pushed aside, and yet, if it hadn't been for them we couldn't have done it". For some of the caregivers, having providers in the home was reassuring, especially when providers affirmed their work or when they arranged access to services on a twenty-four hour on-call basis. Some of the caregivers also appreciated providers' attempts to be non-intrusive. But, most of the caregivers admitted they constantly lived with the paradox of wanting to maintain privacy while needing outside help. This paradox created a "catch-22" situation for many of the caregivers, as this daughter highlighted:

> Sometimes I would think, this is really intrusive. This is her home. She's had so many losses. Now she's lost her privacy....But it's one of those things in theory you think, "Oh, well, we can give all this care at home, it's wonderful". But I think it was kind of a paradox. You know, she hated the intrusion, but at the same time, she was thankful that they [providers] were there. It's a catch-22.

Reinventing Self

Much like nurses who are responsible for providing care for the dying in the hospital setting, the caregiver participants assumed this responsibility in the home. Consequently, many caregivers reinvented themselves to become "nurse-caregivers" by assuming responsibilities for providing personal care, assessing symptoms, planning and coordinating health care services, monitoring the health status of the patient, and mediating family tensions. The caregivers frequently referred to their family members as "patients" and many talked of engaging in "shift work". The caregivers also hoped to "buddy" with HCNs so they could gain expertise in order to provide care:

> What we needed [at home] was to be able to set up a hospital situation in the house. With a nurse to come in everyday and show us what to do. Then we'd do what had to be done. Give him enemas, change his oxygen, give his morphine, whatever. So, she could show us how to do that so we could care for him. Because we were willing but we just had no expertise.

Assuming the organization and management of care at home meant that the caregivers had little time to devote to maintaining their core identities as wives, husbands, daughters, sons, and so on. Many of the caregivers spent so much time completing the tasks of caregiving, they had no time to "just be myself". As one caregiver stated, "you become a different person, you stop being a wife and you start being a caregiver and a professional". Taking on the role of nurse-caregiver produced changes in the relationships between family members. Some of the caregivers became irritable with, and resentful towards, their dying family member. Some dying family members also became impatient and critical of their family

caregivers. One caregiver reflected on her experience in caring for her elderly
mother at home and how this experience made her feel:

> My mother died of lung cancer and there was no room for her in the hospital
> so I stayed with her. She fell out of bed and I had to get her onto the bed.
> And, in order to do that, I had to put my arms around her and by this time, she
> had cancer in her bones so you can imagine her pain. And she was so mad
> at me. She wasn't a very nice person in the first place but she was so mad at
> me. When she finally got onto the bed and lied down, she called me a "God
> damn amateur". She apologized to me afterwards but you know, that's what
> we were. We were amateurs. We didn't know what we were doing.

A young woman, who had previously cared for her father at home, explained that
every time she lifted him from the bed to the commode, they "battled" over lifting
procedures. Each subsequent interaction became a battle and eroded their father-
daughter relationship. As this daughter reflected on her experiences, she came to
see how her role in the family had changed; she had relinquished her role as a
daughter and saw herself as the person inflicting unpleasant procedures onto her
father. This realization made her consider the benefits of having an outside person,
like a nurse, involved in the caregiving process, and she contemplated whether the
hospital might have provided a better care option:

> It came to us having to fight all the time, instead of spending my time saying
> goodbye to him. All that [caregiving] gets in the way. Like the fact that he
> was mad at me because I was the one inflicting all of this stuff on him. That
> gets in the way. Whereas, if a nurse came in, he'd just do it and not argue
> about it. When he was in the hospital, I could just be there and support him
> and help him and have more of a comforting type of relationship….I guess
> your role changes [when you are at home]. Because instead of your job
> being to just sit there, spend time with him, comfort him, and hold their hand,
> suddenly your job is to look after their pain, their nourishment, their bodily
> functions. So, you feel like you don't really know what exactly it is you should
> be.

The intimate nature of providing personal care also contributed to a
reinventing of self. When people enter the hospital, there is typically an

understanding that nurses will provide personal care. However, in the home, the

caregivers assumed this responsibly, although they sometimes had help from the

providers. Some of the caregiver participants, uncomfortable with intimate aspects

of care -- such as bathing, giving enemas, or doing catheter care -- explained they

"disengaged emotionally" from their caregiving activities because they felt

embarrassed. Yet, unlike their nurse counterparts in the hospital setting, who often

have the benefit of discussing patient care with each other, the home-based

caregivers often did not have opportunities to debrief or discuss situations that were

difficult. One daughter theorized these opportunities do not exist because of the

hidden, unspoken, and private nature of palliative caregiving at home:

> There are intimate things that go on that you just don't discuss with people.
> You know what I mean? You don't sit around the coffee table and discuss
> what bed sores are like and when they're weeping and running and you buy
> these sheep skins and try to cradle them under their body because their
> bones are sticking practically to the flesh. I mean, people don't really know
> what's going on behind closed doors.

Some of the caregivers struggled to maintain their core identities, realizing

they needed outside help in order to sustain their relationships and retain their sense

of self. However, their efforts were hampered when the patient resisted outside

assistance. As previously mentioned, some patients were averse to having

strangers in their homes providing personal care. Accordingly, they flat out refused

to have providers in the home. When this happened, family tensions heightened

and contributed to a disintegration of family relationships. Some of the caregivers

were then placed in positions of mediating family tensions. One caregiver, who had

recently given birth and was providing care to her newborn child while caring for her

dying mother, explained how she was placed in the position of mediating the

relationship between her parents:

> It was hard in the hospital, but it was even worse at home, because my Mother didn't want 24-hour care. She wanted some privacy. So, it was my Father that was having to wake up every two hours to give her pills because she wasn't mobile. That caused a lot of friction between them....He was so exhausted. He would sleep through the alarm or she'd wake up to get him awake to get the pills. My parents were fighting. My Mother cried constantly. I was staying downstairs and I could hear her crying every single night. Crying, crying, crying. And I was trying to figure out what to do. A lot of it had to do with my Dad not being able to give her the attention she needed because he was so fatigued. After working with them, I finally convinced them that she needed to have home care at night so that he could get some sleep, to look after her better, emotionally and physically during the day.

The provider participants confirmed that caregivers and patients are often unwilling

to accept help from outside the home. One provider speculated that caregivers and

patients who are resistant are more likely to have difficulties with palliative care

being provided at home:

> If you have somebody who abhors the idea of strangers coming into their home and helping them and just pushes that aside with all they can, they're going to have a much harder time and things will fall apart for them....Then the crises keep happening and you may recognize and talk to them and help explain what's going on, but they can't stand to have somebody in their house. They've never had it. They're very private so they keep struggling. And it may be the patient who's not allowing the caregiver who's getting worn out, but they won't go against their spouse's wishes. Or the caregiver thinks they can manage....But again, one or the other of them are not allowing help in.

The providers rarely talked about caregivers' reinvention of self and the

possible implications to caregivers when the hospital was re-created in the home.

As with other aspects of palliative home care, the providers tended to focus on the

beneficial aspects. Many providers gave credit to caregivers, referring to them as

"experts". For example, one provider described the outstanding organizational skills

of family caregivers, citing how they were often easily able to coordinate and manage complex tasks such as scheduling their allotted home support hours (a task typically reserved for managers within health care agencies). This provider maintained that, with encouragement, many caregivers were able to take on this role and other roles that were commonly performed by providers. Encouragement such as this, while supportive and welcomed by many caregivers, also served to reinforce the caregivers' reinvention of self. These providers seldom examined the implications of their actions and how their encouragement might be perceived by caregivers.

<u>Feeling Abandoned</u>

Similar to the abandonment described by involvement with institutionalized health care systems and its providers, some of the caregiver participants also felt abandoned while providing palliative care at home, particularly by physicians. For example, once a cancer diagnosis was made and the patient was deemed "terminal", cancer specialists often minimized their involvement with the family. Family doctors, reluctant to do home visits, often did not see patients and their family caregivers for many months, or at all. As one caregiver said, "they drop you like a hot potato". The caregivers had better experiences with home health care providers and were generally appreciative of the supports they received. At the same time, some of the caregivers felt unsupported by providers and felt their needs were given little consideration. In my observations, I witnessed instances in which providers focused their entire attention on the dying person. In these situations, the patient was usually in distress and conversations focused on the provider getting a status

report on the patient and on alleviating distressing symptoms. The caregivers talked

of abandonment in situations where home health care providers either failed to

provide adequate support or failed to keep their promises:

> Up until the last few weeks before he died, things weren't going too bad. But then he started to deteriorate and that is where everything started to fall apart and where we really needed help and information. We didn't get any of that. And one of the HCNs said to me, "We failed you Mrs. X". I didn't realize the nuts and bolts of looking after somebody....Another home care nurse had a few minutes and she phoned me, two days before he died and asked me how I was doing. And I said, "I'm absolutely panic-stricken. I don't know what to do and where to turn". So she came and helped me give him an enema and helped me out. That was when she told me this. She sat us down and told us how they [the HCN] were going to walk our journey with us. She ordered a whole bunch of medical equipment that we didn't know what to do with....But after talking to us and telling us that they would walk the journey with us, we never heard from any of them again.

The ways in which health care personnel communicate with caregivers has a

lasting effect on them. When providers were sensitive to the needs of caregivers

and supported them with information or encouragement, the caregivers were better

able to cope with situations that arose and had fond memories of their providers.

The caregivers in this study also remembered and vividly recounted providers'

insensitive remarks. When support was lacking and communications were

insensitive, the caregivers felt abandoned by, and were unimpressed with, the

providers:

> 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. 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. She said, "Take her to emergency". I said, "She can't walk". Well, "Call an ambulance"....The reaction from the nurse was the worst thing of all....She was very blunt.

Caregivers and providers in this study indicated that abandonment can be minimized when the health care team is consistently sensitive in their care approaches, when they vigilantly anticipate caregivers' needs, and when the family physician stays actively involved in the care process.

In summary, the nature of the home changes when it becomes the site for health care provision. In some instances, the home ceases to be the home it once was and, instead, takes on many of the characteristics of a hospital setting with health care providers bustling around, medical equipment and supplies competing for precious space, nurse-caregivers working shifts, and health care personnel sometimes enacting their own goals regardless of the goals of the family. Previous research demonstrates the problems family members have with invasions into their home (Bruera, et al., 1990; Dubois & Santos-Eggimann, 2001; Stajduhar, 1995) and how caregiving contributes to a reinventing of self (Anderson, et al., 1991; Davies, et al., 1990; Hull, 1989; Wellisch, Landsverk, Guidera, Pasnau, & Fawzy, 1983). Studies with caregivers of the chronically ill also suggest caregivers and patients often resist outside help in the home (Wuest, 2000). However, there is little written about what actually unfolds when palliative care is provided in the home setting. Most of what has been written is at a theoretical level, with little to no research conducted in this area. Yet, this analysis clearly uncovers some of the assumptions that operate alongside the provision of palliative care at home. As this quote from a daughter suggests, providing home care for the dying, while providing some benefits, can also foster feelings of frustration, anger, resentment, and disillusionment:

In some ways, it was good and bad....Mostly bad....We were going to the hospital to pick up a certain kind of pad for the bed. And then we went to the medical supply store to pick up a chair for the shower and a wheelchair. My Dad was spending a lot of time running around picking up equipment and I think it could have been done differently....I mean, my Mom was going, "Where is my family?" And we're running around trying to organize things. I was really shocked at how disorganized it was. There was the social worker, the person at the hospital, and the home nurses phoning at the same time and I'd get them confused....There is just too much bureaucracy involved. I just wanted to deal with a couple of people and have somebody else organize it. When somebody has three months to live, we need things to happen now and have it organized so that we could live the little bit that was left. And if somebody just said, "You need this, and this, and this and it's going to cost this much and we'll have it delivered," that would have been great because you spend all of your time doing the organizing and coordinating. I mean, my Mother was telling us what to get for her. She had been a nurse. She knew what she needed. The nurses were also giving us lists of things to go out and buy and find but you know, do you think I wanted to go shopping then? I guess I thought I'd been really deluded about the idea of coming home and spending the last days at home. It wasn't peaceful. It wasn't calm. It wasn't relaxing. The time spent with her wasn't quality time. It was just chaos. And if I ever do become ill with terminal cancer, I'm going to say, "Take me to hospice now". Because it was so horrible at home. I don't even want to be at home. I'd just want to go straight to hospice for my family's sake. Because at least there we could talk and the care was taken care of....At home, the care was overwhelming because of the disorganization.

The experiences arising from re-creating the hospital at home lead some of the caregivers to consider death as a hoped-for opportunity, a phrase used by Coyle (1998) in her ethical review of dying at home. Some of the caregivers indicated they came to a point where they "just wanted it to be over". Caregiving had taken a toll on their lives and they were exhausted from the daily demands placed on them. They wanted to resume their lives and move forward and, yet, they were ambivalent with this realization:

In a way, everyone is tired of the experience. My Dad's tired, I'm tired, my Mom's tired. Everybody is tired of it and wants it to be over. But, of course, it can only be over if he dies and it appears that no matter how long a period you've had to get used to the fact that the person's going to die, you still don't really realize it. So, it can only be brought about by an event you dread but I

find myself thinking that I hope my Dad doesn't die in the next few weeks until I'm finished writing my papers. Or, I hope he'd die because I can't take it any more. And you think, "God, what am I saying? This is too weird".

Talking about death as a hoped for opportunity often facilitated discussions about euthanasia and assisted suicide.

Discourses on Euthanasia and Assisted Suicide

The issue of euthanasia and assisted suicide[82] did not come up in all of the interviews but, when it did, caregivers (and sometimes patients) spoke passionately about it. The following interview segment with a dying man and his retired wife exemplifies the multi-layered and complex nature of events that unfold when families consider euthanasia and assisted suicide:

> P: I want to terminate. I want to put an end to all this lingering business. I've got a terminal disease. I want to put an end to it. The government should allow me to do it the easy way. But they won't do that so I've got to resort to this other thing called hospice.
>
> R: You're getting tired of being here.
>
> P: Oh, this lingering business. I'm never going to get any better so why not put an end to it. I've got these miserable spasms and there is no joy in living that way so I just want to end it all.
>
> R: How do you feel about that [researcher speaking to the caregiver]?
>
> C: Well, my Father died at home here when he was 83. If anybody had death with dignity, he did before they invented that term. So, that is what I would hope for. Intellectually, it makes a lot of sense but every once in awhile I think, oh god, this is such a decision.

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[82] In this study, participants used the terms euthanasia and assisted suicide interchangeably. However, it is important to acknowledge that there are specific distinctions between the two. Euthanasia is commonly defined as the "act of bringing about the death of a hopelessly ill and suffering person in a relatively quick and painless way for reasons of mercy" (Elgie, 1994, pp. 9-10). Euthanasia and assisted suicide differ in the degree of physician intervention (Arras & Steinbock, 1995). In euthanasia, the physician performs the immediate life-ending action, such as a lethal injection, whereas in an assisted suicide, the physician facilitates a patient's death by providing the necessary means or information to enable the patient to perform the life-ending act (Hendin, 1998).

P: Never mind dignity, just get me the hell out of here. The sooner the better. I'll tell you, I'm a coward. I don't like pain. I can starve myself to death but that's painful. But I just want to do it the easy way and no pain if possible and just get it over with. I just wish I could terminate. Oh god, I wish I could.

R: You have pretty strong views about this.

P: Well, at my age they should allow me to decide if I want to live or not. Hell, I was in the service during the war. They didn't mind then if I was in a position to get annihilated. Why should they care now? The sooner the better. If she can do it [looking at his wife], I'll be damn grateful. It would be a time for rejoicing because this is no way to live. I've got no independence. I'm dependent on everyone. I can't go anywhere or do anything unless I have people looking after me. This is no way to live. And I'm a burden, a hell of a burden.

C: I told him frankly and I'll tell him again that I'm not about to spend the last years of my life in jail.

P: They won't put you in jail.

C: Look at what they did to the specialist back East for god's sake.

P: They didn't put Kevorkian in prison.

C: He is in prison right now.

P: Well, if he is, he's not getting killed. Anyhow, I'm sure they wouldn't hurt you.

C: I couldn't do that. I'm not comfortable with the process.

P: You know how much misery I'm in.

Like other empirical work examining euthanasia and assisted suicide (Seale &

Addington-Hall, 1994; Seale, Addington-Hall, & McCarthy, 1997), the participants in

this study indicated that they viewed it as a means by which to take control over

one's death and to end physical distress, emotional suffering, and dependence on

others. An interview with a lobbyist from the assisted suicide movement revealed

that many people who are terminally ill or who experience incurable suffering

consider euthanasia, confirming that such a decision allows for self-determination or

is a means to stop irrevocable physical distress:

> You see this [requests for assisted suicide] with a number of AIDS patients
> and other people where it is really an autonomy drive that they want death,
> the time of death to be an option for them. In other words, it's not necessarily
> driven by physical distress. It's driven by a philosophical attitude to personal
> autonomy and control....The Netherlands certainly substantiated that a
> reasonable percentage of people wanting suicide, it was driven not by
> physical distress, but by the autonomy issue and the control, and the "I want
> the option of my life, and I want the option of treatment, and I want the option
> of my death at my choosing". So when we look at euthanasia, physical
> distress is part of it, but it's not the whole picture.

The caregivers who spoke to this issue told me that they and the patient had

contemplated the patient's suicide at some point in the illness trajectory. Some

participants seriously contemplated the issue, contacting Right to Die Societies and

even Dr. Jack Kevorkian in order to obtain information on the "best ways to make it

happen". Other caregivers indicated they and the patient had "suicide plans" in the

event that suffering became unbearable. Some spouses admitted they and their

partners had made promises to one another that if in the event that either became

terminally ill, they would help the other to die. The caregivers contemplating the

issue felt euthanasia and assisted suicide were humane and intelligent options to

pursue to end needless distress:

> I don't know what the answer is, but it's terribly sad that one has to die like
> that. You know, in a way we treat our dogs better in that we look at them and
> we say, there's no quality left to this dog's life. And so, you put them to sleep
> nicely and quietly. The last couple of years was certainly not worth living. It
> truly wasn't....There were times when I felt that there was something very,
> very kind and caring and intelligent about the opportunity of euthanasia
> because over and over again she would tell us how much she hated her life,
> how much she wanted to die and have it over with.

None of the caregivers in this study admitted to assisting their loved one to die although, as other studies have indicated (Ogden, 1994), some said they would have assisted if they were guaranteed not to suffer legal repercussions as a result. However, the providers in this study gave examples of incidents where suicide plans were enacted, illustrating how some dying patients will take desperate measures to end their life:

> He had a plan with his family to kill himself, entirely within the family because he couldn't get the support obviously, to die. The plan was to drive to the end of his street to a vacant lot very early in the morning, get out of his car and shoot himself. And then his wife would go, "Oh, he's not here, I wonder where he is?" Then call 911 and pretend she knows nothing….But, he was too weak to get in the car and he was too weak to drive. He didn't want to implicate his family so he walked out the front door of his apartment, crossed the street and shot himself in the head in front of a bunch of school kids.

As depicted in the opening quote to this section, some of the caregivers felt pressured by patients to consider an act with which they were uncomfortable. This pressure placed them in particularly difficult positions, especially when they were determined to do all they could to support the patient. Some of the caregivers were able to talk to their providers and were supported in their decisions not to assist with dying. Other caregivers who sought dialogue and guidance found that some providers were uncomfortable speaking about the issue:

> I can see why people want assisted suicide. I looked at those morphine pills and thought to myself, "How many do I have to give him to stop him from breathing?" You think of these things when you're in the situation….When the nurse came in I tried to talk with him about it but he looked at me and said, "That's not the business we are in". And I thought, "Okay, there is a message here. Don't ask"….They won't allow you to talk about it. You ask and then they clam up.

This experience was confirmed when I interviewed providers. A few of them were openly uncomfortable with the concept of assisted suicide. One provider stated she did not agree with the idea, citing her own personal beliefs:

> Personally, I think because of my own beliefs, we're in this life on our journey, and whatever that journey is, we are expected to have it and be it and live it and come to the end of it. And I don't believe that we have the right to make the decision either for ourselves or anyone else about when the end of that journey is. That's my own personal belief so I definitely don't agree with assisted suicide. I agree that it's very traumatic sometimes to watch people but I try to understand why this is happening. There must be a reason.

Another provider hoped she would never have to deal with the issue. Others pointed to the amount of responsibility the decision entails, especially in light of the various motivations behind such requests and because many people change their minds. Those providers who were uncomfortable with the complexity of the situation said that while they would not stop someone from following through with their suicide plans, they would also not actively assist a suicide. They preferred to encourage people to see dying as "an opportunity to allow those who love you to care for you".

No empirical evidence was found to suggest that caregivers may feel pressured into assisting their family members to die. However, studies examining health care providers' experiences with requests for assisted dying show that such requests create moral, ethical, and legal dilemmas (Matzo & Emanuel, 1997; Howard, Fairclough, Daniels, & Emanuel, 1997; Volker, 2001), particularly when providers have little opportunity to discuss these issues. Some providers in this study said it is easier to discuss the topic of euthanasia and assisted suicide now than ever before. However, others pointed out that some agencies have policies that do not allow discussion of the topic at all. This makes it very difficult to explore

the intentions of the individual and to provide proper information. As has been

demonstrated in another study, within the AIDS community, information about how

to commit suicide, as well as the actual death itself, is driven underground (Ogden,

1994). Some of the providers felt that caregivers and patients needed to discuss

euthanasia and assisted suicide, suggesting that talking about it does not

necessarily lead people to act on the discussions as this home care nurse

suggested:

> When I was younger and I hadn't practiced as much, I would stop people from
> talking about it. I now will sit and talk with them about that and acknowledge
> that because that's what they need. So I've grown from somebody who
> looked at life differently and I've learned to understand that you have to hear
> that and not stop them from saying it. It's okay for them to talk about suicide.
> It doesn't mean they'll do anything or need to do anything about it. They just
> need to talk about it.

According to participants, part of the concern associated with making

decisions about euthanasia and assisted suicide is that some patients may change

their perceptions about the issue once their physical symptoms are controlled, or

once they receive care and information as had been documented in another study

(Chochinov, Tataryn, Clinch, & Dudgeon, 1999). In a few instances, caregivers in

this study, and their respective spouses, had made previous agreements to assist

each other to die, but changed their minds once one of them became ill and was well

supported by the health care system. Other caregivers who strongly supported

euthanasia and assisted suicide described their struggles when faced with the

choice of assisting their loved one to die. In a vivid and emotional account, this

husband demonstrated the difficulties inherent in making decisions about euthanasia

and assisted suicide and how he would have regretted the decision had he gone through with it:

> We had agreed a long time ago that when things got really rough, that we would stand by each other and help each other....When she was in her psychotic state, I'd go to the hospital and she would spend the whole time pleading with me to kill her. "Kill me, please kill me", she said. Oh, shit, that was hard (sobbing)! And I couldn't because she was in the hospital. And I don't know if I could have carried it out, honoured my promise if she'd been home. But that pleading was incredibly hard. But then she came out of that space and the time was so beautiful. And I think it's hard to say what position I'd take now. It's very easy to make those agreements when neither of you is sick, but you're foreseeing them. Carrying them out is another situation which every person would have to meet in his or her own way....If I had taken the steps as she asked me to do, begged me to do, if somehow it had been possibly feasible, we would have missed those last six months of great joy and great beauty.

In summary, I have provided my interpretations of the circumstances that unfold as caregivers live with their decisions to provide palliative care at home. Some of the caregivers constructed their experiences as life-enriching while others perceived them as life-draining. It should be noted, however, that all of the caregivers in this study talked of both the life-enriching and life-draining aspects of their experiences, demonstrating their dual positions in the caregiving role. The preceding discussions have also highlighted how the hospital is often re-created in the course of caregiving at home, and how the discourses of euthanasia and assisted suicide permeate the lives of some of the caregivers and their dying family members.

Changing the Decision

Not all caregivers in this study were able to continue to care for their dying family member at home. Caregiver exhaustion, uncontrolled physical symptoms, increasing financial burdens, loss of functional status, and complex family dynamics

were all cited as reasons why some of the caregivers changed their decisions.

These reasons have also been well documented in the literature (Brown, et al.,

1990; DeConno, et al., 1996; Emanuel, et al., 2000; Fainsinger, et al., 2000; Grande,

et al., 1998; Lubin, 1992; Wyatt, et al., 1999). The caregivers who changed their

decisions (or were unable to keep their promises) suggested the care required at

home was becoming increasingly complex as they assumed duties that were no

longer provided by the health care system. Consequently, they coped with

increasing demands and more complex situations, especially as the patient's health

status declined. Yet, as this daughter, who was also working full-time while

caregiving described, there came a point where she could no longer manage the

complexity of the situation:

> We really thought that Dad would be able to die at home. That's really what
> was in our minds but there were so many unknowns. My Dad was a big man.
> He didn't have the wasting that people with cancer often do. Once he
> became unable, he was totally unable. He was too big for us to manage
> physically. He was unclear in his mind. His level of consciousness was quite
> variable and sometimes he'd recognize me but lots of times he didn't....His
> pain was becoming difficult to manage and his bowel care....We just could
> not manage the enormity of the situation and the physical care that he was
> requiring. We didn't know what the trajectory would be in terms of how long it
> would be and we just couldn't manage the physical demands....We couldn't
> manage at all. I think intuitively we felt it was the right decision [to take him to
> the hospital].

When caregivers in this study changed their decisions, they experienced

extreme guilt and a sense of failure. Some of the caregivers changed their decisions

only when the patient became unconscious, believing that they would be unaware of

their transfer to the hospital. Other caregivers disclosed they deceived the patient,

letting them think they were only going to hospital for a few days to get their

symptoms under control:

> She did not want to go to hospice. She did not want to die in the hospital and it was like it was forced on her. We had to tell her, "We can't look after you anymore at home"....The people from hospice who were coming in were really pressuring us....But she had the impression that she was going into hospice for a couple of days to get her pain under control and then come home. And it was almost like we had to let her believe that so she'd go because it was horrible the way it was.

This daughter-in-law commented that caregivers need to be given ongoing opportunities to reconsider their decisions because of the inherent difficulties in knowing for sure whether they will be able to cope with the caregiving process as it unfolds:

> I think that dying at home can add a lot as long as they [caregivers] choose it and they get ongoing choice. I don't think you necessarily know what you're getting into....As your condition changes you can look at it differently and I know that from personal experience, when I looked after my mother-in-law, we very quickly one night determined it wasn't working for us.

One provider agreed that circumstances might necessitate a hospital admission. He recommended providers should be intervening earlier to help caregivers recognize potential difficulties. He implied that such interventions might minimize the guilt many caregivers feel when they change their decisions:

> Some of the things I see that are distressing are the promises that people make to keep him or her at home. You know, they say "We promised we'd keep her at home". And now you know they're desperately guilty because the person can't stay home. I often say to them, "You know, circumstances change". I think when we meet families and we ask them where they would like them to die and they say home, we should probably say to them "Fine, but circumstances change and if it changes, you shouldn't feel guilty". Like we should start at that point in saying to them "You don't have to feel guilty" because it's too darn late to do that to them afterwards. We should be saying to them, early on, that problems may arise which make this impossible for you to carry out and you must not feel guilty about it.

Summary

By starting from the standpoint of caregivers in this chapter and extending my interpretations to include health care providers, the groundwork has been laid for the further explication of the social context of home-based palliative caregiving that follows in the next chapters. Caregivers' experiences are neither uniformly rewarding, nor disintegrating. Rather, their experiences of providing palliative care at home are exceedingly complex. My next task is to situate these interpretations in the meso context as I focus on how the organization of health care and regional health care reforms have shaped caregivers' experiences.

CHAPTER FIVE:

DYING AT HOME: THE COMMUNITY CONTEXT

In the preceding chapter, I described home-based palliative care from the standpoint of caregivers and extended these interpretations to include the perspectives of health care providers. I now build on my foregoing interpretations and examples of data to situate these family caregiver experiences within a broader social context[83]. As suggested in the previous chapter, the provision of palliative care at home is mediated by much more than the individual experiences of family caregivers. Caregiving takes place within the complex web of health care provision, demonstrating that the everyday experiences of caregivers are organized and determined by structures and processes inherent within the health care system. In this chapter and the next, I aim to describe that complexity, and how it affects the day-to-day experiences of caregivers. My goal here is to demonstrate how regional health care systems and reforms influence caregivers' experiences. Given that each local situation determines, to a large degree, the existence, dimensions, and quality of care, I begin by providing an overview of the organization of health care in the region where I conducted this study. I then explore the organizational tensions existing among health care systems mandated to provide palliative care, demonstrating how the historical context can influence the delivery of care in the home. A discussion of specific health care reforms follows, delineating how the rationalization of health care services has shaped the experiences of caregivers who

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[83] In this chapter and the next, I extend my interpretations to include the perspectives of caregivers, health care providers, and administrators. I also have used a number of documents to supplement these interpretations.

were part of this study. My overall intent in this chapter is to present an account of how local health system structures and processes come together to shape caregivers' experiences with the provision of palliative care at home.

The Organization of Health Care

In order to contextualize the provision of home-based palliative care, it is important to gain some understanding of the system in which such health care is provided. At the same time, comprehending the intricate and complex nature of health care organizations is a challenging endeavour. Health care organizations and systems are rarely stable; rather, they are in a continual state of change. Like other provinces and regions across Canada, the health care setting in which this study was conducted was, and continues to be, in the process of reforming the management and delivery of publicly funded health care. The regionalization of health care services was almost completed and regional planning for palliative care services was in progress. Thus, the interpretations presented here are a reflection of "what was going on" at the time of this study.

Health Care Regionalization

A central aspect of Canadian health care reform has been the introduction of regional decision-making structures. Although somewhat ill-defined in the literature, health care regionalization[84] generally involves,

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[84] The primary goal of health care regionalization is to improve the efficiency, effectiveness and responsiveness of health care decision making and service delivery (Church & Barker, 1998). One of the defining characteristics of regionalization is its emphasis on shifting care provision from institutional settings to community-based settings in order to contain costs, to integrate and coordinate services, and to improve the quality of health care to the public (Burgess, 1996). Moves to coordinate decision making and to integrate regional systems for health care are not new ideas, but were introduced as early as 1969 by a federal task force on health care costs (Armstrong & Armstrong, 1996). In the past decade, regionalization, as a strategy, has gained new popularity within most Canadian provinces.

> ... an organizational arrangement involving the creation of an intermediary administrative and governance structure to carry out functions or exercise authority previously assigned to either central or local structures. Accordingly, regionalization may entail the shifting of responsibility for public health from a series of local boards to a regional agency, or a general devolution of power from a central governing agency to regional bodies (Church & Barker, 1998, p. 468).

Following, in part, recommendations arising from British Columbia's Royal Commission on Health Care and Costs (Seaton, 1991), many health care services in Victoria's Capital Regional District (CRD) were brought together under one umbrella to form the Capital Health Region (CHR) in 1997. The goal of regionalization was to create client-focused, integrated, and efficient health care delivery systems (CHR, 1998). The newly formed CHR serves a population of approximately 340,000 within the region itself, and acts as the major referral centre for Vancouver Island's 650,000 residents (CHR, 1999). Health services of the CHR are provided in over thirty locations and range from acute care hospitals and long-term care facilities, to local health units and outreach services provided by public health nurses, HCNs, and mental health workers. The CHR spends about $540 million per year on health services[85] (CHR, 2000).

I explored the topic of regionalization with participants in order to uncover whether the process had influenced the experiences of family caregivers. When asked directly about regionalization, most of the caregivers were unclear about the meaning of the term, but understood that "there were changes happening in the health care system". Many of the caregivers fervently described the reforms that

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[85] The payment of physicians and prescription drug costs are not included in the CHR budget (CHR, 2000), but are paid through the provincial Medical Services Plan and the provincial Pharmacare Plan.

had resulted from regionalization, most prominently in the home support sector[86].

The health care providers and administrators who were interviewed also talked

about these reforms, emphasizing that the regionalization process had reduced

support provided to some caregivers. For example, some community caregiver

support groups on Vancouver Island were unable to secure continued funding

because they "were caught in regionalization, in a transition time where the Ministry

[of Health] hadn't transferred over authority and funding to the region".

Consequently, some groups that provided support to, and advocacy for, caregivers

disbanded because of a lack of funding from regional health authorities. Others

faced challenges in trying to negotiate a health care system that was in a constant

state of change. They experienced difficulty in knowing who to contact when family

caregiver issues needed to be addressed and when the government was offering

little support:

> For a long time, it was hard to know who it was you were supposed to talk to.
> I guess part of it is just the nature of what's gone on here with regionalization.
> I mean, there's no point in even dealing with the Ministry [of Health] anymore
> because they have basically covered their windows and bolted the doors and
> unplugged their phone. Anytime you have an issue to bring up with them,
> they push you into the region. This region, as you know, has gone through
> numerous changes and is always in restructure. Basically, the whole thing
> hasn't settled down yet, and it's still a work in progress….But it's still difficult to
> know who to talk to.

Some of the providers and administrators believed that regionalization would

ultimately improve continuity of care and facilitate better service to palliative care

patients and their families. They championed the benefits of regionalization,

admitting the process was intense but predicting care would improve as a result.

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[86] At the time of this study, major changes to the organization and delivery of home support services
were occurring. These issues are explored later in this chapter.

They extolled the virtues of regionalization, specifying its potential to enhance care effectiveness. Others were skeptical suggesting "the focus was not so much on enhancing community care but on saving hospital dollars". However, the prospect that regionalization, and the resultant shift from hospital care to home care, would lead to more efficient health care[87] was an idea that appealed to some participants:

> I would have to say that the regionalization process was very intense....But I feel all in all that it has been excellent. I think it will make the care better. The care will be delivered more efficiently and I think the plan of care will become tighter. It caused some turmoil initially but I think now, I do believe it will be good and it will be more efficient.

One of the primary goals of regionalization was to shift health care services "closer to home". According to participants, such an approach would enable families to receive health care in close proximity to where they lived or to receive care in their own homes. Family caregiver advocates criticized closer to home approaches indicating community resources were inadequate to address the needs of those requiring home care. In a newspaper article reporting on the shift from institutional to community care, critics like Dr. Neena Chappell of the University of Victoria's Centre on Aging, argued "you just don't dump people out of institutions - you need the other half of it" [i.e., funded community care] (Chappell cited in Volkart, 1998, p. A9). The extension of health care services into the home has also captured the attention of journalists who have suggested a "crisis in home care" currently exists at

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[87] Many participants used the terms "care effectiveness" and "cost efficiency" interchangeably without acknowledging that these were different concepts. Those that focused on efficiencies were more inclined to expound the virtues of regionalization without considering the implications for home-based caregivers. Others emphasized how the shift from hospital to community-care was essentially a mechanism to off-load costs onto caregiving families. These ideas are further developed in Chapter Six.

both local and national levels[88]. Many of the providers and administrators supported

closer to home initiatives, believing home-based palliative care would provide a

better alternative to institutional care. However, their initial optimism faded as they

realized the resources to support home-based palliative care were short lived.

Consequently, some participants maintained that the original vision for closer to

home had little meaning in the current health care context:

> The provincial government has had on paper, the words of "closer to home"
> which they have been using following from the Royal Commission back in the
> early '90's. And certainly the region has instituted closer to home and they
> did provide some additional dollars to support that and palliative care got
> some additional dollars. Back in 1994 and 1995, closer to home did have
> some meaning. The government was saying "We're going to shift and we're
> going to support" and they did add in some dollars. It was looking like the
> politicians would actually do what they said. In the last part of the 1990s, it's
> not that it's been necessarily reversed, but it's just been flatlined and the
> resources have not kept up with the escalating needs.

According to some of the providers, caregivers are now challenged to get the

support they need when they most need it: "Caregivers simply fall into a black hole

because there is just no support. A few years ago, it was closer to home but now it's

more like they're closer to the street. That's where we're going …. They can't get

what they need anymore". Difficulties in accessing services to support home-based

palliative care were also issues that the caregivers spoke about. I address this issue

later in this chapter.

Some of the participants, particularly those working in community care,

criticized regionalization because they believed some health care reformers had little

understanding of the community care system and the resources required to support

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[88] For example, see Argyle, 2000; Harnett, 1999a; Harnett, 1999b; Lindgren, 1999; MacKinlay, 1996;
Walker, 1996a; Walker, 1996b; Young, 2000a; Young, 2000b.

care in the home. They maintained the regionalization process was directed primarily by hospital administrators who focused on "the bottom line". However, according to one health care provider working for the CHR, an understanding of community health care is fundamental to incorporating it effectively into a regionalized health care system:

> One of the problems with regionalization was that they basically recycled the same people….So a lot of people who ended up being in decision-making positions were people who worked in the hospital system. And, hospitals are disease focused and injury focused. Community care is something totally different and yet community care has never been a focus of our so-called health care system. It's been neglected for so long and yet it's foundational….Understanding it is foundational to knowing how to bring it into the fold….The paradigm hasn't been made to expand what the concept of health is. First of all, we don't have a health care system we have an illness care system. That's what it is. And once we start to take a really good look at that, then maybe we can start realizing that we've got to change our ideas if we want to create a truly regionalized health care system.

Evaluating the impact of implementing regionalized health care systems is difficult. Some evidence suggests that the integration of health care services has improved the quality of health care (Howard & Alidina, 1987). However, other researchers demonstrated that service integration has failed to enhance efficiency and improve outcomes for patients and families (Dowling, 1995; Shortell, 1988). Church and Barker (1998) argue there is a little evidence to judge whether regionalized systems will ultimately enhance efficiency and effectiveness of health care within the Canadian context. They contend that unbridled faith in regionalization has limited the systematic analysis of its impact. It is clear, however, that regionalization has had some influence on how home-based palliative care is experienced by caregivers. At the same time, the long-term outcomes of regionalization are yet to be determined and will require further investigation.

The Organization of Palliative Care Services

The CHR is only one of four health care systems that interface with palliative care patients and their families. The CHR partners with the Victoria Hospice Society (VHS), home support agencies, and the B.C. Cancer Agency (BCCA), each playing a major role in the provision of health care to persons diagnosed with life-threatening illnesses. The CHR is responsible for the organization and delivery of both hospital (i.e., acute and long-term care) and community-based services (i.e., long term care, home nursing care, and community rehabilitation) for people at the end-of-life. Although there are no designated inpatient palliative care beds that are managed by the CHR, a clinical nurse specialist in palliative care is employed at one acute care hospital site, and a community manager in palliative care oversees regional planning, by working in partnership with the VHS, an agency that provides both inpatient and community-based palliative care within the CHR. The CHR and the VHS recently signed an affiliation agreement whereby VHS has maintained its own governance structure and control of the day-to-day service operations. The CHR provides space and core funding to the VHS, and the remainder of operational funding comes primarily from donor support (Field Notes, May 2001). The VHS manages a seventeen-bed acute and long-term palliative care unit within one of the acute care hospitals of the CHR. It also manages the PRT, provides outreach counselling and bereavement support, volunteer support, and spiritual care, and plays a primary role in educating health care professionals. The CHR, through the Long Term Care Program, is also responsible for home support services, which it contracts out to nine affiliated home support agencies. Finally, the CHR works in

partnership with the BCCA to provide inpatient and outpatient cancer treatment.

Accordingly, patients who are diagnosed with life-threatening illnesses will typically

encounter at least one of these health care systems, although many participants in

this study came in contact with all of them:

> Jessie told me that Matt started losing weight a few years ago and that he was "as thin as a rail". He was "having all kinds of tests" but nothing was showing up. Eventually after visiting their doctor several times, Matt asked to be referred to a specialist. After another "batch of tests" Matt was diagnosed with cancer and went into the hospital for surgery. After surgery, the surgeon referred Matt to an oncologist at BCCA. Matt was admitted to a medical ward at one of the hospitals in the CHR where an oncologist from BCCA was responsible for his medical care. Jessie explained that the chemotherapy gave Matt "a little more time" but eventually his cancer progressed and she said, "The doctor [oncologist] said there was nothing more that they could do". Matt was discharged from the hospital with a referral to home nursing care [a CHR managed program] and did not have any further contact with the BCCA. On one of her weekly visits, the home care nurse suggested to Jessie and Matt that they register with the VHS for palliative care services and that they get some home support to help Jessie with Matt's care. A nurse from long term care [a CHR managed program] came and conducted an assessment on Matt and arranged for a home support worker from the local home support agency (Field Notes, October 1999). Jessie and Matt also registered with VHS.

Continuity of Care

The caregivers who participated in this study rarely experienced continuity of

care along health care systems. More commonly, organizations operated according

to a division of labour with each agency "parceling out" specific functions. The lack

of continuity exists while both accessing treatment and receiving care at home as

this husband caring for his dying wife explained:

> I don't want to say that I didn't appreciate the help we got because I did. But nobody seemed to be talking to each other....It was the same questions over and over again and it just seemed that one didn't know what the other was doing. You know, it's exhausting. At first we were with the Cancer Clinic and when we moved over to palliative care, it just seemed like one group didn't communicate with the other....When we went home, well that was another

story. There were reams of people coming in and out all asking the same stuff and you get tired of that after a while....The system certainly broke down in our case and I think there are just too many branches and they don't all get together....I don't think the system is very efficient and I don't think there is a firm enough network of someone that's at the top who knows the various components that can fit in for the person.

Similar to other research findings (Bruera, et al., 1990; Grande, et al., 1997; Hinton, 1994a), the provider participants acknowledged continuity of care was problematic and negotiating the number of providers and agencies becomes overwhelming for many families. This home care provider could only resort to humour when taking about the situation: "They get dumped out into the community and you know I make a joke about it because they've been through the QRT, the OT, the PT, the LTC, the HSC and now the PRT! ... It's just crazy". He later acknowledged the situation was not humorous at all and suggested further "streamlining" of services was needed to reduce the numbers of people going into the home.

A major difficulty with achieving continuity of care was that information systems were not set up to efficiently access patient and family data, particularly between health care agencies. Notwithstanding the fact that some organizations have established cooperative working relationships and developed communication tools for working together (such as the in-home chart[89]), continuity of care remains problematic. For example, providers rarely read the in-home chart and, instead, conducted their own assessments, neglecting what had been previously

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[89] Several years ago, the VHS and home nursing care collaborated on the development of an in-home chart that is used as a communication tool for health care providers, patients, and families in palliative care. The intent of the in-home chart is to promote continuity of care between providers and health care agencies. For this reason, families are encouraged to take the chart with them to medical appointments or when patients are admitted to the hospital.

documented. This was confirmed when I witnessed nurses and HSWs coming into homes and performing assessments that had already been done, sometimes on the same day (Field Notes, April, 2000)! It was impossible to achieve continuity with the numbers of different providers involved in care provision. To improve continuity, HCNs were often assigned to visit the same families and act as coordinators of care. However, some of the administrators who participated in this study were surprised when I mentioned the caregivers continued to have difficulties with continuity of care and the present systems were not always working:

> P: One of the big things is continuity. And I think the in-home chart goes a long way towards that if you can get people to use it. At least that's one place where there is continuity. If a physician writes in it or a physio, or someone writes just a little update about what they did, it reduces the amount of time that someone who's ill needs to answer questions.
>
> R: Some caregivers have told me that when people come into the home they ask the same questions.
>
> P: And this was what we were hoping to avoid.
>
> R: This is a major issue that they talk about. They cannot remember the names of people. They don't often know who the point person is.
>
> P: Even with the home care nurse as the coordinator of care?
>
> R: Yes. I don't know that they always see the home care nurse as the coordinator of care.
>
> P: Actually, that is something that they probably need to look at in terms of how we introduce what we are doing for them.
>
> R: Well, caregivers are clearly saying that there are too many people coming in.
>
> P: Oh yeah. Well, one of the reasons why we wanted to have something like this [the home chart] was in fact that reason. We had a man on our program and in one week, he had 17 different people come through, asking the same questions....But none of this information was forwarded around even within

our own department. Nobody talked to each other. And this individual was exhausted of course, after about visit five.

Important information that may be derived from long-term involvement with patients and their families is lost when a continuum of care does not exist. Yet, as the providers explained and as nursing scholars have documented (Benner, 1984), such involvement provides crucial information that can only be gained over time and not from a single assessment. As such, some of the providers and caregivers recommended further action was required to ensure that continuity was maintained. They advised that a consistent person be assigned to patients and their families and suggested information systems needed improvement:

> I think what they need to do is to have one person involved who knows everything. Someone who could come with us when we went to the doctor and when we went to the Cancer Clinic and when we went to Hospice. Sort of an advocate of sorts. Someone who would see us at home and kind of play an intermediary role. I don't know if that's possible but something could definitely be improved….And certainly there is a lot of room for improvement around making the resources known because it's not that easy to figure out … I mean maybe they have to start working electronically so they can share all the information.

Organizational Approaches to Palliative Care

Some of the caregivers in this study also faced challenges with the organization of palliative care because there was no "palliative approach" outside of VHS, at least, organizationally. While many of the caregivers acknowledged they received adequate support from providers employed at agencies outside of VHS, these agencies did not always support the philosophies and principles of palliative care. For example, the caregivers' experiences with acute care hospital systems

were permeated by attention to the symptoms of the disease[90], with little regard for

the "whole person" or for attending to the needs of the patient and family as a unit of

care:

> You're basically treated like a number in there [the hospital]. They don't look
> at the person and what's going on for the family. They just look at the
> immediate problem....I mean, we had all kinds of things going on in our family
> and we needed help but those things were just ignored. I don't blame them in
> that he was having a lot of pain and they had to look at that. But once that
> was looked after, it just seemed like that was it....They have to be able to look
> at the whole person and what's going on in the family and that's what we got
> from Hospice....You know, we've had lots of lumps and bumps on the road
> and in lots of situations there needs to be major surgery to some sections of
> our health care delivery system. But the Hospice model is solid, it is sound, it
> is humane. It recognizes the person and their family.

Interviews with the health care providers and administrators confirmed that some

agencies and providers are better attuned to meeting the needs of palliative care

patients and their families. They suggested psychosocial care, a central component

of effective palliative care, is often neglected and "the whole person falls through the

cracks". This is true particularly when accessing acute care systems, a finding that

is well supported by previous research (Armstrong & Armstrong, 1996; Mills, et al.,

1994; Seale & Kelly, 1997; SUPPORT Principal Investigators, 1995). However, some

of the providers, working outside of agencies specifically mandated to provide

palliative care, pointed out that palliative care approaches are required regardless of

where families are located in the health care system:

> You know, people are cared for everywhere when they are dying. We can't
> expect that every person will be able to stay at hospice if they can't be at
> home. So, we have to make the care better in other places where dying
> people are....For them and their family. So whether it's in long term care or in

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[90] Acute care systems have been criticized for their focus on disease symptoms at the expense of the
whole person. However, biomedical influences also permeate the home environment, an idea I
further develop in Chapter Six in my discussions of reductionism in palliative care.

acute or whatever location they happen to be in. The principles of palliative care have to be transferred to that situation.

According to some participants, continuity of care is difficult to achieve when divisions exist between health care agencies and disciplines, a finding supported by Field and James (1993). For example, patients who were treated for cancer were typically seen by oncologists and counsellors at the Cancer Clinic. Once deemed palliative, the relationships with these providers often ended abruptly and families were shunted from one agency to another. Several caregivers felt abandoned when these relationships ended; they had established "trusting bonds" and were hesitant to be introduced to "a new set of faces". Rocker, Shemie, and Lacroix (2000) contend that one of the greatest challenges for providers is to learn to make the transition from attempted cure to optimal palliative care as seamless as possible. Many of the caregivers and providers interviewed in this study advocated for "seamless" systems of care, again recommending that a consistent person be involved with families throughout the disease trajectory. Such an approach would enhance continuity of care, reduce families' feelings of abandonment, and help to mediate relationships between care agencies and care providers.

The providers theorized that families might be shunted from agency to agency because of some providers' discomfort in dealing with palliative care situations. There was a general consensus that providers in cancer agencies did not like to use the word "palliative". Instead, staff will often say "we are not looking at a cure". A provider who was also a cancer patient summarized the subtle, but very real, attitude that characterizes the system outside of those agencies that are specifically mandated to provide palliative care:

I think it comes down to being afraid of dying and afraid of death. You don't want to write people off. You don't want to push palliation beforehand and that's the whole sort of thrust of acute care medicine and cancer treatment. But there's a prevailing sense and I got this as a patient more than anything else, that as long we can fix you and keep trying to fix you, there's a hopefulness and once we can't, well that's it....It's so subtle that you can't even point to a person. You can't point to a particular branch of cancer medicine or anything. But I saw it once when I saw this young patient in the Cancer Clinic and one of the receptionists I spoke to there said, "Well, we don't have anything to do with Hospice. I don't know what you're talking about". And this was 18 months ago. It wasn't that long ago. And it was her sense of fear and hesitancy and all that stuff that was just so present and it was like, "We don't want to deal with it because, you know, we're about hope and you are about death. Now get away".

Discharge Planning

Transitioning from hospital to home was also problematic for some of the caregivers in this study. For instance, some patients were discharged from acute care without support systems in place, leaving caregivers to fend for themselves until support was arranged. The caregivers recommended that having discussions with hospital providers in advance of going home might have prevented them from making promises that they later found difficult to keep:

I think there's another thing that's lacking in this whole home care thing. When we left the hospital, there should have been a conference of some kind before we left. You know, the doctor, the caregiver, the patient, to lay out and say, "This is what is going to happen". And probably it would have been not too pleasant of a conversation but it's something that needed to be done so we would know what we were in for. And they could have said then that there might come a time when you can't do this anymore. But, having this conversation before we brought him home....Before we ever made all these pie in the sky promises to him because then, boy, when you have to change that, you can't....Even when you need to. So, yeah, doing some planning ahead of time would have been good.

Having services set up prior to going home would have been helpful for caregivers and would have prevented unnecessary anxiety as this husband explained:

> They [the hospital] just kicked us out. And we didn't know what to do. We didn't know how to care for her and what we needed. And it was just a nightmare for awhile. I mean, I was pulling my hair out and then the doctor said we could get a home care nurse. Well, I just thought, "Why wasn't this arranged earlier? Why did we have to go through all of this?" I mean, it was great when the home care nurse arrived….She set us up with everything we needed and told us what to do but I just thought, why couldn't they have done this before we came home?

Some of the hospital administrators who participated in this study admitted

discharge planning could be improved, but maintained that many strides had been

made in this area; it was uncommon for people to "fall through the cracks" and

inadequate discharge planning was generally "the exception rather than the rule".

The providers commented discharge planning was difficult because of heavy

organizational workloads. And, as previous research has demonstrated (Jewell,

1993; Kadushin & Kulys, 1994; McWilliams & Sangster, 1994), there is a tendency to

exclude family caregivers from the discharge planning process:

> In acute care, my experience is the staff don't have a lot of time and they don't have to interact too much with families. There's staff turnover, they talk to some on the phones. Not often do they get a chance to see families in action, a group of them, whatever family it is that's making the decisions…. So they don't have the time or maybe the willingness to make a good assessment about it [home care services]. Or they don't really include families in the process.

While some of the home health care providers described discharge planning

situations that enhanced continuity of care, others acknowledged it was "hit and

miss" and was highly dependent on hospital personnel taking a leadership role:

> When you have a really good person, like the social worker or liaison nurse in the hospital it can go really well. I remember one instance where there was a street involved person in the hospital and the social worker called me up and said, "I think we better have a conference on this guy". So we both collected everyone together because this guy was going to present some challenges in the community. He had issues around substance abuse and street involvement and manipulation of the system that we all knew about

individually but we'd never actually sat down and said, "Well this is my story". So we put it together and it worked out well for everyone and for him and his wife too....But there are other cases where it doesn't go so well and where we try to talk to them [at the hospital] and tell them we need to have a conference and then I get a call the next day saying, "The person's gone home. Can I get resources in right away?" So, it's a bit hit and miss. It's pretty dependent on the people involved.

Continuity was an issue regardless of where palliative care was provided. The number of service agencies and providers involved made it difficult to plan care that was consistently coordinated and implemented. Providing continuity of care throughout an individual's interactions with a variety of service providers and organizations has been identified as a major problem facing Canadian health care systems (Canadian Health Services Research Foundation, 2001). Communication is a key element to enhancing continuity of care according to many of the participants. However, some of the providers and administrators indicated that developing a continuum of care has been slow to develop in the health region. This problem was acknowledged and agencies within the health region were working together to develop palliative care as a core service.

Visioning the Future: Palliative Care as Core Service

Health care agencies in the CRD have a long history of working together to plan and deliver services for those at the end-of-life. For many years prior to regionalization, a Palliative Care Advisory Committee was in operation, working to address inequities and service gaps for palliative care patients and their families (CRD Palliative Care Advisory Committee, 1994). The Committee was able to make some inroads in accessing funding to support enhanced palliative care services in the community, but it eventually disbanded. There were a number of

reasons for this but some previous Committee members who participated in this study suggested the Committee lacked the decision-making power to enact changes at a systems level:

> Our old palliative care steering committee, well it ended up that we didn't have the right players at the table. They didn't have the power. They didn't have decision-making authority within their groups to do anything with what we were suggesting. We had a bunch of people coming to meetings and talking about what was happening in their areas but nothing beyond that....You need the right players there to make decisions at a broader level.

Following health care regionalization, the CHR Palliative Care Review Steering Committee was formed. Like other regionalized health authorities in Canada[91], health care leaders in the region believed the regionalization process offered an opportunity to develop a regionalized model for end-of-life care[92]. Among other activities, the Steering Committee was vested with the responsibility, authority, and accountability to review palliative care services, and to make recommendations that would provide direction for the development of an effective and integrated regional system for palliative care (CHR Palliative Care Review Steering Committee, 1998b). Around the same time, the CHR was in the process of restructuring and was moving to a program management model. As such, the palliative care review had not started at the time of this study. As one home care administrator explained, the continual restructuring of health care organizations can serve to inhibit and delay service planning:

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[91] For example, the Calgary Regional Health Authority (1996) has implemented a regional model for palliative and hospice care. This model has gained much attention across Canada as a benchmark for the development of regionalized systems for palliative care.

[92] A regional system was defined as "an integrated network of hospice/palliative care services, consisting of multiple providers coordinated across a continuum of care through policy, planning, systems thinking and service provision" (CHR Palliative Care Review Steering Committee, 1998a).

> We have sort of been stymied along the way because all of a sudden you go into restructuring of program management. And we realize that a lot of the work we thought we were going to do is getting done but it has slowed down and we are not where we expected we would be. You know, the constant changes can sometimes get in the way of making progress.

Recognizing that palliative care permeates almost every health service area, it was deemed a core service within the program management framework. The Steering Committee was then faced with proposing its vision for palliative care as a core service within a regionalized system. This was facilitated by another change process initiated by the CHR to develop a fifteen-year plan for the delivery of health services. A Palliative Care Advisory Panel was established to assist the Regional Services Steering Committee in planning health services for those within the CHR who would be faced with needing palliative care over the next fifteen years (CHR Palliative Care Advisory Panel, 1999b). The Steering Committee proposed the core service be administered and coordinated by a Palliative Care Regional Council made up of representatives from various service areas and organizations. The operational model builds on the provision of palliative care at home, assuming the home as the primary location for care with expansion of services into the home as well as expansion of hospital-based services to meet the palliative needs of long-term care patients and those in acute care. At the time of this study, the proposed model had not been approved.

The providers and administrators interviewed for this study expressed a level of frustration with the progress of planning, but were optimistic about the potential for a regionalized model. They saw the process as an opportunity to bring stakeholders together in a spirit of collaboration. Although optimism was

expressed, some participants were concerned their visions for palliative care might be challenged. For example, one of the first tasks of the Steering Committee was to develop a region-wide definition for palliative care but, as one supporter of palliative care suggested, developing a definition does not mean it will be wholeheartedly adopted:

> We have just finished developing a definition for palliative care and I was really excited about that....It is fairly broad and it goes beyond a person who is terminally dying. It goes to those who could benefit from the skills and knowledge of palliation. So, I was really excited about that. It will be recommended to the CHR and that will be a huge hurdle because it makes it operationally a much tougher thing to get your hands on than if you want to just say people that are dying in the last three months of life and that's when they get palliative care....It's very different. It also goes beyond cancer so that's going to be a huge one for the region to accept.

Most of the caregiver participants were unaware of the processes going on to reorganize palliative care services, but when it was explained to them most thought "it was a good idea", particularly in relation to home support. Some front-line workers said "they should just get on with it". Others commented that the time put into creating a regional model was well worth it if the vision became a reality. Enacting the vision will, as this administrator discussed, lead to care improvements and better access to quality palliative care regardless of where families are in the system:

> When we start thinking of ourselves as a whole and we start looking at the standards of palliative care and have some common language and way of treatment across the region it will be much better. That's our dream. So staff will have ongoing education and will have consultation available to them in a timely way. If you're in a long-term care facility, those who consult with you will have special knowledge in geriatrics. If you're a pediatric nurse that needs some expert help with a complex case, those that consult with you will have special knowledge of children....The quality of care will be just be better.

However, other participants were concerned that specialized palliative care services may be "taking on too much". Others were worried that leadership was lacking to enact a broad vision for a regionalized palliative care model:

> The palliative care program here sees itself as a learning centre and now they are going to go province-wide with that concept. It makes me a bit antsy because I wonder, "Is that gong to make them so watered down that they won't have time for their primary mandate?" This is going to be a huge project and it's gong to take time and effort and it's not going to end....So, I think that's a concern....Also, in my view, there is a lack of medical leadership for palliative care in the region. In hospice, they have medical leadership, but not in the region. I think that's an intricate piece, the clinical and medical leadership side. I think if we had a medical leader in the region and then a clinical nurse specialist leader in the region, those are two keys to even begin on the road to regionalizing palliative care services. Of course you need admin [istrative] support but I see that a medical practitioner and a clinical nurse specialist need to drive the vision....But I haven't seen a lot of interest in that approach so I'm not optimistic at this stage.

At the time of writing, the core service model is still being discussed. The palliative care services review was completed and the Steering Committee was in the process of examining the recommendations. This review, according to some participants, will provide the needed direction to plan and implement a system of care that will be responsive to meeting the needs of those at the end-of-life. However, some participants acknowledged there were historical factors that slowed the overall planning for palliative care in the region. An examination of these factors demonstrates how the historical context of health care provision can serve to influence the development of systems of care that might ultimately benefit family caregivers.

The Historical Context: Exploring Organizational Tensions

We have tried really hard to develop some bonds.
But, there are some real barriers in place to do that.
Palliative care always wants to be someone's claim to fame.
So, it becomes very much political.
It seems to me that palliative care is always a political football.

-   Health Care Administrator

Since its inception, the modern hospice and palliative care movement has been "unashamedly reformist" (James & Field, 1992, p. 1363). Focusing its attention on, and advocating for, humane and compassionate care for people at the end-of-life, the development of palliative care has been, by necessity, a political movement (Kastenbaum, 1999). Developments in palliative care, while initially separatist in their approach, have now become part of mainstream health care systems and practices. In Canada, palliative care, as a program of care for the dying, has been largely part of the fabric of mainstream health care since its inception. The goals of mainstream health care, focusing on cure and treatment of disease, have not always been congruent with the goals of palliative care (Cowley, et al., 1992). These philosophical divisions created a number of tensions that have thwarted the progress of palliative care development within the health region.

My critical interpretive lens directed me to explore some of the historical factors embedded within the development of palliative care. My intention here was to uncover whether or not such factors played a role in shaping the provision of palliative care at home. Having worked in the region for several years, I was aware that a history existed between organizations. Yet, I was surprised that some participants were reluctant to talk about it. I wondered whether a climate of "political

correctness" might have inhibited participants, and questioned whether this stance posed a barrier to organizations getting their "issues out on the table". When I shared these impressions with some participants, most agreed, stating "I think that's a fairly accurate interpretation".

Some of the providers and administrators were reluctant to discuss the organizational tensions but others were more forthcoming. These participants acknowledged that tensions were easing and a spirit of collaboration was developing, but maintained these factors played a role in limiting palliative care development. For palliative care advocates, tensions arose when the importance of palliative care provision was minimized. Some participants said the health region had progressively dismantled palliative care services. For example, a palliative support team in long-term care once provided consultation services and education programs; the team was dismantled when project funding ended. A palliative care resource nurse position in acute care was lost through retirement. And, more recently, the palliative care clinical nurse specialist position was reassigned to take on acute care as well as palliative care functions. These historical developments made some participants wary of engaging in a process to regionalize palliative care services. Many participants admitted that relationships were improving, but were concerned that history would repeat itself and that palliative care programs would take a secondary position to the more primary position of acute focused services. Proponents of palliative care suggested the larger health care system might not be ready to fully embrace the visions and philosophies of palliative care:

> If I look at it from the palliative care history and look at what the region did within their system with palliative care, they've dismantled whatever they've

done. So, I am hesitant to be in a system that dismantles things....When I look at some of the gaps in this system, I shake my head. I shake my head at the system. I mean, had they built what was already there instead of taking it away, it would have been a lot further ahead now. The gaps are clearly evident. So, there is some trepidation....I think there is a better prevailing attitude than what there was a few years ago. I think it's moving in a good way, this idea of a core regional service. But again, you see, history repeats itself. Last year when they were putting together the Regional Services Plan, where was palliative care in the report? Zero! You know and they said, "Oops, we forgot. How could we have left it out? It's an oversight". How could it be an oversight? How could people at a senior level, if they really purport palliative care, end-of-life care, and aging population issues to be important, how could they not have it in their report?....So, that's where I say, "When this system is really ready, I think we can move things ahead much further".

According to some participants, philosophical differences were at the root of organizational tensions. There were those who strongly advocated for comprehensive and dedicated palliative care services, while others believed that professional education was all that was required to improve the delivery of care to those at the end-of-life. These differences created some animosity between organizations, especially when they would not back down from their philosophical positioning as one administrator maintained:

There have been philosophical differences over the years because with a few key people fairly high up a number of years ago, they just wanted to make palliative care simply education. They thought, "All we need to do is some teaching and then everybody will know palliative care and then everything will be fine". So, it's not that they were not acknowledging palliative care. But part of the attitude of some individuals several years ago, and even currently, was that this was all that was required....So those attitudes, those philosophies, which some senior bureaucrat people in the region had, well, we were at loggerheads. I would not support that we didn't need a palliative care unit or a community response team. I wouldn't support that "You don't need those dedicated services". Therefore, there were differences in opinion and attitude.

Not all participants constructed organizational tensions in the same way. Admittedly, while many agreed philosophical differences played a part in hindering palliative

care program development, others maintained that there existed a long-standing history of struggling for power and control over palliative care services. Some of the participants working outside of agencies specifically mandated to provide palliative care explained, "if you're not a part of the dedicated palliative care program, then some of them [working in designated palliative care programs] don't think you know anything about palliative care and what might need to be done to enhance it". Accordingly, these participants felt their perspectives were minimized and they were perceived as not having legitimate expertise in the area, even if they had worked with palliative care patients for some time. Others suggested "some organizations want to have *total* control over what happens with palliative care in this region", implying that partnership arrangements had been difficult to achieve. According to some participants, agencies dedicated to the delivery of palliative care, while playing a central role in care provision, may not be able to meet all palliative care requirements within a regional system. Instead, they recommended agencies work together, pool their resources, and develop effective care delivery systems. Nevertheless, some of the participants maintained that certain agencies wanted to drive the vision for a regional palliative care model, which was supported, only if a broader vision for palliative care was established that incorporated the needs of the region:

> My observation in this region is that Hospice has been thought of as taking care of palliative care period. But, within the mandate of Hospice, they don't have the ability to look after all of the region's needs....Hospice is an intricate part of the model but I don't know if there is a willingness on the part of Hospice to be part of a regional model. My observation is they want to drive the model. And you know, that may be fine too, but then it's got to be a broader vision than what it currently is.

Some of the participants working within mandated palliative care programs did not agree that power and control were issues but, rather, saw themselves as advocates for palliative care. Wanting to ensure palliative care remained situated within mainstream health care, they saw their efforts as necessary to the continued development of palliative care. At the same time, they acknowledged "turf wars" existed and partnerships in care needed to be developed. However, as this interview segment implies, even those who talked of partnerships felt threatened when they perceived other agencies encroaching on their territory:

> You know people say, "Oh Hospice just can't let go". I don't think they see it. They don't see palliative care as a program of care and that's why good ideas get watered down....I think also the Cancer Clinic needs to be a part of this and not want to take over right away. When they want to start playing the game, well the turf wars are happening now. I say, "Be a partner instead of a boss"....Partnerships can give us all many benefits if we can work together to make a good palliative care system....But you know, the biggest challenge to palliative care right now in the province is the Cancer Clinic. They have now decided that they're in the job of palliative care.

While organizational tensions existed, many participants recognized the need to honour the work that had been done by dedicated palliative care programs. The expertise of agencies that were specifically mandated to provide palliative care could not be neglected:

> We need to honour the work that our hospice has done and the work they do because there is a piece that can't be negated when you are dedicated to palliative care and you can put more expertise and focus on it as opposed to those of us who also do other things....There is a level of expertise there that has to be respected and honoured.

Competition for scarce health care dollars also contributed to organizational tensions. When dedicated palliative care programs were initially established and expanding, they were competing with other agencies to secure palliative care funds.

According to some participants, this competition set up adversarial relationships between organizations. Although some participants advised these issues no longer existed, others suggested otherwise. Some of the provider and administrator participants believed dedicated palliative programs had "lots of bucks" and could, therefore, provide adequate service. Conversely, other provider and administrator participants felt the CHR needed to dedicate more resources to address service gaps in palliative care. But, as this hospital administrator explained, funding programs for palliative care is not straightforward, especially when the model for care has not yet been developed. He suggested palliative care may not need further dollars, but rather, existing services might need to be re-examined and re-organized:

> The money is an interesting question and to me it becomes a barrier when it really doesn't need to become a barrier. We can't go out and scoop up every dollar that is attached to every patient in the region for palliative care and give it to a palliative care program. None of us can do that. Patients need access to acute care systems as they are getting cared for there. So, there are no excess dollars that can be scooped up and given away for palliative care services. What it takes is putting the pieces and linking the pieces together that we have in the region. I'm not sure it needs more money. It may mean re-shuffling and re-looking at things. But until we know what model we want and what all the pieces are going to be and who is going to do what, it's hard to know if we are going to need more money.

How financial donations were utilized also created tensions. Families who access palliative care services typically donate money to dedicated palliative care programs, even though providers from other agencies have been extensively involved with care provision. These situations created tensions, particularly when staff who were employed at other agencies were unable to access funds for professional education. These participants mentioned, for example, that they should have access to donor funds to attend palliative care conferences like their

colleagues who are employed with dedicated palliative care services. At the same time, they acknowledged many families are unsure about where to direct their donations and may believe their donations are being used to fund the entire system of palliative care instead of one organization. It was not only the ways in which donations were utilized that was bothersome; the providers who worked outside of formal hospice programs did not always receive recognition for their work. This interview with a home care nurse demonstrates the tensions that can arise when financial and recognition issues exist, suggesting further efforts are needed to ensure families are both fully aware of how their donations are used and are cognizant of where their services are coming from:

> I find it really difficult after I have spent 6 months or a year or more with a family, that all the bouquets go to Hospice. And often they see us as Hospice nurses. I'm sure they think it's all one big system. That gets very tough to take when it happens over and over....And then one time a family told me, "We have sent a $5000 donation in the name of palliative care nurses for education". But the money went to the Hospice Foundation and we don't have access to it....It's something you don't like to talk about and seem ungrateful about but I feel we deceive them because they think their money is going to us and I'm not about to tell them. If they asked me, I would tell them. But I think it should be clear for families and it's not.

Not all of the providers felt the same way. Some believed donations sent to dedicated palliative care programs helped to build the existing services and donations should continue to be directed to those agencies. Others were concerned donations funneled to larger organizations, like the CHR, may not be used for palliative care:

> You know the donation thing. Well, sure it would be nice but the donations to Hospice, that's helped that program to grow and we all know that we need that program. So, it's a natural place for it to go rather than to the HCNs that have been there....And god knows, we don't want the CHR to have it!...Who knows what would happen with it then.

The providers and administrators in this study believed these historical developments and the resultant organizational tensions had influenced caregivers' experiences. They maintained that organizational tensions inhibited the progress of palliative care development and, therefore, hindered the creation of a coordinated and comprehensive continuum of care. This, in turn, influenced caregiving families because they could be receiving a higher quality of service if organizations were able to work through their issues and move forward. I was unable to find any studies that specifically addressed organizational tensions within palliative care, but research examining other organizational structures demonstrates that interagency tensions inhibit the creation of comprehensive care systems (Cain, 1997).

Fortunately, many participants were optimistic that progress was being made and that organizations were finding new ways of relating to and communicating with each other. While a climate of political correctness continues to exist, interagency relations are more open and honest. Some of the administrator participants suggested changes in the political environment have necessitated the creation of collaborative working relationships. At the same time, these participants acknowledged it was also time to listen to one another and to place their own preconceived ideas aside. In this way, progress could be made to enhance palliative care service delivery in the community:

> I think progress is being made....It's like forming a new friendship....You keep telling people how important they are and why you're important to each other. So, it's a new way of relating....I think we are being more open and honest than ever before. I mean, there's always been nitpicking and there's always been resentment because of the turf stuff. And there has always been a passive-aggressive approach. Few of us really laid things out on the table. And you know, people tried but sometimes not everyone wants to hear it. But now, we're in a different political environment. We have no choice. We have

to work together....So I think we are learning to be more forthright in saying what we need and to figure out what we need from each other. It means conflict resolution sometimes. It means walking away from your preconceived ideas of how you provide service. It means sharing knowledge in a way that perhaps you never have before. It means listening to your community.

Health Care Reform and the Rationalization of Health Care Services

As previously mentioned, a primary goal of regionalization is to shift the provision of care from institutional settings to the community. Armstrong and Armstrong (1996) suggest that regionalization and the resultant reforms focus strategies on keeping people out of institutions and on reducing the length of stay in institutions. These reforms are often cloaked in extolling the virtues of home care and self-care but many scholars expose them as efforts to rationalize health care services and, thereby, reduce health care costs (Armstrong & Armstrong; Fierlbeck, 1997; Rachlis & Kushner, 1995; Storch, 1996). The family caregivers in this study spoke of their experiences with such reforms. They had difficulties in both accessing institutional care and felt their ill family members were "pushed out" of institutional settings before they were well enough to go home. These difficulties were exacerbated when they realized that reforms in community health care resulted in lower levels of service and support than what they had originally anticipated. In this section, I provide my interpretations of how reforms in health care have shaped these caregivers' experiences, illustrating how institutional health care reforms can serve to pressure caregivers into providing palliative care at home. Additionally, I will explore how community health care reforms have influenced caregivers' experiences, specifically focusing on how changes in home support services have influenced caregivers' experiences with at-home care.

Pushing Out and Pushing In: The Scarcity of Institutional Practice

The shortage of acute beds and hospice beds
and the shortage of staff
are pushing people out of the hospital
sooner than they are ready for.
Or, there are no beds if they want to go in.
The thing now with hospitals is,
"Get them out. Get them in, get them out".
That's not good care.

- *Health Care Provider*

As this introductory quote implies, health care institutions are facing many challenges, not the least of which is shortages of inpatient beds and personnel to provide health care. The downsizing of institutions is now deeply stitched within the fabric of Canadian health care reform (Anderson & Parent, 1999; Church & Barker, 1998). Pressured by increasing costs, hospital beds are being closed, outpatient clinics are being opened, and added demands are being placed on community care (Armstrong & Armstrong, 1996; Hollander, 1999). The aging population and resultant demographic shifts have also alerted us that there will most certainly be increasing numbers of people requiring health care over at least the next two decades (Chappell, 2001; Closson, 2000). The consequences of a dwindling health care workforce are also now a part of public discourse, especially with regard to nursing shortages (Closson, 2000; Picard, 2000; Registered Nurses Association of B.C., 2000). The caregivers in this study frequently mentioned the scarcity of inpatient beds and nursing personnel. Not only had they read about shortages in the newspapers and heard about them on the nightly news, but many experienced them as they struggled to obtain adequate support for their family members and themselves. Many of the caregivers felt "pushed out" or "thrown out" of institutions

because of the lack of available beds. Even when their ill family members had

secured a bed, this was no assurance they would be able to keep it:

> He had to go to one hospital for tests and when he came back, they had
> given his bed away. So, we were told to take him home. Our doctor was on
> the phone to the doctor in the hospital and it was absolute chaos. There was
> only one nurse on the floor and there was no bed for him. We were being
> thrown out.

Some of the caregivers believed the patient to be too ill to return home or felt they

were unable to cope, but felt pressured into taking the patient home because of bed

shortages. These experiences opened caregivers' eyes to the realities of health

care, leading them to theorize where changes needed to be made:

> I was very angry because I thought, "This man is very ill". The person who
> was coming through was the manager of the floor and she was putting
> pressure on the doctors and me and anyone she could because her ward was
> full. So the pressure was definitely there....And I didn't feel prepared for it
> and didn't know how I'd cope with it but I took him home. After a few hours,
> he was just in like a semi-comatose state. I had wanted to admit him to the
> hospital again but there wasn't a bed. Our family doctor just said, "Well, just
> keep close track of him". So, it was a very tense situation....I mean, my eyes
> have really been opened to the whole health system. I feel where the
> breakdown is and why there is such a shortage of beds is because there are
> no beds for stroke victims....They don't have enough extended care beds ...
> That's were they should be putting their focus.

Some of the caregivers who were able to keep their family members in hospital,

however, eventually took them home because nursing staff shortages meant they

had to be at the hospital to provide some of the necessary care. Very few of the

caregivers held nurses responsible for the lack of care. Rather, they understood the

challenges nurses faced when short staffed:

> Against our better judgement, we eventually took her home. We all know what
> it's like in the work force today. I mean, they are critically short-staffed. I
> thought the hospital was kind of grubby to tell you the truth. I mean, I would
> empty her garbage can and stuff like that. I sort of got to the point where I
> would do those things....We would help change her bed. Like a nurse would

come and we'd say, "Well, we'll help you now". Because there would be one nurse for four patients in that room and she probably had another four [patients]. She had a lot....But they were always very kind and very nice ... I already explained to my daughter that when you go in there [the hospital] you will have to feed her because you know, the girls [nurses] don't have time. They bring the tray and if she doesn't eat it, they take it away. They don't stay there and feed it to her....I'm not questioning the quality of care that they give in any shape or form. They are doing more than they can do. They just don't have the time....There are just not enough of them.

The caregivers in this study also had difficulties with accessing inpatient care

for their ill family members. Some of the providers and administrators explained

caregivers will often "panic" when death is approaching or when they become

overwhelmed with their caregiving. In such instances, they will often consider

institutional care. However, as one home care administrator suggested, "Usually

they just need a bit more support in the home and then the crisis resolves itself".

Yet, as I described in the previous chapter, many caregivers struggled with decisions

to hospitalize the patient and did not seek out institutional care unless it was

absolutely needed or when they were so exhausted they could no longer cope.

Their promises to the patient and previous experiences with institutional care made

these caregivers reluctant to seek support outside of the home. Therefore, when

faced with the prospect of not being able to access hospital care, some of the

caregivers became upset and worried about the future as was the case on one of my

field visits where Mary, a retired nurse, explained her concerns in caring for her

husband Hugh :

> Hugh [patient] is deteriorating. He is barely eating and can no longer move himself in bed. His pain is worsening even though Mary [caregiver] is vigilant in her efforts to assess and manage it. Last night Mary told me "He was incontinent of both number one and number two and it was such a mess". She said, "We've talked about him going into hospice and he is okay with that even though we hadn't planned on it". Mary told me that "I just can't handle it

anymore and I don't want to". She is trying to get Hugh into a hospice bed but she said, "When I called, they told me that there's no beds right now". While I am in the home, the telephone rings and Mary answers it. She begins to cry on the phone and her breathing quickens. She finishes her phone call and with tears in her eyes she says to me, "They still don't have a bed. I don't know what I'm going to do. What will I do if they don't get a bed?" (Field Notes, June 2000).

The caregivers who were unable to access inpatient beds "managed" and "did the best they could", but not without suffering consequences. Their bereavement was complicated, prolonged, and their caregiving was life-draining. At the same time, the following interview segment implies that caregivers may have to demonstrate a serious need for inpatient care before providers believe they need it. This passage also shows how providers can inadvertently assume families are "doing well":

> We had a family just recently where we were all working towards the death being on the inpatient hospice unit. And we were asking, "Do you *really* want this?" Because the family had done *really well* at home in terms of rallying behind her. You know, working shifts and giving medications. But, they were just saying, "We don't want to do more personal care, more nursing care. We just want to be a family". And we said, "We'll do our best". But it turned out that she was home until she died another two weeks or longer....There weren't any beds. So, that was a tough one because they were *really seriously* saying they couldn't go on. *And it wasn't just "Maybe we can't do it".* They knew they just couldn't do it anymore....And she died at home....But home wasn't where they wanted to be. So, it will be interesting to see how bereavement goes for them and what they think of this hospital system now that we couldn't come through for them.

Desperate to get the patient into a hospital, a few of the caregivers used the emergency department "as a last resort" when they could not access hospital beds through other routes. This strategy did not always work and these caregivers faced repeated visits before providers acknowledged they needed help. Some of the

caregivers took back-up support with them when they went to emergency

departments, fearing they would again be turned away:

> We went to the hospital and they checked him out and said nothing was
> wrong with him and so they sent him home....They told me that they didn't
> have any beds and I would have to look after him. When we got out of the
> car he got to the front steps and he fell. So, I called the ambulance again and
> we went to the hospital again. This time they kept him in emergency until
> they could arrange for home care support. I mean, he had fallen and I had to
> get the neighbours to help pick him up....So the home support person came
> and I fed him supper and then he couldn't talk or move or anything. I mean, I
> couldn't handle this any more. So, we called the hospital and this was the
> third time on the same day that we called the ambulance and they took him
> again. At this point, I remember calling my neighbour. I said, "Would you
> come to the hospital with me because I'm not going to let them send him
> home again and I need support". Three times in one day....So, they finally
> admitted him to the hospital.

Most of the caregivers were frightened at the prospect of having family

members die in acute care, never mind entering the hospital via the emergency

room. The reality of dying in the hospital during a bed shortage and a nursing

shortage was described by one hospital provider as "being in some little hole, in area

E, F or G, and with a nurse zipping in whenever she can manage". Many caregivers

would not consider acute care hospitalization even when they were desperate. If

they could not get a bed on an inpatient hospice unit, their fear was enough to keep

the patient at home, even when they were struggling. Caregivers were also

concerned, not wanting to place undue pressure on a health care system they saw

as "strapped". However, my interview with Beth, a middle-aged woman who had

cared for her father at home, illustrated how caregivers' concerns can be exploited,

leaving them to feel the subtle but very real pressures facing the health care system:

> The nurses were so busy. They wanted to have time but they didn't and they
> were very busy with doing the IV bags and other work. So, I felt guilty being
> there taking up the nurse's time and taking up the bed when they have acute

patients to deal with. I mean, we had real needs too, but they were not like the crisis needs of the patient down the hallway....It just didn't seem right for us to be there, even though we needed it. There was always this sense of "should we really be there?" And the nurses were great but still, I got the sense that maybe we were taking up a bed.

Some providers and administrators admitted (sometimes reluctantly) they too felt pressured to keep people out of hospital and acknowledged they sometimes unintentionally transferred their feelings onto caregivers. Others hypothesized the "bed and staffing squeeze" had contributed to caregivers' lack of choices about where palliative care was provided. Although there were very few participants who supported using acute care beds for palliative care, many recommended the number of designated palliative care beds be increased and distributed geographically, arguing that seventeen inpatient beds for the region was not enough to meet the needs of the population. However, as one palliative care provider warned, simply increasing beds and distributing them geographically does not necessarily make for good palliative care:

> The challenge is always, "What kind of structural supports are in place to provide good palliative care?"....And when you look at satellite beds, like you could put a palliative care bed in every nursing home in the community. But, if you don't have a support structure around that, that includes regular physicians, counselling, and all those things, then you don't have palliative care. Well, you don't have good palliative care....So, yes, you can have satellite beds and certainly we need more beds, but it's not just the beds that make palliative care.

In a study examining health care reform in Canada, Armstrong and Armstrong (1996) found bed and staffing shortages contributed to people being pushed out of institutions before they were ready:

> Being pushed out the door of a hospital is not like being asked to leave your hotel room after check-out time. Few people want to hang around simply to

enjoy the luxury of it all. Those who resist leaving often have a very good health reason for doing so (p. 76).

The findings from this study suggest bed and staffing shortages have created a situation where caregivers feel pressured to maintain the status quo, keeping the patient at home even when they feel they are unable to do so. Contrary to the assumption that caregiving can be maintained in the home with increasing community supports, these findings suggest this is not always possible. The caregivers in this study who were faced with considering institutional care did not make their decisions lightly; they certainly did not want to access the acute care system, but when hospice beds were in short supply, they often had little choice.

The Rationing of Community Care: Home Support

> *That's the whole problem with this whole idea of*
> *Closer to Home and everything is provided in the home.*
> *It's more like, nothing is provided in the home.*
> *They just don't want people in the hospital!*
> *That's all it is!*
> *Closer to Home is more like get up and go home.*
> *There are few options for people.*

> *- Home Support Worker*

In the previous section, I situated caregivers' experiences within institutional health care reforms. I now move to an explication of how reforms within community care have shaped caregivers' experiences. Many changes were happening or had occurred at the time of this study, but modifications in the delivery of home support was an issue arising in almost every interview. The home care administrators typically talked of these reforms as a way to enhance service effectiveness and efficiency, conceptualizing such changes as beneficial for caregiving families. Most of the caregivers and health care providers did not always see these reforms in the

same light; indeed, many were critical of the reforms and spoke passionately, and sometimes with anger, about them. A number of general concerns about the delivery of home support were previously described and are further explored in Chapter Six. My focus now is on two central reforms that directly influenced the provision of palliative care in the home setting and, thus, caregivers' experiences. I begin by examining how the restructuring of home support affected the palliative caregivers in this study and then move to exploring how reductions in service provision shaped their experiences.

Reconstructing Home Support

When health services were regionalized, home support agencies became affiliated with the regional health authority. Following regionalization, a study was conducted to determine those aspects of the community care system that were working well and to identify areas for improvement (CHR, 1998). One of the primary themes arising from that study was the need for continuity of service and the desire for integrated health care provision. As such, community health programs were reconfigured to form a geographical model for service delivery. An article written in a local community newsletter, The Network News, described the restructuring of community health care:

> The Capital Health Region is moving to a new model of delivering health care in our region. As a consumer, you may receive service through one or all of the following programs: Long Term Care, Home Nursing Care and Community Rehab[ilitation]. In the new model, each area of town will be serviced by one office that will house all three programs. The rationale behind this approach is better communication between programs and more efficiency in delivering service (Maathuis & Miller, 2000, p. 3).

Along with these changes came changes in the organization of home support. Community health programs had organized into nine geographic teams. Because there were more home support agencies than geographic teams, the agencies were invited to submit proposals to compete for contracted home support dollars. In the end, nine agencies were chosen as contractors for home support. This process resulted in controversy because several home support agencies closed and patients and their families had to get acquainted with new HSWs and a new agency. This was very difficult for some of the patients and caregivers in this study, especially when they lost workers who were familiar to them, and with whom they had established trusting relationships:

> Mom was getting home support, unfortunately at the time when the home support agencies were doing their changes, taking the number of agencies down in the community to nine. Her complaint was that everyday she got a new home support worker who she didn't know and she didn't trust. To have to start all over again and explain how you want something done [was hard]. And you have the right to do that. It's your home, and you have the right to have things done the way you prefer. Home support workers are taught that, to find out how their client would like things done. And to have to start all over again was so exhausting. "Here's a new one. Oh my goodness, I have to start all over again". It was very vexing for all of us.

Some of the caregivers were concerned the geographical model would reduce their choices. Within this model, for example, the caregivers were forced to work with the home support agency that covered that area. While back-up agencies were assigned in the event that problems occurred[93], some caregivers had to "fight" to have their choices respected. Fighting for the right to have a choice in how services

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[93] For example, some caregivers experienced conflicts with agency personnel that they were unable to resolve. These conflicts necessitated a change in agency or resulted in caregivers terminating their home support services.

are delivered can have ramifications according to this caregiver, who was also a

health care provider:

> Home support is highly regulated and you don't have a choice of agency. We fought very long and hard to stay with the agency we had because they were not the people who serve this geographical area other than as a back-up. So fortunately, they're the back-up agency and we've been able to maintain with the same agency we're very pleased with….But there is definitely the fear of recrimination. We paid for it with that agency. Our relationship with that agency ultimately ended very, very badly….And of course, we now have a reputation.

A central problem created by the new model was the lack of any formal

mechanism to resolve disputes with the agencies. In other words, if the caregivers

had difficulties with the home support agency assigned to the area, or with the back-

up agency, they had no recourse, were left feeling vulnerable, and had the sense

that there was little accountability within the system:

> I guess the biggest problem with home support is that there is no mechanism for resolving your disputes. There's nothing in the system that will resolve a point of conflict….So, Mother and I feel very, very vulnerable in this whole situation right now because of our experience….When we first tried changing agencies, it was a very painful situation. We tried to work it through and there was no way that we could work it through. We had meetings with people. There were different people at every single meeting. The agency was never held to account. There was absolutely no accountability in the system at all.

However, the following excerpt from a column written by community health care staff

pointed out that caregivers do have choices when they are in positions of conflict.

Yet, as the excerpt implies, choices are only available for those who can afford

them, illustrating how "two-tiered health care is alive and well in community care":

> If you are experiencing problems with the transition, you may talk to the R.N. supervisor with the home support agency you deal with or contact your Long Term Care Case Manager. They will endeavour to deal with any difficulties and may want to meet with you at home to sort out the options….In some instances if a concern cannot be resolved, service from the back-up agency may be instituted. Another alternative is for clients or families to hire service

privately either through a home support agency or through their own private network (Maathuis & Miller, 2000, p. 3).

Caregivers who are unable to resolve their disputes and do not have the financial resources to hire privately can apply to a program that would allow them to self-manage their home support services. According to the government policy (B.C. Ministry of Health and Ministry Responsible for Seniors, 2000), applicants are required to establish a non-profit society and are responsible for hiring, scheduling, and supervising HSWs. The program claims to provide freedom and flexibility for caregivers so they are not ruled by the policies and structures of home support agencies. However, some of the caregivers who applied for this program said the associated bureaucracy prevented them from accessing it, even when they and the patient could have benefited. One son, who operated a small business and had previous accounting experience, was frustrated when the government bureaucracy prevented him from accessing support programs to care for his dying elderly mother:

> We understood that there was an alternative to this home support thing and that's where we could essentially handle it ourselves. We would be allotted a certain amount of funds and we could get our own people and we thought, "Well, we could do as well as this [home support]". Then you don't have to see a different person walking up to your door everyday and we had both decided it would be good for all of us. We could get away for a few hours and there would be someone there that we knew and could trust. I mean, we thought, "Forget this, we'll run our own railroad". So we actually applied and they came here and told us "Well, we think you're too late in the scheme of things. It's too late for you to now take this in your own hands". Therefore, the bureaucracy won't let us do it. And you know I'm thinking, "I've run small businesses before. I have experience with this. I mean you have employees and there's the Societies Act and you've got to deduct UIC and CPP and you run the little thing....This isn't the toughest assignment in the world you know". But those turkeys said, "No, you've got to put up with this" [home support]....So, I chose not to have a confrontation and we just thought, "Fine, we'll run our own railroad". But now we can't do that....They said it would take three months for me to set up a company under the Societies Act and open a bank account. Have you ever heard of such unadulterated

poppycock? It may take them three months to do it but it's not going to take me three months. It wouldn't take me three days to do it.

When I asked health care providers about the changes made in home support, the reviews were mixed. Some were optimistic the changes would ultimately improve continuity of care, although they acknowledged they had not seen remarkable improvements at the time of the interviews. Others were more critical, explaining the changes had not improved anything but, instead, had made the situation worse:

> Home support right now is in a shambles. It's in a mess. They made some major blunders when they decided to go with this whole neighbourhood idea. People are not getting enough support and they've cut the hours back again too. People aren't getting enough services and it's not consistently the same person so there's really no chance to build a relationship. That's a hugely important piece when you are doing intimate things like personal care. You need to trust that person and feel comfortable with them....And with palliative situations where the stress level is even higher, it's going to be more important....When they say that "home is where the health is" and when they reorganize with a fancy dancy model [so that] they can reduce the number of people that go into client's homes....They have failed abysmally. They have not even evaluated that. They have not addressed it and it is just unbelievable. It is absolutely chaotic. And this system, the community has been in chaos since it started and nobody is addressing that. It's awful.

Both hospital and home care administrators participating in this study were more upbeat about the changes, stating that continuity of care and integration were improving. At the same time, they recognized home support was in transition and postulated that this might have been why some caregivers and providers were critical of the reforms. They predicted that once the transition period ended, things would "settle down" and positive outcomes for patients and families would be realized. Those who supported the reforms and the affiliation of home support agencies felt that these arrangements provided specific benefits:

I think the geographical model is good and it will ultimately be more effective in reducing the numbers of HSWs going into the home. Continuity will improve. And, I like the partnership model with the CHR. As a community based agency, we're not philosophically in line with "The CHR manages and delivers all services". I think that by using partners for some of their services....And obviously my sub-interest in this is as a provider of a contracted service....But I think that in having partnerships to deliver some of the services, you bring into the culture, just an outside perspective. I think there is opportunity for the incestuousness of the organization if you had no outside people. I think you would see the quality of the service degenerate.

Reducing Access to Home Support

In 1995, the B.C. provincial government instituted a program to prevent hospital admission and to facilitate early discharge. Funding was provided to provincial Long Term Care programs to increase the total amount of home support services that could be accessed by families who required high levels of support. These programs ran budget deficits but the provincial government always absorbed these costs. With regionalization, these deficits became the responsibility of the health authority. In 1999, the health region announced the elimination of this program and its plan to move to levels of home support consistent with other health authorities. The policy change resulted in the total number of subsidized home support hours being gradually reduced from a maximum of 360 hours per month to 120 hours per month[94] (CHR, 1999c).

With this policy change came new ways of making decisions. An assessment tool was developed and used to determine whether families qualified for home support (i.e., whether the care needs of the client were sufficiently complex to

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[94] This policy change resulted in a furor of media activity (see, for example, Kimpson & Argyle, 1999; Paterson, 1999; Watts, 1999a; 1999b). It also led to the creation of the Home Support Action Group, a coalition of people with disabilities, family caregivers, seniors, and other concerned citizens, who are working to lobby against the growing cutbacks in access to subsidized home support (Hillman, 2000).

warrant assistance). According to providers, the assessment is based on preventing hospital admission and does not consider the needs of caregivers. Thus, caregivers who may be overwhelmed and burnt out from their caregiving may not be able to access home support or enough of it to assist them in caring for the patient. Most caregivers, however, were able to access home support. The care needs of the dying are usually sufficiently complex that there are few instances where families in palliative care are denied help, according to administrators. However, the caregivers often reported accessing "live-in" support to get a break, to sleep at night, or to gain assistance with the heavy physical demands associated with caregiving. Therefore, the 120 hour allotment of home support per month shrank quickly. When this happened, the caregivers worried and wondered what they would do if their hours ran out. One retired wife, living on a small government pension, expressed concern with the possibility of facing the ramifications of reduced home support service:

> I was told that if he wasn't dead by November 1st that I wouldn't have any more home support hours left. So, I'll have to take him to the hospital. Hospice is full, it's booked....I mean, I worked it all out so that I'd have enough coverage....You know, spread the 120 hours around....But, if he's not dead by November 1st, I don't know what I'll do.

The providers participating in this study confirmed the reduction in home support hours had affected some palliative caregivers. Not only were caregivers faced with taking on further responsibilities, they were also worried about whether they would be able to maintain their promises. Caregivers placed in these positions were faced with dealing with bureaucratic problems at just the time when they wanted to place their energies with the patient. This home care nurse provided an

illustrative example of what can happen to caregivers when they are faced with

service reductions:

> I had a palliative [patient] who was at home and being cared for. She was in her 90's, and being cared for by her husband who was also almost 90. And he had home supports a couple of hours a day, and then it got to the point for about a week where they needed a live-in, and it was great for him. He had a daughter who was also very supportive and helped….But they really needed help….When all this came about, they were called by long-term care and informed that if she didn't die in a week they would have to start paying privately. Well, she was going to most likely be dead in a week or two weeks, but this man was devastated. And then the option was she could go to hospice but there wasn't a bed at that time. So this man, for the last three or four days of his wife's life, was filled with turmoil. If she didn't die then maybe he could second-mortgage the house to pay for private care and all this stuff….I mean, it probably would have turned out okay but in the last week of her life, that's what he had to worry about.

The reforms in home support made some of the caregivers in this study feel taken

advantage of and exploited. In an emotional interview, this woman, caring for her

dying husband at home, described how the system had let her down and had

contributed to her guilt:

> We have been completely taken advantage of and made to feel guilty. When the case manager came in, I mean, he [the patient] could barely get out of bed and he's really deteriorating….And one day the home support worker just decided that we didn't need the service. She went back to her agency and said, "They don't need two hours a day. We should cut them down". And instead of the case manager talking to me and saying, "This is what you're getting. What do you think?", they cut the service down and then called me and said, "We're cutting you down to 1 hour a day," whereupon I freaked out because I was on the edge of falling apart trying to keep everything going, running home from work at lunchtime, and doing all this other stuff. Anyways, I had a meeting with the case manager and the case manager explained to me how much the service has cost them. "Do you know how much it costs us to have a home support worker come into your home?" So, it plays on the guilt that you're already feeling because I'm asking for help in the first place. It was a clear example of the system taking advantage and exploiting me and it's despicable.

Not only was there no formal mechanism for handling disputes between agencies and their clients, there was no process, external from the health authority, for appealing decisions about home support services. While an advocacy group has recently developed a proposal for a fair and transparent appeal process (South Island Seniors Advocacy Society, 2001), at the time of this writing, an external process had not been put in place. This previous caregiver, who was also an active and strong advocate for family caregiving issues in the health region, claimed that an external process is necessary to ensure that palliative caregivers (and all caregivers for that matter) are provided with fair and equal treatment:

> I think that had I not been able to get home support, I would have been pretty angry. Most people don't ask for it unless they need it, at least in palliative care situations anyways. Probably for any situation. In any event, they should have something where if you've got a problem, you can go to someone and talk to them about it. When I asked them [CHR] about it, because I have a friend going through it now, they said, "You can come and talk to us and we'll have another person review the case". Well, that's fine and dandy but how do you know it's going to be fair? They all work for the same system....So, it's got to be external. There's got to be someone else otherwise, it's not fair.

Some of the caregivers who needed a break and were unable to access enough home support hours used palliative respite care services. Some described respite care as "wonderful" and as "just what I needed"; they were able to get a complete break, often going out of town on a short "vacation from caregiving". Most of the caregivers who accessed respite care had difficulty in setting aside their obligations to the patient, a finding that has been well supported by other research (Chappell & Dow, 2000; Home Support Canada, 1994). Some of the caregivers required a high degree of certainty that their roles would be competently assumed during respite. They often assumed expert roles providing palliative care.

Therefore, it was necessary for these caregivers to fully trust the respite care situation. Otherwise, they continued to visit, supervised the respite care setting, and were unable to ever get a break from their caregiving. Even when the caregivers accessed respite and trusting relationships were built, some were still unable to truly get a break because they felt they were abandoning the patient:

> It was a nice option to have [respite care] but I just found that I was there all the time anyways. And the girls [nurses] were great and I knew they were doing a good job but I just couldn't stay away. I knew he didn't want to go into the hospital and I said to him, "Just for a week, so I can get some sleep". But, I felt that I really let him down and I still think about that. So, because I felt like I was abandoning him, I just kept going up there. So, I didn't end up having a break after all. I mean, I got some sleep for sure, but it wasn't a total break.

It is clear the reorganization and reform of health care services played a significant role in shaping these caregivers' experiences. Any time a system changes there are consequences to individuals. Most health care systems do their utmost to minimize the detrimental outcomes resulting from health care reforms, but these outcomes do, nevertheless, exist. In the desire to improve continuity of care and integrate health systems, caregivers, as consumers of the system, can get hurt in the process. Their established relationships with providers can be minimized, they can be placed in vulnerable positions, and can feel exploited and taken advantage of. Their choices are taken away at a time when they already perceive themselves to have few choices. Instead of being able to savour and share the last moments with their dying family members, some palliative caregivers worry, wondering how they will cope with the increasing demands placed on them in a climate of fiscal restraint. And, when they have to fight for adequate care, their

vulnerabilities intensify. Even when alternatives for health care services exist, bureaucratic structures can inhibit access to them.

Some of the palliative caregivers in this study were deeply affected by the reforms in home support. I would be remiss, however, if I did not acknowledge that the study took place in the midst of these changes. As some of the administrators suggested, caregivers' perceptions might change over time as the reforms are fully implemented and become a part of mainstream practice; this is clearly an area requiring ongoing evaluation. Yet, the impact of service reductions, especially in community care, will likely be felt by caregivers for many years to come. The participants recognized the need for changes to improve the system of care but believed that policy decisions were made on the basis of economics, with relatively little attention given to the implications that such changes might have for families in palliative care. As a result, some of the caregivers lost faith in a system they believed was set up to support them. Others believed things would improve because they "can't get much worse". Yet, as this home care provider concluded, the rationalization of health care services often affects those who are most vulnerable:

> How many limbs are going to be broken because people fall at night? How much more do we expect people to endure? How much more do we expect them [caregivers] to cope with? ... It's on the backs of the people who are suffering the most. The ones who don't have a voice. The ones who are most vulnerable. They are the ones who are affected.

Summary

In this chapter, I have situated caregivers' experiences in the meso context, focusing on how the organization of health care and regional health care reforms

shaped caregivers' experiences. In doing this, I have begun the project of making visible the organizational features that mediate caregivers' experiences. In Chapter Six, I offer a further analysis of institutional and organizational structures as I provide a macro level analysis of the sociopolitical context, uncovering how dominant ideologies influence the provision of palliative care at home.

CHAPTER SIX:

DYING AT HOME: THE SOCIOPOLITICAL CONTEXT

The interpretations I have presented thus far have described caregivers'

experiences and have located these experiences within the community context. In

concluding my explorations, I now turn to making visible some of the more abstract

features that shape the provision of home-based palliative care. Kleinman (cited in

Anderson, et al., 1991) argues that individual meanings and experiences are nested

within a complex personal, socioeconomic, and political nexus. As such, a

dialectical relationship exists between individual meanings and the wider social

organization (Anderson, et al.). Anderson and colleagues explain "the vocabularies

of the larger social organization are reproduced in micro level interactions between

[patients/families] and health professionals through a set of ideologies that structure

health care delivery" (p. 102). In this chapter, I uncover some of the ideologies[95] that

structure the provision of palliative care at home. This examination reveals how

ideological influences are brought to bear on family caregiver experiences.

The Power of Ideology

If ideologies are taken to mean a set of fundamental beliefs, attitudes, and

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[95] I understand an ideology to be a fundamental set of beliefs, attitudes, and assumptions that are taken-for-granted and are used to justify, define, legitimate, and preserve a specific set of circumstances (Boutain, 1999; Thomas, 1993). Many of my claims about ideologies suggest that dominant discourses played a role in perpetuating and sustaining assumptions about dying at home. I recognize that the ideas inherent in these discussions may require further analysis using different research techniques. Recommendations in Chapter Eight highlight the need for further study using methods like discourse analysis and outline the need to foster a critical consciousness about the idea of dying at home. My intent here is not to provide an analysis of the discourses but, rather, to point out that methods such as discourse analysis could extend understandings about the ways in which language, textual practices, and conversation reflect common thinking and also organize thinking (Smith, 1987).

assumptions that are taken-for-granted, it would stand to reason that ideologies can powerfully influence how family caregiver experiences are constructed. Examining some of the assumptions inherent in the provision of palliative home care can, therefore, expose how ideological preferences may distort and reproduce (Thomas, 1993) conceptions of dying at home. Specifically, I want to discuss four ideologies that were reflected in comments made by the participants in this study[96] and that seem to underpin the structure and function of home-based palliative care. The first of these is that all people have equal access to quality palliative care; the second is that family members willingly choose to provide home-based palliative care; the third is that care in the home is "free" from biomedical influences; and the fourth is that the home constitutes the "ideal" place for dying and death to occur. The accounts presented here illustrate how some of the participants came to challenge each of these beliefs on the basis of their experiences in palliative home care.

The Illusion of Equal Access

The Canadian health care system has been widely praised for creating equal and universal access to health care. Under the Canada Health Act, provinces are legislated to observe several principles including the principles of universality and accessibility (Fierlbeck, 1997). Therefore, it is assumed all Canadians, including families in palliative care, will have equal access to quality health care. However, the findings challenge this assumption in two ways. First, people living "at the margins" often have limited access to palliative home care and palliative care

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[96] Throughout this examination, I was aware that the assumptions that were reflected in the comments made by participants in this study might also be assumptions that I, as a health care provider in palliative care, might hold. I problematized these assumptions and dealt with them reflexively in my reflective journal.

inpatient services; and second, families who are unable to afford the costs of dying at home might not be able to provide care at home[97] or, if they do, the care received is sometimes substandard.

Palliative Care for Marginalized Groups[98]

The providers in this study who worked with people from marginalized groups constructed dying at home differently from what has previously been described. There were a number of reasons for this, two of the most important being the concept of family and the concept of home. According to the providers, many marginalized people do not have the natural caring support network of a family. Instead of unconditional caring towards one another, a commodified system of caring exists where "you scratch my back and maybe I'll scratch yours if the price is right". This is because,

> … looking after their most basic needs falls short of getting that fix. So, everything else is commodified in their lives. Their bodies become commodified, particularly if they're women. They learn to trade sex for money, or for drugs, or for a place to sleep, or any multitude of other needs. And with men, I think there's similar pressures. We don't necessarily have a big identifiable male sex-trade here but certainly, men are involved in the drug trade and in the pimping game.

Many people from marginalized groups also live without a "stable" home. According to the providers, people from marginalized groups typically live in transition between parks, downtown hotels, shelters, and, the street itself. Consequently, they are often disqualified from community health services, including

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[97] The point I wish to make here is that families may not have access to *home-based* palliative care if they cannot afford it. They still may have access to inpatient palliative care although the limited number of designated palliative care beds in the region often precludes access to them.

[98] I am using the term marginalized group to refer to people who are living with drug addictions, are "street-involved," and may not have access to a "home" in the traditional sense. I recognize that other groups of people could be defined as marginalized.

palliative care, because they do not have stable homes with a fixed address and because many of these places are predetermined as "no service" areas for safety reasons. Thus, palliative care is commonly provided by outreach workers, street nurses, and shelter workers who may not have the knowledge and skills needed to provide quality palliative care. Because palliative care is not within the mandate of many agencies that serve the marginalized, these people are often not able to access places like shelters when they need palliative care. Without the basics that a stable home provides (e.g., shelter, running water, a place to store food), participants reported that many marginalized people seek palliative care in inpatient settings (e.g., acute care or inpatient hospice care), a finding supported by Seage and colleagues (1993). But, as I highlighted in Chapter Four, marginalized people often feel "punished" by providers for engaging in lifestyles that are judged as "inappropriate". Therefore, many quickly discharge themselves even though they desperately need health care. The providers working with marginalized groups praised inpatient hospice programs for meeting the needs of the "mainstream" population but, like Cox (1999), they indicated that hospice programs may be unprepared to deal with the complexities of caring for people from marginalized groups:

> I don't think that Hospice, as it is now, is necessarily prepared to deal with the whole host of issues that go along with the dying process of somebody who is street-involved and drug addicted. For the most part, as I've mentioned, their health issues are not their first concern. We try to impose that....We're always trying to impose our values on drug users, like "This is what you should be thinking is the most important issue for you", when it isn't. You know, having a really nice bed to sleep in, and a TV to watch, and a beautiful roof-top to sit in sounds glorious to a typical drug user, but whether they would feel comfortable where everybody was looking at them, where their friends might not feel comfortable coming to see them. Those are issues.

When marginalized people are dying and do not "fit into" mainstream services, they are sometimes refused care because they are "drunk or stoned". However, the providers working with the marginalized said that most people with drug addictions continue to use drugs up until the time they died or until they became too sick to procure money for drugs. They suggested mainstream systems needed to recognize this reality and design programs that were sensitive to these needs. When care systems are not designed to meet the unique needs of the marginalized, they will not have access to quality palliative care (Johnson, 1995). Thus, as one street outreach worker stated, they die alone in places "that you and I wouldn't choose to live". Research conducted with people from marginalized groups suggests that they do not have access to the kinds of supports and environments required for adequate and quality health care (Lindsey, Stajduhar, & McGuinness, 1998; Stajduhar, et al., 2000), including palliative home care. These inequities were increasingly difficult for some of the providers to reconcile, especially when health care systems that were supposed to provide care and relief from suffering were unable or unwilling to do so. A counsellor, working with people with drug addictions, explained:

> People who are hurt and vulnerable need even more care and they seem to receive less care. They are blamed and stigmatized and shamed for their lot in life, a lot of which has been out of their control. I think that is just so inhumane. And when you look at sort of the philosophical vision of a perfect death and what the reality is for people, there's such a big gap there. I've had discussions with people who are sick and who are seeing themselves confronted with the notion of death, the reality of death, and the deep sadness there. They need to heal before they die. And, they're not given that opportunity. That is tragic, to still be struggling with the basic entitlements at the very end stages of your life. It's criminal. I think it's absolutely not okay.

Affordability

Many authors acknowledge that dying at home is made possible when the family is financially able to shoulder the burden of costs (Beck-Friis, Norberg, & Strang, 1991; Field & James, 1993; Whynes, 1997). Likewise, the providers in this study maintained that the ability to die at home usually depends on whether it is affordable for the family; those who have the time (e.g., they are retired) or have an income to hire private help can afford home care. The providers in this study suggested it is more difficult today than in the past to maintain people at home. Others have observed this trend. People who are able to support their families at home are typically middle to upper class, or are older and have the financial reserves to pay for extra care and supplies (Armstrong & Armstrong, 1996; Beland & Bergman, 2001). Many families require two incomes to sustain themselves (Baker, 1993; Scanzoni & Scanzoni, 1988). When one family member becomes ill and can no longer contribute a wage, staying at home requires a great deal of support. Otherwise, as one HCN in this study observed, dying at home may not be possible:

> My clientele is mostly younger people. So, often what we'll get are people who have heavy mortgages. When I first started in home nursing care for example, we had two people on care who were dying of breast cancer who had three or four children, the youngest of which was 3 years old and a husband who was trying to work full time. They had a mortgage, they had to pay for their medications, they had to pay for all of their bandages, plus they didn't have the income of the person who was ill. Often, HSWs are quite expensive. So, what do you do? What do you do for those people and how do you help them? How do you help their kids and what do you do for adequate home care. I mean, they just can't afford it and sometimes they just can't do it [facilitate a home death].

For some of the caregivers in this study, the promise to care for their loved one at home is made long before they realize how much it will cost. As the financial

burden builds and sacrifices are made (see Chapter Four), some of the caregivers

(and patients), for example, held back on purchasing medications because they

could not afford them. When this occurs, physical symptoms get "out of control",

with the patient receiving substandard care. Yet, the providers recognized that

many families are reluctant to admit their financial difficulties: "People don't like to

talk about it. They don't like to say, 'We're really hard up', because they're proud and

so on". Families who cannot afford to pay for medications or supplies will either "get

by" and "suffer in silence", or the financial burdens will become so substantive that

hospitalization is required. Both Arno and associates (1995) and Wodinsky (1992)

argue that the costs associated with palliative home care can be so substantial that

they limit the ability of the family to continue care at home.

Costs differ depending on location of care. When dying at home, families

become responsible for the cost of many items (e.g., medications, wound supplies,

meal supplements). When patients are hospitalized, they are usually not

responsible for any of these costs. These inequities, pointed out by Armstrong and

Armstrong (1996) and Fierlbeck (1997), can influence whether dying at home is

possible. Some of the caregivers in this study were thankful when others "stepped

in to help", indicating they would not have been able to afford the costs associated

with home-based palliative care. As this mother caring for her son with AIDS

explained:

> We were very fortunate to have a neighbour that was with the social services
> department and she got him on to welfare because he wasn't earning at the
> time. And without that, I think we would have been broke because with that,
> all his drugs were paid for. Those shots I was mentioning were $100 per shot
> and he had to have 10. And while he was in the hospital, they were paid for
> but when he was an outpatient....Oh, it would have been terrible. It would

have been terrible because we were both retired and we have our property but we don't have a lot of cash. And those drugs! I mean, he was on about 5 or 6 medications at a time. And, they were always changed. You'd get one lot and then they'd be changed and you'd have tons of stuff left over....We did inquire at the Cancer Society but if you have a big house or something then we wouldn't have qualified to be covered. I think it would break you. It would have actually been crippling....We couldn't have afforded to keep him at home.

While the principle of equal access has been entrenched in the Canada Health Act (1984) for almost two decades, these findings suggest that equal access to the spectrum of palliative care services may be more illusory than real. Findings suggest that caregivers who cannot afford the costs associated with home care made financial sacrifices, were faced with hospitalizing the patient, or were placed in positions where the care provided was less than optimal. Findings imply that people who are more advantaged (i.e., the middle and upper class) may have better access to health care. The Report of the British Columbia Royal Commission on Health Care and Costs (Seaton, 1991) recommended strategies to address access issues, including endorsing moves to bring health services "closer to home". Some authors have theorized that closer to home strategies have served to disadvantage certain groups, noting that shifts to move health care out of institutions and into the home are shaped by the trends of cost containment and efficiency (Anderson, 1996; Armstrong & Armstrong, 1996; Lefort, 1993; Wagstaff & van Doorslaer, 1992; Wuest, 1994). Other authors have hypothesized that those who have the least difficulty accessing health services (i.e., the more advantaged) are those who are most likely to get them (Beland & Bergman, 2001; Haines, Heath, & Smith, 2000; Smith, 1994; Tolle, 1998). There is a growing body of literature that supports the idea that socioeconomic barriers influence access to health care (Gillis, 1993;

Neslon, 1994; Williams, 1990), and it is well established that people from marginalized groups have difficulty accessing health services (Bogner, Legare, & Ross, 1998; MacPherson, 2000, Millar, 1998; Stajduhar, et al., 2000). The findings presented here also expose the "hidden" inequities; those who have homes and families to provide care may not have the financial capacity to support dying at home. Thus, it seems that both social and economic circumstances may play a role in whether people have equal access to quality palliative care at home and in institutions. This illusion of equal access complicates the development of effective and equitable palliative care systems.

The Ideology of Free Choice

Inherent in most discussions about home care for the dying is an implicit assumption that caregivers willingly choose to provide palliative care at home (Dunlop, et al., 1989; Gilbar & Steiner, 1996; Ramsay, 1992; Townsend, et al., 1990). As I discussed in Chapter Four, the willingness of some of the caregivers to provide care at home was not so much rooted in their ability to freely choose to provide that care but, rather, in their feeling obligated to do so, particularly among women. According to participants, the health care system takes advantage of women, assuming they willingly choose to step into caregiving roles. Indeed, it has been well documented that women provide the majority of care at home and are expected to bear the chief responsibility for family caregiving (Anderson & Elfert, 1989; Aronson, 1998; Gerstel, 2000; McKeever, 1994; McKeever, 1996; Neysmith, 1991). These expectations stem from a central contradiction between public and

private interests, based on the belief that caregiving is a family (woman's) responsibility (Bunting, 1992). Burgess (1993) argues:

> This implicit acceptance of a model of family-based burden of care, the burden of which falls primarily upon women, is a convenient social assumption that permits the saving of health care related dollars but has significant social costs and implications ... (p. 160).

McKeever (1996) contends that while care in the home has been touted as economically and socially beneficial to society, the influence on women, when family care is substituted for professional care, has rarely been an issue seen to be in need of critique.

Findings from this study suggest that health care providers reinforced the assumption that women freely choose to provide care at home. For example, an administrator stated: "They [women] know how to do it. Many have been caregivers their entire lives and it's just natural that they would take this on". Anderson and Elfert (1989) found that health care personnel often reinforce women's caregiving roles, and there is a large and expanding body of research and theoretical literature that demonstrates how gender inequities are perpetuated within the health care system (Armstrong & Armstrong, 1996; Aronson, 1992; Aronson, 1998; Graham, 1985; McKeever, 1994; McKeever, 1996; Rutman, 1996; Saillant, 1998; Sherwin, 1992b; Wilson, 1982; Wuest, 2000). Husbands can also reinforce the assumption that their wives are "willing" to provide care. For example, some of the caregivers said their husbands "barely noticed" the strain they were under and the burdens that caregiving imposed. They explained their husbands had been the "head of the family" and made the major family decisions; the decision to provide care at home was no different. The provider participants suggested that middle-aged women were

particularly vulnerable because it was often assumed they would willingly care for both their dying parent and their own families (e.g., husband, children), often with little support. Like in other research findings (Arber, Gilbert, & Evandrou, 1988), participants in this study suggested that women often felt undeserving of support from the health care system, feeling they should "just do it". Although most of the caregivers and providers who spoke to this issue believed that the assumption should be challenged, they also acknowledged that it was necessary for many women caregivers (because of their strong obligations) to simultaneously maintain their "willing but taken advantage of" positions, a finding supported by other researchers (Croft, 1986; Opie, 1992; Wuest, 1997). A social worker, who was also a family caregiver advocate, reflected this position:

> One of the reasons why people continue to cope and just do it is because it's a moral obligation. You don't even think about it. You just do it. And often, because they're women, they don't feel that they deserve to get some help. Like, "That this is my role in life and this is what women do and I'm the daughter, or I'm the wife, and this is just my lot in life". So, you're dealing not only with the system attitude, but it's dealing with that. It's not that I want to change that attitude, but it's to expand it for people to understand that you can get assistance and you have a right to that help. Nobody is going to take that role away from you, but there's support that you need and you have a right to it, and it's okay to ask for it....Many women have to, because of the obligation they feel, they have to take this [caregiving] on even if they are not totally feeling good about it. And so my point is, that's fine because lots of people have to do that. But, we need to let them know it's their *right* to ask for help.

At the same time, the caregivers said they would feel less exploited if providers recognized that they had other lives and responsibilities outside of caregiving. They recommended that providers and health care systems be more flexible. For example, some caregivers suggested that appointment schedules be adjusted so that caregivers who were employed did not have to take time off work to

accommodate providers' schedules. The providers proposed greater efforts be

made to ensure caregivers were included in the formal family assessment process.

When caregivers' needs were not fully assessed and attended to, their obligations to

provide care at home resulted in devastating consequences. As one HCN

commented:

> The system takes advantage of the fact that one, family members are around
> and two, that people will do it out of obligation often. Well, many do it out of
> obligation whether they want to or not. One of the things that should happen
> is that family caregivers should be included in all assessments so when you
> talk to the client, they should be talking to whoever the principal family
> member is that is around and there might be a few of them. But the
> assessment has to include willingness on the part of the caregiver, not just
> their ability to do it. It has to include willingness because probably one the
> most extreme instances that just stays with me forever was a woman who
> was looking after her dying father. She was the only relative nearest to him in
> the city. No one else lived in the area. This woman was on the verge of a
> nervous breakdown because her father had sexually abused her all her life.
> Now, she felt morally obligated to look after him but it was tearing her apart. I
> mean, it's an extreme example but families shouldn't feel that they *have* to do
> this.

Some of the participants emphasized the importance of ensuring decisions about

care in the home are based on the willingness of family caregivers rather than on the

expectations of the health care system. However, questions about family willingness

and system expectations can create a number of problems that are not easily

resolved. As one physician provider suggested:

> If there are available family, who in their own individual circumstances, can
> and do decide to set aside the time to be able to come and help, that can be
> very supportive....The family all gets together and it works out well. Those
> are really good, memorable experiences. It's partly why dying at home can
> be really good. When we go the extra step and say we *expect* you to come or
> the government or health care system expects that you will do this and
> daughters are coming from Toronto and Calgary and are giving up their family
> life and their jobs and come here for weeks on end to look after people, then
> we enter into another sociological question of care....It becomes a moral
> problem and there's no easy answer to that.

The assumption that caregivers willingly choose to provide care at home is influenced by self-care[99] ideology. Indeed, Anderson and colleagues (1991) argue that one of the most powerful ideologies underscoring the organization of home care is the ideology of self-care. This ideology, along with the ideologies of individualism[100] and neo-conservativism,[101] has been supported by health care systems as a strategy to empower people to take responsibility for their own health (McKeever, 1996; Steiger & Lipson, 1985). According to some providers, palliative care patients and their families want to have control over their own health. As such, self-care models empower caregivers and, therefore, enhance the quality of care provided. Providers who talked about self-care acknowledged there was a need to balance what the system could offer with what caregivers were willing to provide in supporting the patient at home. However, as discussed in Chapter Four, health care personnel were much more likely than caregivers to focus on caregivers' resiliency and independent functioning, sometimes implying that the health care system need not have to supply all of the necessary services. Similarly, Ward-Griffin and McKeever (2000) found that health care providers were very concerned about enhancing caregivers' independence and delegated as much care as possible to family caregivers. These authors contend that this shift in care responsibility results from the health care systems' efforts to reduce health care costs, a finding that I have discussed in Chapter Five. Yet, an interview with one health care administrator

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[99] The basic premise of self-care is that "individuals are empowered through self-care; by taking more control over their lives, they come to rely less on health professionals. It is one way, then, of eroding professional dominance" (Anderson, et al., p. 102).
[100] By "individualism", I am referring to a social theory advocating the liberty, rights, or independent action of the individual rather than advocating for common or collective interests (McPherson, 1990).
[101] Hooyman (1990) used the term "new conservativism" to refer to the emphasis on fiscal restraint, cost effectiveness, and efficiency in health care.

illustrated how the ideology of self-care can be perceived as reducing the apparent

dependencies of some caregivers on the health care system:

> I think it's a privilege as a family member to be considered as a team member and I know that burden is a real issue, specifically with women in our society. And so I think it's a fine balance. And what that fine balance does is it puts weight on the caregiver to indicate what support is needed. Now that support can come in a number of ways. It may be through formal health care systems but it might be through neighbours or other services in the community....I mean the formal system is only a piece of it....I mean we are moving to a model of self-care. So, instead of saying, "Oh, we'll get you home supports or whatever you want" we are now saying, "What would be helpful for you in order to maintain your health?" as opposed to, "What can we do to take over?" And, it's a shift....But we're going in that direction because otherwise you create dependencies and I've seen this happening a lot.

The preceding interview segment implies that when caregivers state their

needs, the system will respond with services to support those needs. I asked the

administrator for clarification, wondering whether the system would actually respond

in this manner (i.e., would the system really give caregivers what they wanted if they

asked for it?). I was told the amount of service was based on an assessment of the

patient's needs (not the caregiver needs). Therefore, even when caregivers

requested services they thought would be most helpful, there was no assurance they

would get the help they needed. My line of questioning made the participant visibly

uncomfortable, so I did not pursue it further. Later in the interview though, the

administrator suggested that part of the push to implement a self-care model came

from a belief that many caregiving families took advantage of the system. However,

as findings discussed earlier show, most of the palliative caregivers who participated

in this study aimed to minimize their interactions with the health care system and did

not ask for help unless it was really needed, a finding supported in a recent

Canadian study by Anderson and Parent (1999). The assumption that

caregivers will "try and get what they can" was challenged by some of the providers

who argued that the "system's attitude" had been detrimental for some caregivers

who sought support. They disagreed that caregivers took advantage of the system,

arguing it was a myth perpetuated by senior health officials trying to off-load

responsibilities onto family caregivers:

> The system's attitude is that if we open up our doors and say, "Yes, we're here for you," then we're going to get inundated because everybody wants the government to do everything for them, which is a complete and total myth. There's nothing to back that up. And it's unfortunate that bureaucrats use this as a way to get people to take more responsibility because it's just off-loading it onto families. I mean I don't know why they think people are trying to take advantage of them. It's just puzzling to me, that whole thing. Some of us have been trying to get that shift in thinking to the system that, "You've got it all wrong and it's to the detriment of people out there that you don't change your attitude"....But I don't know how much that's filtered down into the policy shops or to senior level bureaucrats. I mean, treating a family caregiver as someone who needs to be respected, who needs support, who needs instruction, who needs some follow-up, goes a long way to validating what they do. Then they feel supported. Because they're gonna do it anyway. The point is, are you going to be there to do it with them, and support them in the process, rather than thinking, "Well, if we go in there, they're going to want us to take over". That is not the case. The system needs to believe and be assured that people will always care for their loved ones. And the small minority of those who choose not to, for whatever reason, need to be accommodated. Not everyone is going to be able to do it [caregiving] but by and large, most people will.

In a letter to the editor of the region's local newspaper, Lorna Hillman (2000), the

Executive Director of the Family Caregivers' Network Society, summed up the

important contributions made by family caregivers. She also publicly challenged

whether it was caregivers who were relying on the system or whether it was the

system that was relying on family caregivers:

> There is a prevailing attitude in the health-care system that the general population rely too much on government to provide care for aging and/or disabled family members and friends living in the community. One could almost refer to this attitude as a myth because there is no evidence to support

it. A growing body of research since 1985 tells us that informal caregivers are both the first resort for care and the predominant source of care, providing between 75 per cent to 90 per cent of all personal care. The National Respite Study reported that even when assistance from health-care services is received, informal caregivers still put in the most hours. Assistance from all other sources taken together does not come close to the contributions made by informal caregivers. So, who is relying on who? Family caregivers are essential to the health-care system. Without their contribution, the system as we know it would not exist (p. A11).

The perception that caregivers willingly choose to provide care implies that caregivers were available. The providers in this study explained, however, that there were many situations in which dying patients had either no living relatives or family members who lived elsewhere. Although some of the caregivers moved from their primary city of residence to support the patient at home, they often had to sacrifice their own needs to do so; some caregivers quit their jobs and left their own families to partake in caregiving. There is increasing concern that the changing structure and function of the Canadian family will significantly influence the extent to which family members can care for one another in the future (Anderson & Parent, 1999; Chappell, 2001; Robinson, 1997; Rosenberg & Moore, 1997; Vanier Institute of the Family, 1997). June Callwood, a noted Canadian social activist and caregiver advocate, was quoted in the Edmonton Journal as saying,

> I for one support the overall move from institutionalized care towards the more loving environment of the home....But to assume that we're back in the 1920s where people lived in stable communities with all their family around and neighbours who would come in a pinch is an outrageous assumption, and that's what the governments still seem to believe (McKay, 1998, C2).

Field and James (1993) suggest that smaller families, changing household structures, and an increasing involvement of women in the labour market, will likely lead to the progressive reduction of the availability of unpaid family caregivers to

provide palliative care at home. The participants in this study predicted the health

care system would be overwhelmed if it did not recognize the impending realities

and plan for the future. One caregiver's comment reflects these predictions:

> I don't know how that's going to play out in the end, or what happens with the generation coming up from the boomer generation, but that has to be looked at too because most of us aren't having children. Like, I don't have kids, so I know that there's not going to be anybody in my family looking after me. So, I have to prepare for that kind of eventuality and what that's going to mean. And an awful lot of my friends don't have children. So, I think that's going to be a huge issue because we're going to be the bulk of the population and a lot of us won't have family members to look after us, so what's that going to mean? I think that's actually almost a bigger issue because I think the boomer generation having children has been reduced drastically....Family caregiving is going to take on a whole other meaning in the future. The system is going to really be in for a big shockaroo.

Caregivers do not always willingly choose to engage in home-based palliative

care, but their engagement stems from an obligation to care, especially if they are

women. Moreover, even if women willingly choose to provide care at home, there

may be too few caregivers to meet future demands for home care. Baker (1994)

contends that policies that establish the family as the primary providers of care fail to

recognize that the structure and function of the Canadian family has changed

dramatically in the past three decades. Furthermore, Parent and Anderson (2000)

suggest that:

> We should not assume that families have the capacity to cope; presence, moreover, does not assume commitment. When coupled with changing family dynamics, more women in the workforce, the geographically dispersed nature of families and pressures on work life; the effects on the emotional, social and financial well-being of the informal caregiver can be considerable (p. 4-5).

Approximately 85% of all care at home is provided by family caregivers, the large

majority of whom are women (Chappell, 1993; Hooyman & Gonyea, 1995;

McKeever, 1996). Like findings from this study, many researchers have found that women can feel exploited in their caregiving roles. As earlier noted, many women caregivers may need to maintain their "willing but taken advantage of" positions in order to fulfil their obligations to care (Croft, 1986; Opie, 1992; Wuest, 1997). It appears that caregiving roles are reinforced by health care providers and are reproduced through the ideologies of individualism, neo- conservativism, and self-care. Interestingly, self-care ideologies, while meant to empower caregivers, were also seen by some of the providers in this study as a way to reduce caregiver dependency when providers felt caregivers took advantage of the health care system. Caregivers who shared their experiences with me, however, did not take advantage of the system, but rather, sought help from the system only when it was most needed. Some authors have argued that strategies that are meant to empower individuals (such as self-care) can in fact conceal and sometimes justify paternalistic practices (Arksey & Sloper, 1999; Opie, 1998). It is possible that, in their efforts to be supportive and empowering, some of the providers in this study may have inadvertently enacted their deeply rooted "expert practitioner" role, instead of respecting the caregivers' needs and engaging with them in a collaborative manner, a finding supported by Paterson's (2001) research with people experiencing chronic illnesses.

One of the challenges of unpacking the ideology of free choice is that there are several assumptions embedded within it. I have endeavoured to demonstrate how taken-for-granted assumptions influence caregivers and to show how providers, and the systems of care in which they work, can shape, and deeply influence,

caregivers' choices about, and experiences with, the provision of palliative care at home.

The Hidden Biomedical Imperative

A common assumption operating alongside palliative home care is the belief that care at home will afford better quality health care for patients and families. Armstrong and Armstrong (1996) critically describe the biomedical model as one in which,

> ... homes are seen as havens from a heartless institutional world, the place where treatment and care can be combined in a safe setting that offers comfort, independence, and choice. Care in the home or 'community' is assumed to be better for virtually everyone and to be preferred by virtually everyone (p. 136).

Critiques of the biomedical model are prevalent (see, for example, Armstrong & Armstrong; Capra, 1982; Rachlis & Kushner, 1994; Thorne, 1993) but, with few exceptions, these critiques have not been applied to palliative care itself or to palliative home care. Indeed, palliative care has been described as a response to the inadequacies of Western medicine in caring for the terminally ill (Dudgeon, 1992; Finn Paradis, 1985; James, 1993). Here, I submit that biomedical influences do permeate palliative care in the home (and palliative care itself for that matter) and, therefore, shape caregivers' experiences.

Paternalistic Practices

Biomedical perspectives influence palliative care at home through paternalistic practices. Data collected in this study revealed that paternalism operated on many levels: between providers and caregivers; nurses and HSWs; palliative care nurses and HCNs; physicians and nurses; palliative care physicians

and general practitioners; and between employees and employers[102]. I observed

paternalistic practices, particularly between caregivers (and patients) and HSWs[103].

For example, on one of my field visits, a HSW was preparing an elaborate

"nutritious" meal. When the caregiver expressed "he doesn't really like that", the

HSW said "but it will be better for him" (Field Notes, March 2000). On another field

visit, a HSW was preparing a patient for bed. The patient said, "It's only nine o'clock.

I never go to bed this early. I'd like to stay up for a while". The HSW responded,

"But you're sick, you have to get your rest ... I'll read to you for awhile and then you'll

feel more like it [going to bed]" (Field Notes, November 1999).

The caregivers, struggling for control over their own environments and

situations, sometimes felt HSWs devalued their input and expertise. On the same

field visit where the HSW had prepared a meal, the caregiver later told me, "She

doesn't seem to take into consideration that I might know what he needs" (Field

Notes, March 2000). There were also instances where the caregivers felt their

positions as family members to the dying were usurped by HSWs. When this

occurred, it left caregivers angry, prevented them from being involved with decision-

making, and interfered with their participation in their loved one's death:

> I noticed and the home care nurse noticed too that there's a sort of a
> proprietary air from them [HSWs] that they get to feeling like they almost own
> the patient....I found in the last days of Mom's life, I got the sense that this
> worker who was with her the most was almost trying to take a primary
> position over myself in her importance to Mom. There was a little overtone,
> always very correct....Well Mom got quite ill one night and she [home support

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[102] It is not my intent to examine how each level of paternalism operated. I only wish to make the point that I observed and heard about many levels of paternalism.

[103] I am singling out HSWs because they were frequently in the home when I conducted observations and the issue of home support came up repeatedly in my interviews. This is not to suggest HSWs were the only providers who practiced in a paternalistic manner. Rather, I use these illustrations as a device to make my points.

worker] had called the PRT which is what she should do. But, she didn't let me know and I was really angry because I got there and I found out that the PRT had been there and put the butterfly in to feed more anti-nausea medication....And she didn't tell me....And when Mom died, this woman, with all her experience, I know that she knew how close Mom was to dying. I know that. And even though she's not allowed to make a diagnosis, she could have phoned me up an hour or two before I came in the morning and said, "I think you might want to come over and see your Mom now". She didn't. And when I walked in, it's hard to say, but she almost looked like the cat that ate the canary. It was the impression I got. And I thought, I know that she knew enough. Even though she went by the rules, she could have tactfully suggested that I come over earlier. Because I really wanted to be there [when she died].

Many of the caregiver participants acknowledged they "put up with" these situations because they were in desperate need of help. The caregivers were appreciative when they encountered HSWs who comprehended their experiences, respected their expertise, and focused on the individual rather than the task. They found it difficult when they were unable to find a HSW with these attributes:

When you get desperate enough you'll take anything and put up with the consequences....It was such a joy to have this one woman who comprehended and respected his needs. The other person that came in put a plastic sheet on the bed and whatnot, thinking that Dad was going to wet the bed. It would have been simpler if she'd asked me because that was just degrading to him. Even though he might not be able to remember, there are some things I think you know inside you. So that was difficult for me and she should have asked....I know there were stains on the bed and she thought she was doing right, but she should have asked. That was an emotional difficulty as a caregiver that I had in that knowing that he might be....I don't know what the word is....not neglected....but not honoured. He was treated as a case from the books rather than as an individual.

In contrast, some of the caregivers had "wonderful experiences" where they felt supported and respected and where HSWs became "part of the family". Throughout the course of their experiences, however, some of the caregivers became aware that HSWs were instructed by their agencies to "be professional". The providers, administrators, and HSWs confirmed that home support agencies do

not give priority to relationships developed on the job but rather to ensuring assigned

tasks (e.g., bathing, meal preparation) are completed. According to a home care

administrator, the health region,

> … demands a certain set of protocols and there is a scope of authority and
> very serious repercussions to going outside that scope of authority. You're
> quite correct, HSWs are in fact explicitly instructed not to form personal
> relationships with their clients.

This administrator acknowledged these protocols were paternalistic but explained

such directives were put in place to prevent "dependent relationships" from forming.

She suggested some HSWs become "over involved" with families in palliative care

and lack training to handle the emotional repercussions of such work. She also

recognized that many HSWs were easily able to form relationships with families

without becoming over involved, but maintained that protocols were required to

prevent any possible problems from arising:

> I believe in pushing down decision making, but I think we have to be very
> aware of some of the shortcomings of some of the HSWs. This is another
> problem….Some HSWs are outstanding because of their personal attributes
> of caring and professionalism. Some are RNs. I mean, they know what
> they're doing….But, let's be very frank about it….Many HSWs started out as
> cleaning women and they've sort of evolved. But at the end of the day, they
> haven't had any training…. They've never worked in facilities….They're sort of
> unfamiliar with accountability, with consequences of certain actions, with
> liabilities, with all of those kinds of things. We can't, on the one hand, say that
> everyone is going to be held accountable for everything they do, and then on
> the other hand say, "Do what makes sense. Use your common sense"….We
> have to make sure we have our bases covered so we don't get into trouble.

Protocols such as these have contributed to a "pervasive lack of respect" for

HSWs. They are often labeled as "task oriented" and thought of as having little to

contribute to the health care team, a finding supported by other research (Neysmith

& Aronson, 1997). Yet, HSWs were often in the best position to inform the health

care team because of their ongoing contacts with families. Interestingly, although

HSWs were afforded little respect, they were often sent into homes to provide the

most intimate of care. A HCN pointed out the irony of this situation:

> What I find ironic is some people think HSWs are just beneath us, right? But
> you know what? We send them into peoples' houses alone, unsupervised, to
> perform the most intimate of functions, and with unfettered access to peoples'
> personal belongings, personal assets, personal lives. They're going to know
> more about that individual than any of us....I mean the home care nurse is
> probably only going to know what the person wants them to know, right?
> Well, the HSW is going to learn things that people don't want them to know
> about....Yeah, I think that we don't provide enough respect.

Some participants theorized that the paternalism operating within home support

agencies had shaped how some HSWs interacted with families in palliative care.

Others maintained the paternalistic practices between HSWs and other providers

had created hierarchical structures in community-based care. As this home support

administrator explained, the "pecking order" that exists has influenced how health

care is provided at home:

> I'm grinning because I'm not a nurse and I come into an environment and my
> reaction to it is that it's highly paternalistic. And it's almost like you can see,
> "OK, doctors to nurses, nurses to HSWs right?" And it's interesting....But I
> think there's more pettiness and I think there is a pecking order and a
> snobbery to it all....And that filters down right to the home, where you're
> providing care. Here's what I found as a startling example. I went to a
> palliative care conference and they were doing a skit about taking a client
> through death kind of thing. Somebody played the doctor. There was a
> doctor, there was a nurse, there was a case manager, there was physio. It
> was all focused on them. The HSW was mentioned but I thought, in many
> cases, the HSW is the one in the home 24 hours a day. But these people
> were just all on another level....So there is a pecking order there.

There is evidence that home support work is undervalued in our health care

system much as domestic or women's work is undervalued in our culture at large

(Neysmith & Aronson, 1997). Findings from this study suggest that a lack of respect

afforded to HSWs may contribute to their paternalistic behaviours. In essence, a "ripple affect" occurs: when health care providers or employers exert power over HSWs, HSWs, in their attempts to regain power, may unintentionally exert their power over caregivers. Furthermore, paternalistic policies restricting HSWs from forming relationships with caregivers may in fact reinforce paternalistic practices. While the reasons behind these policies may be valid, such directives neglect the reality that many caregivers need to develop trusting, respectful, and collaborative relationships with providers. Similar to other research findings (Clark, Corcoran, & Gitlin, 1994; Ong, 1990; Powell-Cope, 1994), the caregivers in this study were most appreciative when they developed relationships and were better able to get a break from their caregiving. A number of writers have identified the contradiction between task-focused and interpersonal aspects of care (Bartoldus, Illery, & Sturges, 1989; Eustis & Fischer, 1991; Kaye, 1986; Mercer, Heacock, & Beck, 1994; Warren, 1990). What is less visible in these analyses, but that is supported by findings from this study, is how organizational structures and policies come to bear at the point of service delivery.

Like other authors have indicated (Corser, 2000; Salvage & Smith, 2000; Snelgrove & Hughes, 2000), interactions between physicians and nurses in this study were also characterized by paternalistic practices. According to participants, some physicians will not refer their patients (and caregivers) to home care programs because "they feel there is nothing we [HCNs] can do". Other physicians reportedly "allowed" HCNs to be involved with palliative care patients and their families but disregarded their recommendations. Home care nurses who participated in this

study reported that they often had to negotiate "power obstacles" in order to provide effective home-based palliative care. For example, some HCNs had difficulty treating the patient's pain when they could not get analgesic orders from physicians. In these instances, they felt "hamstrung" when trying to deliver care. Fortunately, many HCNs were resourceful, finding alternate ways to maneuver around physicians, as one HCN who participated in this study explained:

> Often we work with the GP's and they may not listen to us....I've had a situation with a doctor who acted in a passive-aggressive fashion. When the man became ill, I phoned and the doctor wouldn't answer his call and I phoned again and he wouldn't answer his call and finally I said, "Fine, just give him the message that I'm going to call PRT and have them come in".

Circumventing the physician was not always possible nor was getting support from community-based hospice programs. Home care nurses working outside of geographical areas serviced by hospice programs described the difficulties they faced in providing palliative care because policies did not allow them, for example, to carry medications needed for prompt symptom management:

> Someone is uncomfortable and you don't have the drugs and you don't have the ability....You know, they may have stopped swallowing, they may be suddenly crashing and you don't have the tools available to bring them relief. That can be immensely frustrating, waiting for the bloody Atropine while somebody's choking to death, running out to get the pain medications when somebody's in distress, especially when you've had the ability to have the drugs right there and say, "I can help you".

One caregiver summarized how she felt about paternalistic practices, highlighting how care at home sometimes offers little protection from paternalistic attitudes:

> There were a lot of reasons for keeping them [parents] at home in the first place and one of them was so I could have some control over this. They don't let you! There's always this little push of them telling you what to do. I mean, I guess some were giving advice and that was good. But, it went a little farther than that sometimes. I always felt like I was treated like, "There, there dear, it's okay, we'll do it....You run along and get some tea". And I really

didn't appreciate that. It was condescending, almost patronizing and I didn't appreciate it.

The Health Care Provider Knows Best

Similar to research on the experiences of the chronically ill (Thorne, 1993), family caregivers in this study admitted to entering their experience believing that health care providers "knew best". Their beliefs were reinforced when providers indicated "we will be with you on your journey", implying that caregivers would receive competent instruction and support throughout their caregiving. Over the course of providing care at home, some of the caregivers shifted their beliefs when they realized providers "didn't always know what they were doing". For example, many of the caregivers revered their physicians, placing them "along with God" and putting a "blind faith" in them. They were disappointed when they realized physicians did not know everything and sometimes knew very little about what constituted the everyday life of palliative caregivers. As this daughter explained:

> What didn't impress me was when he [doctor] walked into the house the first words he said to my Mom were, "So, I hear you've been hallucinating". Well hello, if she is hallucinating, she doesn't know it. I mean, get a brain! ... I think we need to quit putting this medical profession on a pedestal. The doctors that I came in contact with were on that pedestal because they thought they belonged there. They really did. My heavens, would you ever argue with a doctor? I don't think so....But he really didn't understand what I was going through and the hardships we faced....He just didn't have a clue.

The caregivers often looked to providers for guidance and reassurance because they had little previous experience with palliative care. Like prior research indicating that those in need of health care enter into health care relationships naively trusting that health care professionals will know the most appropriate course of action (Thorne, 1993; Thorne & Robinson, 1988), many of the caregivers in this

study trusted that their loved one would receive quality end-of-life care because they were told many home health care providers had palliative care experience. Some of the caregivers assumed providers would know how to problem solve and offer concrete suggestions for care. They also assumed all providers would be competent and possess palliative care skills. These assumptions were challenged when these caregivers perceived the quality of care to be less than what they expected. For example, on one of my field visits, Kevin was discussing pain management with a HCN, explaining that his wife Valerie was having difficulty swallowing (Field Notes, February 2000). Having accumulated expertise in pain management, Kevin suggested to the HCN that Valerie's medication be given subcutaneously. The HCN was visibly hesitant, recommending other options. When Kevin insisted, she explained, "I don't feel comfortable doing that … I haven't had much experience". Although Kevin understood the HCN's discomfort, he later said, "I can't believe she was uncomfortable. I would have thought that's something any HCN could do". Caregivers lost confidence in their providers when such situations occurred and felt frustrated when their beliefs were challenged. As this daughter explained:

> Even though they said they were palliative trained, there was only about maybe one or two that we felt were palliative trained and knew what they were talking about. I remember Dad got a really bad sore because his favourite place was on his back. So this nurse came in one night and was rubbing him with Sunlight and dressings and tape up the ying-yang. And I think one of the hospice nurses came in the next morning. She turned him over and said, "What's all this? … All you have to do is use a soft towel, or whatever and a little bit of rubbing....We're not trying to heal the sore, only make him comfortable". I think she felt that what had been done just could even aggravate it....So there was a lot of frustration there because some of them didn't know what they were doing.

The previous interview segment implies that providers with specialized palliative care knowledge may be better prepared to offer guidance and support to families in palliative care. Many of the caregivers spoke positively about providers employed by specialized palliative care programs. They indicated their approaches were respectful, non-intrusive, and inclusive of the patient and family. At times, I watched in awe, as palliative care providers artfully negotiated their way through sensitive situations in a respectful and caring manner. However, not all of the caregivers constructed their experiences with palliative care providers in the same way; some caregivers felt disrespected and disturbed when these providers took it upon themselves to decide what was best for the patient. An emotional interview with Danielle, a thirty year old university student providing care for her dying mother, exemplifies how some caregivers felt when providers devalued their experiences:

> Every time they came out [the hospice nurses and counsellors]....I'm not saying all of them did this, but it happened a lot. I had to put my Mom in front of her [the counsellor] with my Dad because it was like my Mom didn't exist. Constantly. And my Mom would be sitting there and she'd say, "Can you talk to me too? I can hear everything you're saying. I know you're talking about me". It was completely disrespectful. And I said on a number of occasions when they were talking to me, "I would like to include my Mother in this conversation. She can hear us anyway. We are talking about her and making decisions about her care. I would like to involve her". But they did it constantly. I think part of it was because of the drugs and they just thought that she had a really hard time understanding things, so it would have to be repeated again and again, and they found it just easier to talk to a family member. But at the same time, if they wanted to talk to us privately, they should have made some motion and we could have gone to a different room....They did take us to the kitchen table and told us they thought she might die that night. You know, her eyes were closed, but she could hear us. And she was really offended by that and she said to me, "You were talking about me. What were you saying? I could hear part of it". Just because she's sick, doesn't mean she's not a person.

Some palliative care providers who were interviewed for this study admitted there is sometimes a degree of arrogance when working with patients and families. These providers explained that for many years they had advocated to ensure quality end-of-life care, holding strongly to commitments to reduce pain and suffering. In the process, their own values and beliefs became so embedded in their practice that they sometimes clouded their interactions with those who were dying. One physician, with specialized palliative care training, explained how she came to see the arrogance of challenging people's experiences, showing how her deeply held assumptions had previously obscured her practice:

> A lot of people I work with say, "Oh, they're in denial". And I say, "So what?" I mean, that's the way some people have to handle it. Some people will deny it [dying] until the moment they take their last breath. Like it's their life. It's their comfort and who am I to impose my ideas on them. It's like pain management. I mean, if you say to me, "I don't want my pain managing", I may feel very frustrated and impotent but I have to go with that. When I first started practicing, it was like, "Let's get rid of everybody's pain". Well after awhile I said, "Well, this is a bit patronizing". In some ways, you say, "Well, what do you want from me? Do you want to keep 1/10th of your pain? Do you want to keep 1/2 of your pain? Do you want it all gone?" I mean, everybody's different, so if somebody wants to deny their disease, that's perfectly okay with me.

This was the advice one caregiver had for providers who believed they knew best:

> My mother's quite an expert on her body and her needs. I'm an expert as her caregiver. That's what I do very well and I'm quite knowledgeable about that. But boy, you get into the system and that is worthless. That is not considered....Even when you're at home....They [providers] better wake up and smell the coffee! Unless they do that, this system is never going to be better. They need to do a better job of including all of us in the team and they better start seeing us as having legitimate knowledge to bring to this. We do know something you know? ... And sometimes, we know much more than they do.

The Myth of Holism

In previous chapters, I described how acute care models contributed to the depersonalization of palliative care patients and their families, suggesting little attention was given to treating the "whole" person. Believing they were opposing biomedical influences, palliative care providers in this study prided themselves on their attention to the whole person, an approach deeply etched within palliative care philosophy (CPCA, 1995). However, while many of the caregivers felt their "whole" needs were met, some mentioned a predominant focus on symptom management in their interactions with providers. These caregivers appreciated the attention given to ensuring the patient was comfortable but explained there were times when focusing on disease symptoms minimized other equally important issues:

> Well, he was having a lot of pain that day and the nurse came in and she immediately settled it down and that was good. And to her credit, she did ask us how things were going. But, I needed to talk about this whole business [assisted suicide] because he was talking about it a lot and I didn't know what to do. I mean, maybe she was uncomfortable with the whole thing, I don't know but it just seemed like she was in and out. Got the pain settled and then gone....I don't know ... maybe she was really busy that day.

I observed a few instances where the providers focused on symptoms with little attention given to other issues. I also noticed some providers worked in a distinctly compartmentalized manner with physicians and nurses responsible for symptom management, counsellors responsible for psychosocial support, spiritual care coordinators responsible for existential issues, and so on. When I asked the providers about these approaches, most explained it was difficult to focus on the "whole person" (or family) unless symptoms were controlled. They also admitted divisions existed within the various "streams" in palliative care. One hospice nurse

reluctantly acknowledged these divisions had created some tensions, particularly

between nurses who felt counselling was in their scope of practice and counsellors

who believed they were solely responsible for providing psychosocial care. Others

admitted (also reluctantly) they were seriously concerned about the emphasis on

symptom management within palliative care, suggesting that psychosocial, nursing,

and spiritual care often played "second fiddle" to the primary focus on the disease.

They worried that reductionistic approaches of counting biomedical knowledge as

the most legitimate form of knowledge placed in jeopardy the hospice "ideal" (of

focusing on the whole person). Some of the providers argued that equal emphasis

be given to the emotional and spiritual well-being of families in palliative care. As

this hospice nurse explained:

> So much of the work we do with the dying is about grace notes and humility
> and awe and spiritual connection. The [palliative care] movement wouldn't
> have started if it weren't for the basic values that go along with it like
> compassion and things that you can't measure, things that you can't draw up
> in a syringe, things that you can't write orders about, right? So, I think we
> have a lot to teach actually in terms of acute medicine and cancer medicine
> … and palliative medicine for that matter. I mean, those are supposed to be
> the values of medicine anyway but it's gotten really obscured….It just can't be
> about the disease and the symptoms and the mechanics of it all the time. We
> have to make sure that things like psychosocial care, spiritual care, you know,
> all of those things that are equally important, that we keep them from rolling
> off the table all the time.

One participant offered an outsider's perspective on the progression of palliative

care development, theorizing how biomedical influences were shaping palliative care

practice. She suggested there were inherent dangers when the founding ideals of

palliative care were challenged and replaced with an emphasis on the disease:

> You know, I don't work within the system but I've been watching what's
> happened to palliative over the years. I mean, when you're dealing with a
> system that is medically focused like in acute care, it's hard for that not to

influence what is happening in palliative care, right? ... So, I think that part of the problem is that palliative care has to kind of live within that acute model and they struggle for credibility in that. It's just the nature of the system. It's focused on disease....And they've tried to hold strong to their principles, their values, the things that palliative care started out to be. But I think they've gradually shifted over time. I mean, palliative care does a great job but the system sort of perpetuates this need to focus on the disease....I don't know but it just seems to me that when you shift your focus you run the danger of losing what was important in the first place. It's not just in palliative care but it's an area where I see it happening a lot.

The preceding examples indicate that biomedical perspectives have pervaded more than just institutional medical practice; they have also shaped the practice of community-based health care and its providers. A growing body of literature exists warning of the medicalization of community-based care (Arras & Neveloff-Dubler, 1995; Chappell, 1997; James & Field, 1992; Kaye & Davitt, 1998; Ruddick, 1995). Some authors express concern over the encroachment of mainstream biomedical influences into the realms of palliative care philosophy (James, 1993; McNamara, Waddell, & Colvin, 1994; Seale, 1998). While it may be appealing to assume that community-based palliative care is free from the influences of biomedicine, findings from this study demonstrate biomedical influences shape caregivers' experiences with home-based palliative care.

The caregivers were deeply affected when they were treated in paternalistic ways, when providers minimized their expertise, and when their "whole" experience was reduced to focusing on the patient's disease. We have learned from Foucault (1979) and others (Fairclough, 1989; Henderson, 1997; Mills, 1997; Sawicki, 1991) that power explains many of our social constructions and pervades many relationships between care providers and recipients of health care (Halldorsdottir, 1997; Rutman, 1996). Previous research findings have affirmed that providers are

reluctant to acknowledge the expertise of patients and caregivers (Nyhlin, 1990; Paterson & Thorne, 2000; Ward-Griffin & McKeever, 1996). Although some of the caregivers in this study felt they developed respectful, collaborative, and participatory relationships with their providers, others felt providers exerted power over them. Interestingly, some of the provider participants did not recognize their authoritarian approaches, a finding similar to Opie's (1998) study that describes how providers inadvertently position themselves as experts. At the same time, paternalistic practices are not, in themselves, objectionable. For example, caregivers who were seriously overburdened reported they were appreciative when providers exerted their authority and suggested they admit the patient to hospital. As Thorne (1999) argues, the development of egalitarian relationships is not always desirable. However, paternalistic and reductionistic practices became problematic when the caregivers lost total control over their environments, when their perspectives were ignored, when their experiences were reduced to a focus on the disease, and when health care systems and structures exerted control over their interactions with their providers. The findings from this study demonstrate that palliative home care, and palliative care itself, are not immune to the influence of biomedicine. This realization was disconcerting for many who participated in this study.

The Idealization of Dying at Home

I think it's a wonderful event [dying at home].
It's one of the most important events that happens in our lives.

-   Health Care Provider

In Chapter Two, I reviewed some of the ethical implications of home care for the dying. This review highlighted an assumption that the home setting represents the most appropriate place for dying and death to occur. Indeed, the literature is filled with claims that dying at home is "ideal" (see, for example, Bowling, 1983; Dougherty, 1995; Gomas, 1993; Moore, 1993; Reid, 1999)[104]. With few exceptions, this assumption has not been subjected to critical analysis and there is almost no research that challenges this belief. Instead, there seems to be a societal or cultural movement toward dying at home that is sometimes unquestionably promoted by proponents of palliative care and others. I have previously challenged the idealization of dying at home, showing how the home setting may not always constitute the ideal place for dying and death to occur. My intent here is to uncover some reasons behind this assumption and to describe how such an assumption gets reinforced, reproduced, and thereby, influences the dying-at-home experience.

Almost all of the caregivers in this study assumed providing palliative care at home would be much better than having the patient in hospital. As described in Chapter Four, this assumption was based on the caregivers' previous experiences with institutional care and their belief that care at home would provide a more normal environment for care. Like some authors have theorized (De Spelder & Strickland, 1996; Lule, 1995), findings from this study suggest that the ways in which dying and

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[104] While I was conducting this study, I scanned a number of palliative caregiver support books found in the local bookstore (see, for example, Brown & Powell-Cope, 1992; Collett, 1997; Duda, 1987; Pohl, Kay, & Toft, 1990; Van Bommel, 1999). These books provided "step-by-step guides" for being a caregiver and tended to affirm the emotional and spiritual benefits of caregiving at home. The back cover of Collett's book says, for example, "Given a choice, most people would rather die at home ... This practical and spiritual manual shows how we can actually give our loved ones this compassionate option". The only book that I found that portrayed some of the difficulties inherent in caregiving was written by Anna Quindlen (1994), who offers a frank account of the challenges imposed when palliative care is provided in the home setting.

death were depicted in the media reinforced the assumption that palliative care at

home provided a better option for care. However, this assumption was challenged

when some of the caregivers realized these depictions were unrealistic. As a wife

who had cared for her husband with Amyotrophic Lateral Sclerosis (ALS) described:

> I think most of the emphasis on home care seems to be on the more spiritual side of looking after somebody....There's too much that you see on television where people are dying of terrible diseases, but they die slowly and gently and there's no bedpans involved, you know, there's nothing like that involved. This comment that June Callwood got together 60 people to help this woman [die at home], well that's pointless because the average person hasn't got 60 people that they can get together. And, my husband would have been appalled if there had been 60 people tramping in and out of our house....I think the other side of that too is that we deal with TV stereotypes, and the dying person on TV is always warm and gentle and peaceful and loving. He wasn't. He was raging against this, and didn't want this to happen to him....I mean it wasn't like Love Story, that's for sure....That's the idea I had in my head.

Societal attitudes also reinforced the caregivers' idealization of dying at home. For

example, the caregivers told me they were often praised for their commitment to

providing care at home by providers, friends, neighbours, and other family members.

They were referred to as "noble", "committed", "loving", "selfless", and "giving".

While appreciative of praise and encouragement, some of the caregivers began to

question the "idealness" of dying at home. In response to praise, one daughter

caring for her dying father thought to herself: "What do you know? You don't even

know what you're talking about. You have no idea what this is all about". Other

caregivers felt there was a cultural movement toward dying at home as the ideal,

with one theorizing that there had been a "world consciousness" that had shaped

constructions of home as the ideal place for dying and death to occur:

> It just seemed that all of a sudden, the community wanted more care. It was kind of a conscious, kind of like a world consciousness. And so I suppose it

comes from a number of places. I think we read in the newspaper about people, and you think, "Oh well maybe I should do that" [provide palliative care at home]. And your neighbour does it, and your friends do it, or you hear about it from friends. So, it comes from a number of different places....It's kind of like a community feeling where home is thought of as a place to consider....That it is better.

Another caregiver viewed the idea of dying at home as a "the newest best thing":

These things go in cycles don't they? It's like breast feeding. It's the newest best thing. And dying at home is now the newest best thing. And, it's idealized and glamourized and you're made to feel almost guilty if you don't do it. And not everybody's up to it. Let's face it.

When I asked the provider participants about the basis for the assumption, they agreed with many of the reasons posed by caregivers. They also theorized that the "idealization assumption" was driven by reforms intended to reduce costs to the health care system. As I previously mentioned, reforms in health care have placed increasing demands on health care personnel to reduce hospital stays, prevent hospital admissions, and maintain people at home, a finding well supported in most discussions about Canadian health care reform (Burgess, 1996; Fierlbeck, 1997; Rachlis & Kushner, 1994). According to the provider participants, promoting dying at home as a viable option was a way of keeping people out of hospital beds, thereby reducing health care costs. However, maintaining people at home was often disguised and captured under the rubric of providing better care. As one hospice counsellor suggested:

And I think there's a pressure from institutional medicine to have people be kept at home. It's less costly to the system. There's limited beds. I'm not about to propose that people have limitless beds for people to be able to come into the institution but it's interesting to me. In what I call acute palliative medicine, we're focusing on illness and a short trajectory and a short term stay versus this long term dying of old age stuff. We're in a real hurry to try and keep people at home, trying to focus on less bed requests, less people in the unit, supporting the death at home concept, which is great

because that what we're about in so many ways. But I'm talking about the larger medical focus on this. I think there's a pressure on people to get them home. They kind of say, "That's a great program you've got going, supporting people dying at home. Excellent". But, they are really meaning, "It keeps them out of the beds".

Some of the health care providers reinforced the idealization of dying at home because they believed it provided opportunities for families to find peace and resolve issues. Dying at home also allowed family members to participate in the dying process. Some providers used their own experiences and beliefs to influence caregivers' decisions without recognizing how their own assumptions were affecting their practice:

> I remember one family I worked with and they wanted their loved one admitted [to the hospital]. They asked me "What would you do if it was your Father?" And I said, "Well, I'll tell you what I did when it was my Mother. I took a leave of absence and I just stayed with her". And they just looked one to the other and said, "Oh, we can't afford to do that". And I said, "I couldn't afford not to".

Some of the providers who held strong beliefs about dying at home reflected on how their own knowledge and palliative caregiving experiences made them see how they might unwittingly be placing their own assumptions onto caregivers[105]. In their efforts to provide the best of care, the providers sometimes overlooked the reality that palliative care situations change in ways that might necessitate hospitalization.

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[105] Although health care discourses were not explicitly examined in this study, and while I acknowledge there is a need for future research in this area, it is possible that dominant health care discourses shaped providers' conceptualizations about dying at home. For example, I previously implied that the idealization of dying at home is reproduced in textual dialogues. Writings about the benefits of dying at home, based on clinical knowledge and observation, are pervasive in the health care literature. There is surprisingly little scientific evidence to support accounts that caregivers choose the home as the setting for palliative care. I am not arguing the legitimacy of clinical or observational knowledge but, rather, I am pointing out that assumptions that are reproduced in texts may get "picked up" by providers and influence their beliefs and opinions. In turn, this knowledge may be taken as "truth" and may contribute to the application of idealized notions without due consideration of each individual situation.

But, as this interview segment with a nurse who was also a caregiver implies,

challenging the idealization of dying at home made her feel like she "let down" the

palliative care system when she was unable to facilitate a home death:

> P: I guess it was just that I had bought in so wholeheartedly to that idea [of dying at home] but I really realize that it's really different in every situation because I knew of lots of deaths that had been really wonderful at home.
>
> R: You just hoped that for yourself....
>
> P: I guess so. And I guess I felt guilty too, because I was part of the system that was promoting this and yet, I couldn't even do it.
>
> R: So was it a little bit of a let down, maybe?
>
> P: Yeah, I think so. I felt like in a way that I had let Dad down but I also sort of let the system down. And I didn't even really think about it until it was all over and I could sort of pause on the whole thing.
>
> R: You talked about feeling that dying at home is kind of the epitome of that whole experience, but not having had that happen, how did that change your thoughts?
>
> P: I think how it affected me is very much this whole notion of choice and not laying any preconceived ideas on what people can do and what they can't do. I guess it makes me a lot more aware of the fluctuations that happen. It's not a pure science. I mean when they would admit someone to the home care program, they would ask them whether they wanted to die at home or in the hospital. Most people said they wanted to die at home and certainly in our case, that would have been the answer. But there are so many fluctuations and you can't predict.
>
> R: Some people have told me that being a caregiver is a privilege.
>
> P: Yeah well, you stay up seven nights in a row, and then you tell us what kind of a privilege it is, and how wonderful it is and life is so good.

This provider carried on, explaining how her deeply embedded beliefs and

assumptions coloured her own ability to recognize that providing palliative care at

home was an unworkable option for her:

When I was involved with the palliative home care program, I really bought into the notion of people being able to die at home and this was the thing. And certainly when I was practicing I just said to people, "If you want to go home, I'll move heaven and earth to get you there because if that's what your choice is. I'll do whatever it takes". And I could do that. And when Dad was dying, I really believed this, that this is what I wanted for him, to die at home. And we took him into the palliative care unit and got his symptoms managed and then we'd bring him home again. The last time he came home before he died, he said he didn't want to go back to hospital again and I said, "That's fine. You don't have to". So in my mind, I really wanted him to die at home....But I guess because from my background, I wanted it so badly, that when the time came and everybody around me said, "You can't do this anymore. It's time to take him in", I just fought it like crazy because it was in my make-up that he should be able to die at home....And so I never could make that decision ... In the end, it was him who made the decision. When there was a bed, he just said, "It"s time to go".

The caregivers in this study who talked about the idealization of dying at home thanked me for "allowing" them to openly speak about the issue. They explained that their discussions with providers often focused on maintaining the patient at home with little examination of whether this was a realistic option; sometimes they had little opportunity to have "frank discussions" about the issue. Many caregivers acknowledged they received "top-notch" service from health care agencies but felt assumptions about dying at home needed to be challenged because "sometimes people can candy-coat things". They also believed the pressure to conform to idealized practices was placing unnecessary guilt onto caregivers. One of the caregivers, who was also a strong advocate for family caregiving issues, even went as far as conceptualizing the idealization of dying at home as "brain washing" and was especially concerned given caregivers' vulnerability and hesitancy to express their own needs:

I'm worried about people feeling pressured into doing it because they are supposed to do it. This is what I'm worried about. The guilt. What about the guilt when everybody does it and then you can't? ... I think that you have

already seen the bigger picture and it is not as fluffy as we think that it is, but I would say that probably 88% of the people are followers. They don't use their minds....Sometimes it's like brain washing. But the problem is that other people don't think for themselves....And, they don't say what they need. And this is true of many caregivers. I'm not saying I was a follower but I kind of felt talked into doing this [caregiving at home] because it was the acceptable thing to do and I didn't know what to do at the time. And I've always been able to think for myself but in this situation, I just couldn't express what I needed.

A few of the providers in this study confirmed the culturally embedded idealization of dying at home placed undue pressure on some caregivers. While they recognized that it was unintentional, these providers suggested that pressure to conform to idealistic views is often subtly encoded in language and in practice approaches. This counsellor suggested caregivers often want to "fit into" socially and culturally accepted norms, placing further pressures on caregivers to provide palliative care at home:

I think the pressure is there in a number of ways. I think it's there and I'm not necessarily giving it as a value, I'm just saying that it's there. There's a bias, I think, towards [dying at home]. It's there in the kind of emotional and spiritual energy that we create around us, for example, right? Just in the way we choose our words when we talk to people. It's seen I think as culturally, at this point anyway in our history, it's seen as culturally more appropriate and desirable [to be] at home. It's like, "Wouldn't you want to be surrounded by your family?" It's there in the kind of assessments I do where I want to know the patient's or family member's plan re: location of death. So the question is there and it might not even be something that people have thought of....My experience has also been that people want to fit into that cultural and emotional and spiritual desire to be at home....It's socially acceptable and they want to fit into that.

Some of the providers recommended exercising caution when engaging with families in decisions about dying at home, maintaining that patients and caregivers need to constantly have choices about the place of dying without being pressured by providers' attitudes and beliefs:

We've talked here a number of times about the focus of our program, about care at home and dying at home. And sometimes we get so focused in on that and we have to catch ourselves and say, "Okay, that's what we do, that's the most appropriate thing, but can they [the caregiver] manage?" ... So, I really think we have to watch ourselves. I agree that care at home and dying at home is an option that we can do well with, but people have to have a choice about that without us putting our own stuff onto them.

The findings of this study challenge the idea that the home is the most appropriate place for dying and death to occur. The idealization assumption is often driven by powerful societal, cultural, and economic influences that tend to be reproduced by health care providers and their often uncritical application of assumptions onto family caregiving situations. The providers who championed the idealization assumption often did so because they *truly believed* dying at home would contribute to better experiences for families in palliative care. Some also felt they had failed to uphold the tenets of palliative care when they were unable to facilitate a home death.

There is some evidence to suggest that health care providers, patients, and caregivers may differ in their perceptions of palliative care. Studies have shown, for example, that providers and patients differ in their conceptions of what constitutes a "good death" (Payne, et al., 1996). Other research highlights how patients and family caregivers differ in their perceptions about symptom control (Field, Douglas, Jagger, & Dand, 1995; Higginson, Priest, & McCarthy, 1994, Hinton, 1996). While the conclusions of these studies vary, it is generally agreed that caution be exercised when applying the accounts of one group to another. From this, I take it that one should exercise caution when applying idealized notions of dying at home onto caregivers. Nevertheless, these discrepant constructions -- combined with

powerful media images, and strong societal and cultural messages -- contributed (in subtle and not-so-subtle ways) to the pressure that many of the caregivers felt to conform to idealized notions. Such constructions also contributed to the guilt that some caregivers felt when they were unable to sustain their promise or live up to "socially acceptable" norms and practices. It would seem that providing palliative care at home is not ideal in all circumstances. Indeed, the reproduction and reinforcement of this ideal may only serve to further reduce the choices that caregivers have.

Summary

This chapter concludes the presentation of findings. In this chapter, I have highlighted four ideologies that seem to underpin the provision of home-based palliative care and have demonstrated how such ideologies shaped and influenced caregivers' experiences. In these discussions, I have specifically challenged the assumption that all people have equal access to quality palliative care at home. Findings suggest that people who are more socially and economically advantaged may have better access to palliative care, exposing hidden inequities within palliative care provision. Additionally, caregivers did not always willingly choose to provide palliative care at home but, rather, did so because of an obligation to care. Women were particularly vulnerable to being exploited by health care systems as their obligations to care were reinforced by providers and were reproduced through the ideologies of individualism, neo-conservativism, and self-care. While self-care ideologies were intended to empower caregivers, findings suggest that self-care models were sometimes used as a strategy by providers to reduce caregivers'

dependence on the health care system. At the same time, the findings suggest that the caregivers were not overly dependent on the health care system nor did they take advantage of the system. Rather, caregivers sought help from the health care system only when it was most needed.

Caregivers who "chose" to provide palliative care at home often did so because they assumed that home constituted the ideal setting for palliative care. This assumption was reinforced by powerful societal, cultural, and economic influences that tended to be reproduced by health care providers and their often uncritical application of assumptions onto family caregiving situations. When this occurred, some of the caregivers felt guilty and pressured to conform to providing care at home, even when the circumstances were less than "ideal". The idealization of dying at home was often challenged when the caregivers realized the biomedical imperative was operating within the home environment. Findings suggest the influence of biomedical practices, in combination with the idealization assumption, created difficult experiences for caregivers who were also deeply affected by paternalistic and reductionistic health care practices.

The ideologies presented here, along with the findings in previous chapters, illustrate the complex and multi-layered nature of palliative caregiving when it is provided at home. As much of the discussion in the preceding chapters has situated the findings within a larger body of empirical and theoretical literature, I now turn to Chapter Seven to locate these findings within a broader context, theorizing some of the "more global" issues that may be influencing the social context of home-based

palliative caregiving. These theoretical discussions will then pave the way to an explication of recommendations based on the study findings.

CHAPTER SEVEN:

DISCUSSION:
LOCATING THE FINDINGS WITHIN A BROADER SOCIAL CONTEXT

The overall goal of this study was to gain an understanding of the social context of home-based palliative caregiving. I began my study at a micro level, seeking to understand how family members came to the decision to provide palliative care at home and how this decision had influenced their lives. From there, I focused on meso level influences, emphasizing how the organization of health care and regional health care reforms had shaped individual caregiver experiences. In turn, my examination moved to the macro level as I explored how dominant ideologies influenced the provision of palliative care at home. The various contexts that are brought to bear on caregivers' experiences do not exist in isolation but are inevitably intertwined, demonstrating the complex and intricate nature of home-based palliative care.

One of the goals of ethnographies informed by critical perspectives is to make visible how larger structures and processes influence and shape individual experiences (Thomas, 1993). The preceding interpretations highlight the multi-layered nature of home-based palliative care and provide a clearer understanding of how caregivers' experiences are constructed and organized. In this chapter, I intend to locate the study findings within a broader context, considering three themes that undergirded many of the points brought forward in previous discussions: discourses about choice; health care reform; and the medicalization of home-based palliative. In concluding my discussions, I consider these key themes, drawing together some of the central ideas presented in the preceding chapters. The discussion of

key themes that follows, while presented in a sequential manner, is not meant to suggest that these themes are layered in such an order with each influencing the next. As demonstrated in the following discussion, key themes are embedded within each other, uncovering the complex and multi-layered nature of home-based palliative caregiving.

Discourses About Choice

The modern palliative care movement has developed a philosophy of personal choice where the patient and family together comprise the unit of care (CPCA, 1995; Lamers, 1995; Mount, 1986). Motivated by an increasing tendency to medicalize death by mainstream biomedicine, the palliative care movement has sought to reclaim the natural course of dying by focusing on holistic care that equally respects the choices of patients and families (Stoddard, 1978). Seymour (1999) contends that the persuasiveness of the palliative care movement lies in its promise to bring to fruition an image of the late modern "natural" death described by Elias (1985) as being at home, in bed, where the autonomous choices of dying patients and their families are respected. The ideology of choice in palliative care, then, is founded upon liberal egalitarianism whereby individual choice is valued within the context of ongoing social relationships that link the choices of one person (the patient) to those of the next (the caregiver) (Stingl, 1996). As such, equal consideration of the choices of dying patients and their family members is a hallmark of effective palliative care and has been deeply stitched within the philosophy of the modern palliative care movement since its inception (du Boulay, 1984).

Self-determination, or the freedom of choice, is a value that is strongly held by North American society (Goldman, 1995). Indeed, respecting the choices of health care "consumers" has been heralded as an important component of health care reform (Brock & Daniels, 1995). Much of the empirical evidence and theoretical discussion about home care for the dying also highlights the importance of giving choice to families in palliative care. This literature implies that the patient and family have equal choice about where care is provided, concluding that, "families", if given a choice, would opt for the home as the setting for palliative care (Dunlop, et al., 1989; Gilbar & Steiner, 1996; Gomas, 1993; Moore, 1993; Ramsay, 1992; Thorpe, 1993; Townsend, et al., 1990). Yet, instead of the liberal egalitarian view held by proponents of palliative care, the findings from this study suggest that the choices of patients are often privileged over those of family caregivers.

There are a number of possible reasons for this paradox but it has likely resulted from the patient advocacy efforts that began in the early years of the modern palliative care movement. Facilitated by powerful images set forth by scholars like Aries (1976; 1981) who describes the medicalization of death, and combined with empirical evidence that documents the problematic nature of dying in acute care hospitals (Field, 1989; Glaser & Strauss, 1965; Sudnow, 1967; Wilkinson, 1991), the modern palliative care movement has sought to reform how dying patients are treated in the health care system. The movement has also fought to uphold patients' rights to receive compassionate and sensitive care, including their right to choose to die at home. This, combined with the advancement of the patients' rights movement (Frank, 2000; Jones, 2000; Wakefield, 1997) and an

enhanced emphasis on developing "partnerships" with patients (Powell-Cope, 1994;
Reutter & Northcott, 1993), has likely contributed to the long-standing and
sometimes single-minded concern in palliative care to advance the rights of dying
patients.

While not meaning to exclude the rights and choices of caregivers, it is
possible that such a focus on patients' rights has served to conceal the equally
important rights and choices of their caregivers. A strong allegiance to upholding the
rights of dying patients through respecting their choices was a theme that
undergirded many of the points that came to light in this investigation. The
caregivers minimized their rights and choices, sometimes with substantial
consequences. The providers and administrators championed the idea of dying at
home and, in the process, may have overlooked the caregivers' choices and needs.
This, combined with societal and cultural expectations for family members (mainly
women) to uphold their obligations to care, make it increasingly evident that serious
consideration should be given to the implications for caregivers when their choices
to provide palliative care at home are minimized.

In the past decade, there has been increasing recognition given to the
importance of developing partnerships with caregivers (Duncan & Morgan, 1994;
Harvath, et al., 1994; Keating, Fast, Connidis, Penning, & Keefe, 1997). The family-
centred care movement has promoted the idea of a family model of care with equal
status given to the needs of patients and family members (Bowden, Dickey, &
Greenberg, 1998). Despite this emphasis and increasing conceptual acceptance of
family-centred care, the actual practice of this model has been less than optimal

(Broome, 1998). Recent research demonstrates that relationships between family and professional caregivers are more exploitative than reflective of true partnerships (Ward-Griffin & McKeever, 2000). Indeed, home-based caregiving has been conceptualized as an "untapped national resource" with much of the emphasis in research and practice focusing on how the burden and strain on caregivers can be minimized so that they can continue to care (Bunting, 1992).

Recognizing the need to continue to search for the most appropriate ways in which to support caregivers who wish to provide home care, there is also a need to appreciate, and take seriously, the limits of what can or should be expected from caregivers. Dudgeon and Kristjanson (1995) question whether family members should be expected to provide palliative care at home. Without wanting to engage in an extended justice-based discussion juxtaposing the rights of patients and caregivers, it is important to acknowledge that advancing the rights and choices of palliative care patients, while a laudable aim, can sometimes neglect the equally important rights of caregivers. The decision to provide palliative home care often results in caregivers having to drastically shift their lives to fulfil obligations to care for the patient. What might be seen as in the "best interests" of patients, however, may not necessarily always be what is in the best interests of caregivers. When health care providers and the policies that govern them exclude the interests of family caregivers (e.g., when policies do not include caregivers' needs in the formal family assessment process), they fail to recognize that caregivers, like patients, have legitimate rights and needs. An ethic of care that minimizes the choices of

caregivers and negates the importance of their life projects only serves to erode their personhood (Carse, 1993).

Given the complexity of the home care environment when palliative care is provided in that setting and given that each family shares a history that determines, to a large extent, how family members will cope with the physical and emotional demands of home care, there can be no universal "rule" for how to untangle whose rights and choices should be respected. However, in the context of the home, where decisions and choices have immense impact on family caregivers, the interests of caregivers ought to be considered. For example, is it reasonable and just to expect a formerly abused daughter to care for her abusing father in her own home? Is it reasonable to expect a devoted son to change his mother's soiled diapers when he is intensely uncomfortable with this task? Or, is it reasonable to expect a woman to sacrifice her own aspirations and desires to provide home care? Of course, there are no straightforward answers to these questions[106]. The point I am making here is that there are limits to what should be expected of caregivers.

Although it is possible that some caregivers "freely" choose to provide home-based palliative care, the findings from this study suggest that the circumstances surrounding such choices are deeply problematic. Arras and Neveloff-Dubler's (1995) discussions about the ethical and social implications of home care reverberate what has been found in this study. They stated:

> Against the backdrop of strong societal expectations for women to conform to stereotypical roles (e.g. the devoted, caring wife, mother, daughter) and the absence of viable alternatives for equally loving care either in or outside the

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[106] In Chapter Eight I propose some suggestions for how we might begin to look at strategies to ensure the rights and choices of caregivers are taken into consideration.

home, a "free choice" to subordinate oneself totally to the care of another begins to look increasingly problematic, increasingly unfree (p. 20-21).

There are limits to what can be expected of caregivers. Caregivers with limited financial, emotional, or physical resources cannot always be expected to provide care at home, even if they believe it to be ideal. When providers encourage and reinforce caregivers' obligations, their actions, however well meaning and intentioned, can serve to reduce caregivers' choices. Although many providers in this study believed they were supporting the choices and rights of "families" in palliative care, their actions, when uncritically applied, excluded the choices of many caregivers, privileging the choices and rights of patients. In a recent study examining where Canadians die, Heyland and colleagues (2000) conclude that patient preferences for end-of-life care, including the location of death, would provide "a more profound and ethically unambiguous rationale for reform" (p. 14). They indicate that sincere attention be given to the preferences of patients in where they wish to die. I would argue that these same points be applied to thinking about family caregivers, as they are the people who provide the majority of palliative care to those at the end-of-life.

Mediating Influences of Health Care Reform

Since the introduction of universal health insurance in Canada in the late 1960s, both federal and provincial governments have been attempting to reform the health care system (Church & Barker, 1998). These efforts have resulted from a widespread perception that health care costs are spiraling[107] and an increasing

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[107] There are differing opinions among health care economists and analysts regarding the extent to which the health care system is in a state of financial crisis (Northcott, 1994). Wilson (1996) contends that the cost of the Canadian health care system has steadily risen. Canada spends approximately

concern over the implications of changing demographics (Chappell, 1993; Evans & Stoddart, 1990). Most Canadian provinces have commissioned a series of task forces and public forums directed at reforming the health care system (Angus, 1991). The results of these efforts have been remarkably similar across provinces, highlighting the need to contain costs, increase efficiency and effectiveness, enhance responsiveness and accountability, and facilitate public participation (Fierlbeck, 1997). Mhatre and Deber (1992) summarized the central visions for a reformed Canadian health care system, outlining several common elements of health reform[108]. They are: an emphasis on shifting health care "closer to home"; a concern for equality; a focus on efficiency and cost containment; and a move toward regionalization. Each of these characteristics carried ramifications (some more than others) for home-based palliative caregivers in this study.

Shifting Health Care Closer to Home

The provision of health care at home is not a new phenomenon. In the past decade, however, there has been a heightened emphasis on shifting health care closer to home (Crowell, Rockwood, & Stolee, 1996). Several converging trends have precipitated this shift but the most prominent has been the economic climate in Canadian health care. Pressured to contain institutional costs, health care systems

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72 billion dollars on health care per year, or approximately 10 percent of the Gross Domestic Product, up from 7.1 percent in 1971 (Health Canada, 1995). At the same time, some analysts argue that Canada could afford the present health care system if it focused on health promotion, illness prevention, and tackled the accumulated government debt that is essentially taking funds to service the debt that could be used for health care (Evans, 2000; Northcott; Rachlis & Kushner, 1992). Regardless of the debates, health care reform has resulted primarily from the "cost crisis" perception and, according to some scholars (Anderson, Tang, & Blue, 1999; Armstrong & Armstrong, 1996; Keddy, Gregor, Foster, & Denney, 1999), it is having a major impact on the provision of health care services.

have moved to dehospitalize patients, discharging them "quicker and sicker" and promoting home care as an alternative to hospital care. Such health care reforms are based on the welfare safety-net model in which publicly funded health care is considered a last resort (McKeever, 1996). Thus, "home care is considered universally superior and hospitalizations are considered legitimate for severe emergency, acute and episodic conditions only" (McKeever, p. 202). In British Columbia, calls to shift health care closer to home are most evident in the Report of the Royal Commission on Health Care and Costs (Seaton, 1991). This emphasis was felt by many caregivers in this study who had difficulty in accessing inpatient care and who felt that their loved ones were "pushed out" of hospitals before they were well enough to go home. It is now well recognized that such shifts in care location have effectively displaced the economic problems of the health care system onto the family (Armstrong & Armstrong, 1996) and most certainly, as was demonstrated in this study, the resultant responsibilities and costs are shifted onto caregiving families.

The typical response to escalating health care costs has been to close hospital beds with little expansion of home care programs (Chappell, 1993). Even though, on average, provincial spending on home care across Canada has doubled since 1990, reaching almost 2.1 billion dollars in 1997, it has not kept pace with the growing needs for home care (Anderson & Parent, 1999; Health Canada, 2000). Each province differs in the extent to which it takes a "total systems approach" to

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[108] I recognize that there are other common elements to health care reform (e.g., an emphasis on health promotion). I have focused on those elements that are most applicable to the findings from this study.

health care reform but many health care scholars and community care advocates assert that home care is seriously under funded (Canadian Health Coalition, 1999; Fainsinger, et al., 2000; McWhinney, et al., 1995; Parent & Anderson, 2001; Sorochan, 1995; Vogel, 2000). It has been calculated that home care accounts for only one percent of health care costs in Canada, compared to 40 percent for the hospital system (Northcott, 1995). Yet, whether home care programs are adequately funded has major implications for family caregivers. Others have written about the burden placed on family members as health care is dehospitalized without adequate resources (Anderson, Tang, & Blue, 1999; Armstrong & Armstrong, 1996). In this study, for example, policy changes that resulted in a reduction of subsidized home support hours increased the burden of care on caregivers, left caregivers feeling exploited by the health care system, and diminished their ability to spend quality time with their dying family members. When home care programs are promoted without expanding the resources to support them or when these resources are reduced, "caregivers are left not with a new health care system, simply a less adequate old system" (Chappell, p. 48).

Even if home care programs were to be expanded, the implementation of such programs has implications for caregivers. Up to this point, the informal system of care, namely family caregivers, have had little say in how health care services are developed. Instead, caregivers' concerns have been largely overlooked by public policy; caregivers have had to adapt silently to the advantages and constraints set by the public sector (Baldock & Evers, 1991). Yeo (1996) argues that public participation ought to be an important part of determining the course of health care

reform. However, as one provider pointed out, "Caregivers are often too exhausted or don't have the time to advocate on their own behalf". Moreover, even when caregivers have completed their caregiving and might be able to participate in setting the direction for reforms, they may continue to experience some stigma or shame if they admit that their caregiving was difficult and that they would rather have not provided home care. Certainly, the recent inauguration of the Canadian Coalition for Caregivers (2000) is an exceedingly important and exciting development that holds promise for advocating for the rights of family caregivers. Nevertheless, there has been no principled debate, up to this point, examining whether the Canadian public willingly accepts the responsibilities and costs resulting from shifting health care closer to home (Parent & Anderson, 2000). This topic has not received its due attention in the public discourse and currently there are few mechanisms in place by which to publicly engage in a debate of such difficult issues.

Furthermore, it is unclear whether home-based care will result in better outcomes for health care consumers (Anderson, 1990; Church & Barker, 1998). To date, few evaluative studies have examined the outcomes of home care. Instead, it is assumed that shifting health care closer to home will result in better outcomes for families. It is possible that this assumption has contributed to the lack of systematic analysis regarding the provision of health care at home. Anderson contends, however, that an understanding of the complexities inherent in the provision of home health care is "critical if policy is to be developed that will direct the provision of effective health care delivery within the context of North America's pluralistic society" (p. 73). While the contradictions between public and private interests are tensions

that are not easily resolved, they must be recognized as central to health care reform (Armstrong & Armstrong, 1996).

A Concern for Equality

A concern for equality is another component of health care reform that came up as a point of concern in this study. In discussing the ethical foundations of health care reform, Brock and Daniels (1995) argue that the ability to pay should not give some people access to health care services that others cannot afford. Many Canadian health policy documents (e.g., Epp, 1986; Seaton, 1991), as well as policy directives put forward by federal task forces and associations concerned with end-of-life care (e.g., Canadian Senate Subcommittee on End-of-Life Care, 2000; CPCA, 1995; Health Canada, 1989b), highlight the importance of enhancing equal access to health care for all Canadians. As previously discussed, findings from this study suggest that access to palliative care services is not equally distributed among groups and has disadvantaged families who are unable to afford the costs associated with home care.

In an encouraging move, the B.C. provincial government has recently implemented a recommendation from the British Columbia Royal Commission on Health Care and Costs (Seaton, 1991), announcing an injection of 4.2 million dollars annually to cover the expenses of palliative care patients who choose to die at home (Fayerman, 2001). The new plan intends to enhance equal access to home care by reducing the financial strain associated with end-of-life care. The plan provides drug benefits for prescription and non-prescription medications and covers the costs of supplies such as needles, syringes, commodes, and so on. While this policy is a

good first step toward equalizing access to home care for the dying, the criteria for inclusion (e.g., patients who have been told their life expectancy is six months or less) is limiting. Many people who are dying can require medications and supplies well before the six-month allocable time frame. Several researchers, for example, have found that terminal illnesses can last as long as 15 years (Allard, Dionne, & Potvin, 1995; Eastaugh, 1996; Kurti & O'Dowd, 1995). Furthermore, diseases such as ALS, AIDS, and certain types of cancers can extend the dying process. Yet, many people affected by these conditions may be too debilitated to be gainfully employed or they may require ongoing physical care by family members which results in a loss of income to the family. Although policies directed at enhancing equal access to quality palliative care show promise, the criteria for inclusion needs to be expanded. For instance, what would happen in the case where a person did not die within the six-month allocable time frame? Any policy resulting in services being withdrawn because a person does not die quickly enough is highly disturbing and fails to recognize that the dying process does not always proceed in a predictable and orderly fashion. The development of such policies must consider the unpredictability of terminal illness and recognize that the particular peculiarities of individual disease conditions and the human will to live, will, most certainly, influence how the dying process proceeds.

Finally, many authors submit that global trends in health care reform that have resulted in inequities in accessing health care services have only served to further disadvantage already vulnerable groups (Evans, 1997; Jurgens, Cartledge, Kilby, & Roy, 1999; Kapp, 2001; Peabody, 1996). The findings from this study

support the concerns raised by these authors. In an editorial written in the <u>Journal of</u>

<u>Palliative Care</u>, David Roy (1999), a prominent Canadian ethicist, highlighted some

of the same questions that the findings of this study has also illuminated:

> There are probably not too many of us working in well-organized hospices and palliative care programs who have any extensive first-hand experience of how the poorest of the poor, of how those who are socially utterly marginalized, live and die .... But how can persons bereft of all of [the] normal connections, adrift out there in the shadows of the city, ever find their way, particularly when they are very sick and dying, into that space we call humanity? .... How do the poorest of the poor die? Do we really want to know? That knowledge could be very disturbing, loaded as it might well be with imperatives for action. It could also be accusatory knowledge if those of us "in the know" do nothing to mobilize lethargic ministries, governments, health care institutions, and professional schools to develop and organize the services the poorest of the poor need, to have a chance of dying well. But the imperatives cannot stop there. It would be humanly and socially grotesque if our passion for the poor stopped at helping them to die well. If the end of this century is question period, the question of how the poor both *live* and *die* has to be raised clearly, loudly, and persistently.

A Focus on Efficiency and Cost Containment

A focus on efficiency and cost containment, central characteristics of health

care reform, were embedded in many of the discussions with participants in this

study. Storch (1996) argues that health care reforms have been influenced by a set

of values promoting the "business model" of health care. There is increasing

concern that this model, which focuses on cost cutting and efficiency, has led

provincial and federal governments, and health authorities, to adopt measures

toward the privatization of services (Armstrong & Armstrong, 1996). This trend was

most evident in situations where caregivers were encouraged to hire private help

when they were unable to access a sufficient amount of publicly funded health care

services to support them in their home caregiving.

The trend towards efficiency and cost containment in the palliative care sector has been expressed in the literature (Bly & Kissick, 1994; Hayslip & Leon, 1992; Orzechowski, 1996). Some authors are apprehensive about cost containment strategies, indicating that the current focus on fiscal restraint makes it difficult to maintain a philosophy of palliative care that focuses on enhancing quality of life (Di Mola, 1997). Palliative care is founded upon a philosophy that strives to meet the physical, psychosocial, and spiritual needs of patients and family members. When cost effectiveness becomes an overriding programmatic criterion for palliative care programs, the individualized treatment and services offered by such programs may be in jeopardy (Kaye & Davitt, 1998). The major impact of "economic rationalism" (Brown, 1996, p. 139) on palliative care patients and their caregivers is not only that they have to shoulder many of the costs associated with home care but also that they are in danger of losing just those services that benefit them and that assist them to continue caregiving at home.

Moving Toward Health Care Regionalization

The movement towards health care regionalization, discussed in some detail in Chapter Five, has both direct and indirect effects on how home-based palliative care is organized and experienced by caregivers. Restructuring of health care services and concurrent policy changes resulted in a reduction of services for palliative caregivers who participated in this study. While it may be too soon to predict the far-reaching effects of such changes and the long term implications to caregivers as a result of health care reforms, evidence from the U.S. suggests that systems-level integration has failed to support the contention that integration leads

to economies of scale, greater efficiency in services, and improved outcomes for health care consumers (Dowling, 1995; Shortell, 1988).

Admittedly, there is some evidence that quality of care may improve through integration (Howard & Alidina, 1987) and Canadian health care reformers believe that unified organizational structures will improve "systems-wide" thinking among planners and providers of health services (Hollander, 1994). The findings from this study, however, suggest that efforts to reform palliative care have, at times, heightened long-standing organizational tensions between acute systems of care and palliative systems of care. While these tensions appear to be easing, they have, nonetheless, inhibited progress in palliative care program development and have influenced the system's capacity to develop a comprehensive continuum of palliative care.

In my previous clinical leadership position in palliative care, I was often perplexed at why various systems of care seemingly had difficulties in working together to develop a comprehensive and coordinated system of care for palliative care patients and their families. During the process of this research, I have come to understand how a variety of organizational and professional interests can interact in the process of health care reform. Two decades ago, Weiss (1981) warned of the organizational, conceptual, and philosophical tensions that arise when health care services move toward integration. On a conceptual level, service integration may be a positive step to working together to effect improved health care. However, there is often little recognition given to the fact that each service or organization comes with its own culture, values, operating frameworks, and practice lenses that, to a large

extent, influence the ways in which a particular organization or service agency provides health care. When these organizations are obliged to work together, either through mandated processes like regionalization or because it might lead to better outcomes for patients, it is inevitable that these systems will face tensions.

During this investigation, I came to believe that the long-standing tensions existing between service agencies result from philosophical divisions about how care for the dying ought to be enacted within an organizational and regional context. Each of the provider and administrator participants whom I interviewed for this study was genuinely supportive of developing a regional system for palliative care and each was committed to working together to accomplish this goal. At the same time, study findings suggest that there are differences in the extent to which each system of care fully commits to the philosophy of palliative care. These differences have understandably arisen because each system of care has different mandates. Palliative care systems are specifically mandated to provide end-of-life care for the dying and their families. Regional health care systems are also responsible for palliative care but they carry the added mandate to plan and deliver health care to the broader population of citizens. Palliative care philosophy recognizes that dying and mourning are natural parts of life whereas mainstream medicine is driven by the technical imperative to cure and to treat the disease (McNamara, et al., 1994). While each of the systems may reach a general consensus on the visions for reforming palliative care, there will inevitably be significant differences in opinion on the exact nature of these visions. A natural outcome of these differences is often

"straightforward power struggles over control, priorities, or resources" (Rondeau & Deber, 1992, p. 389).

Palliative care systems and the providers working in them, historically, have had to fight to be recognized within a system imbued by biomedical culture. Thus, efforts to advocate for palliative care principles and programs to be included into mainstream health care systems can be viewed as "aggressive" rather than being seen as an attempt to advocate for the rights of dying patients and their families. While it is possible that palliative care advocates have been too narrow and single-minded in their approach, as was suggested by one participant in this study, it is important to recognize that such approaches have likely resulted from a historical tendency to minimize and diminish the needs of the dying and the services to support them. Viewed in this broader sense, it may be that these "politics" of health care (McKinlay & Marceau, 2000) have been necessary to the development of palliative care over the past few decades. While not wanting to suggest that either system of care (i.e., mainstream regionalized systems or palliative care systems) has been uniformly appropriate or inappropriate in its approach, understanding the reasons behind each approach may assist in paving the way toward the development of collaborative relationships that respect the various perspectives held by each system of care.

In summary, health care reform played a major role in shaping the context of home-based palliative caregiving and the organizational structures that ultimately provide support and services to caregivers at home. The health care system in Canada is in a state of flux that has not seen for many decades. While the visions

for a reformed health care system may hold promise, thus far, there has been little evidence that widespread restructuring and cost containment measures have solved the problems facing the health care system (Burke & Stevenson, 1998). The findings from this study suggest that reforms have resulted in a greater burden of care being shifted onto the shoulders of caregivers. This study, along with a handful of other Canadian studies (Anderson & Parent, 1999; Anderson, Tang, & Blue, 1999; Armstrong & Armstrong, 1996), adds voice to the call to critically examine the effects of health care reform on the nature, quality, and provision of health care.

Medicalization of Home-Based Palliative Care

The home is often thought of as a place where we can be ourselves, where family and friends gather in a familiar environment to share in intimate and private times (Arras, 1995). It is a setting far removed from the "busyness" of the outside world where we can partake in the rituals of everyday life and are at liberty to be ourselves (Ruddick, 1995; Rybczynski, 1986). In contrast, the hospital is often conceptualized as a depersonalized setting where rules, hierarchies, bureaucratic structures, and biomedical models dominate (Field & James, 1993). Hospitals are thought of as places of insecurity, discomfort, and intrusion that demand compliance and conformity (Dunlop, et al., 1989; Lubin, 1992; Ventafridda, et al., 1989). When these settings are juxtaposed, it is not surprising that the home setting would be perceived as an ideal environment for dying to take place. The stories caregivers shared with me throughout this study helped me to understand the important and meaningful nature of caregiving when it is provided at home. These same stories also made me realize that dying at home can erode the very things that many people

find important: privacy; the ability to self-determine and control one's own environment; and the capacity to be oneself. As with most contrasts, there are notable exceptions, namely, homes with few homelike virtues and hospitals with various domestic amenities. However, findings from this study suggest that stereotypical images of home may distort the assessment of the extension of health care services into the home.

Given the changes that occur when palliative care is provided at home, it is surprising that the extension of health care services into the home has progressed with relatively little systematic examination of the implications. It is tempting to assume that care at home provides families with greater control over their lives than does care at a hospital (Collopy, et al., 1990). As I have already suggested, institutional care has been predominantly driven by the biomedical model, a Western approach to medicine that focuses on disease and is reductionistic in nature (Dudgeon, 1992). The biomedical model has been viewed as incompatible with palliative care because it focuses on cure, is heavily influenced by the Cartesian dualistic worldview [109], and ignores the philosophical and existential issues involved in dying and death (Capra, 1982; Dudgeon; Schipper, 1991). Biomedical approaches are underpinned by an assumption that health care professionals (mainly physicians) hold legitimate authority and expertise over patients and families and by an assumption that the disease and physical aspects of care are most important (Armstrong & Armstrong, 1996; Sutherland & Fulton, 1994; Zaidi, 1994).

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[109] The philosophy of dualism purported by Descartes' proposes a sharp division between the reality of the mind or soul, and that of the matter or body (Capra, 1982). These divisions have resulted in an emphasis on human body mechanics in isolation of the psychosocial, spiritual, environmental, and historical contexts of terminal illness (Capra; Gaarder, 1996).

In contrast, palliative care approaches are based on a fundamental belief that the patient and family are experts with regard to what constitutes their own health and the philosophies inherent in palliative care reflect the value of attending to each of the physical, psychosocial, and spiritual domains of care (CPCA, 1995; Health Canada, 1989; Jones & Pegis, 1994; Lamers, 1995; Victoria Hospice Society, 1998). Home-based palliative care, then, is appealing because of its intended moral good to maintain holistic and personalized care in an environment that is free from the influences of biomedicine. Yet, the findings show that biomedical influences may pervade the homes of caregivers, such as was the case for many of the participants in this study.

In keeping with the tendency toward medicalizing community care (Chappell, 1997; Di Mola, 1997; Kaye & Davitt, 1998), there has also been an increasing tendency, over the last number of years, toward the medicalization of palliative care. As some have argued, this trend may be rooted in an attempt, mainly by palliative care physicians (and some nurses), to gain legitimacy within mainstream biomedicine (James & Field, 1992). Some authors have vehemently argued that palliative care physicians need to have a more formal status within medicine so that the rationality and scientific credibility of their practice is recognized (Toscani, 1991). Not surprisingly, there has been a perceived need within palliative medicine to subject palliative care to rigorous scientific scrutiny and to develop a scientific basis for the discipline (Schipper, 1991). Although developing scientific knowledge for the discipline has been largely intended to improve the quality of care for the dying, James (1992) cautions that an over-reliance on methods that are dependent on

assumptions of measurable outcomes, for example, may limit the development of other equally credible knowledge in palliative care. An increasing emphasis on the development of knowledge that is valued by mainstream biomedicine is one factor that has contributed to the medicalization of palliative care (James & Field, 1992) and, therefore, the medicalization of home-based palliative care.

One of the major concerns with the medicalization of palliative care is its potential to subvert the totality of the palliative care experience in favour of the more traditional biomedical emphasis on physical interventions (Stacey, 1989). Although Seale (1991c) found that dying patients involved with palliative care programs received fewer medical interventions compared to those involved with conventional care systems, findings from this study and another (Johnson, Rogers, Biswas, & Ahmedzai, 1990) suggest that the physical aspects of care sometimes override other equally important issues. Objectivist, reductionistic approaches that focus on physical care and that privilege symptom control, however, fail to recognize the complexities of the home care experience. Emphasis on symptom management stems from a belief that pain, for example, is the most common concern of families in palliative care; unless pain is controlled, the dying patient cannot maintain meaningful activity and communication (Berry & Lynn, 1993; van Bommel, 1993), an issue expressed by the providers in this study. It is indisputable that relief from distressing symptoms is essential for maintaining quality of life. But, an emphasis on symptom management, at the expense of equally important psychosocial, ethical, or existential concerns, implies a determinate and univocal significance (Bernstein, 1988), and provides an almost fixed and ultimate framework for delivering palliative

care. Such an approach leaves little room to recognize the plurality, diversity, and subjectivity of the families' experiences with home-based palliative care.

Siebold (1992) points out that the introduction of technology into the area of palliative medicine and hospice care have also contributed to the medicalization of palliative care. Somewhat distinct from the hospice ethos where palliative care has historically been viewed as providing "high touch versus high tech" care, more high tech and "hospital like" services are now being provided to palliative care patients in their homes (Kaye & Davitt, 1998). For example, in my interviews with providers, I was told of instances where procedures that were previously restricted to the hospital, such as giving narcotic analgesics by "IV push[110]", were performed in the home by highly skilled "crisis management" nurses. Haddad (1992) warns that the transfer of such procedures and the associated technology into the home can increase caregiver burden as family members are expected to assess when such procedures are needed or are faced with performing them. The increasing use of technology in the home raises many policy questions that have yet to be addressed, including issues of privacy, the development of technical standards, and the extent to which family members should be expected to use such technology (MacAdam, 2000). While there continues to be debate about the extent to which technology will ultimately influence the provision of care in the home, some ethicists and palliative care scholars warn that the tendency toward medicalization and technologization will most certainly shape families' experiences with home care and, in all likelihood,

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[110] The term "IV push" is frequently used by practitioners to describe the action of taking a medication and delivering it directly into a vein by a needle in order to promptly relieve distressing symptoms.

further contribute to a loss of the founding ideals upon which palliative care is based (Arras & Neveloff-Dubler, 1995; Field, 1994).

One of the future challenges for the palliative care movement will be to consider how hospice programs will be able to remain aligned with their founding principles, challenging not just the authority of mainstream biomedicine but also the societal values that have been informed by the biomedical model (McNamara, et al., 1994). Some time ago, Seale (1989) and Abel (1986) warned that the initial ideals and high standards originally proposed by hospice organizations may be difficult to sustain over time. Singleness of vision, an intensity of purpose, and a narrowness of focus, elements that initially helped palliative care to thrive, may now be counterproductive as palliative care becomes increasingly absorbed within mainstream health systems (James & Field, 1992). As hospice programs emerge in an institutional pattern and are influenced by biomedicine, the complexities and challenges of maintaining the founding ideals set forth by the modern palliative care movement will inevitably increase as these ideals collide with the beliefs of mainstream biomedicine. It seems that an understanding of these essential tensions is urgent if hospice ideals are to survive, and if palliative care programs and mainstream health care systems are to work together to promote effective and quality health care for those at the end-of-life and their families.

Summary

In this chapter, I have endeavoured to situate the findings from this study into a broader context, discussing how the discourses of choice, the influences of health care reform, and the medicalization of home-based palliative have shaped and

organized the provision of palliative care in the home. In order to create a system of care that respects and honours the choices and needs of family caregivers and that does not exploit their obligations to care, we need to consider a path forward that offers direction for changes in the ways in which we support family caregivers faced with providing care at home. In the next and final chapter, I suggest such a path forward, offering conclusions based on the study findings and explicating recommendations for practice, education, administration, research, and policy development.

CHAPTER EIGHT:

THE PATH AHEAD: CONCLUSIONS AND RECOMMENDATIONS

The overall goal of this study was to contribute to an understanding of the social context of home-based palliative caregiving. I entered this study believing that an understanding of the broader social contexts in which palliative home care is situated would help to create knowledge with which to influence health care decisions and policies in the area of home care for the dying. I also believed that methods previously used to examine palliative home care were unlikely to uncover some of the broader structures and processes that inherently influence and shape the individual experiences of family caregivers. This study, employing the method of ethnography informed by critical perspectives, has extended existing knowledge regarding the nature and organization of home-based palliative care. In this chapter, I intend to draw on the analyses of the study data to explicate a path ahead, highlighting some of the conclusions I have reached and posing some recommendations for practice, education, administration, research, and policy development.

Conclusions

Through this research, I have come to understand home-based palliative caregiving as much more complicated than typically represented. Under ideal conditions, home-based palliative caregiving would result in life-enriching experiences, marked by negotiated decision making, careful consideration of caregivers' needs, respectful interactions with health care providers, and equitable access to health care. However, a number of factors stemming from idealized

assumptions about dying at home and the contexts of health care provision resulted

in some caregivers feeling "pressured" to provide home care, and consequently, left

some of them feeling that their obligations to care were exploited by the health care

system. Recent shifts toward moving the provision of health care closer to home not

only changed some of the caregivers in profound ways but also transformed the

home setting into one that was infused with the influences of biomedicine. Long-

standing philosophical divisions between mainstream medical practice and the

ideals upheld by palliative care have inhibited the development of coordinated and

consistent systems of palliative care that could ultimately benefit both patients at the

end-of-life and their caregivers.

Based on the interpretations of data, I put forward the following conclusions:

1. The decision to provide palliative care at home is influenced by powerful media images and sociocultural expectations that idealize the home as the most appropriate setting for dying and death to occur. Providing palliative care at home is not a clear "choice" for many caregivers nor is it always preferred. Instead, caregiving is an obligation stemming from caregivers' desires to uphold the preferences of patients to be cared for at home;

2. The idealization of dying at home is reinforced by health care personnel who sometimes uncritically apply their assumptions about dying at home onto caregivers. These assumptions are obscured by the ideologies of care effectiveness and a desire to uphold the rights and choices of those who are dying. The health care system, driven by cost containment and efficiency models, promotes and sustains the idealization of dying at home;

3. Caregivers' obligations are reproduced by the liberal ideologies of individualism, neo-conservativism, and self-care and are based on assumptions that caregivers freely choose to and are available to provide home care;

4. The reinforcement and reproduction of the idealization of dying at home results in some caregivers feeling "pressured" to conform to idealized notions, and can result in caregivers feeling exploited and taken advantage of by the health care system;

5. When palliative care is provided at home, the home is often re-created into a hospital-like setting. Homes become reconstructed as sites for health care provision and caregivers reinvent themselves to become "nurse-caregivers". Care at home is profoundly shaped by the influence of biomedical models of health care;

6. Health care restructuring, reforms in institutional and community-based care, and concurrent policy changes directly shape the context of home-based palliative caregiving and result in reduced access to health services for some caregivers;

7. Home-based palliative care is mediated by organizational contexts. Significant gaps exist between the ideal of a coordinated and continuous system of palliative care and the actual implementation of such a system. These gaps result from a lack of a coordinated regional approach to palliative care;

8. The goals of mainstream health care that focus on cure, treatment, and cost efficiencies are incongruent with the goals of palliative care that focus on comfort, support, and care effectiveness. These philosophical divisions have created tensions that thwart the progress of palliative care development in the health region. A climate of "political correctness", as well as a perceived struggle for control over palliative care services, has inhibited health care agencies from working collaboratively to develop a regional system for palliative care; and

9. Access to quality palliative care at home is inequitable across the region. Equal access is based on whether families can afford the costs associated with home care. Women and marginalized populations are particularly disadvantaged, as are double-income dependent families.

Recommendations

There is no simple "recipe book" solution to many of the issues brought

forward in this investigation. The provision of palliative care at home is a complex

social phenomenon that enhances life for many, but threatens to erode the

conditions that tend to foster important social goods and opportunities for others.

The stories that caregivers shared with me throughout this study extend

understandings about the important and beneficial nature of home-based palliative

care. These same stories also demonstrate the profoundly difficult nature of

caregiving when palliative care is provided at home. As the findings of this study

show, home-based palliative care provides many positive opportunities for family

caregivers; it can also, however, provide the means for exploitation. To maximize

the former and minimize the latter, we must begin to think more critically about the

phenomenon of dying at home in order to develop a path ahead that best serves the

needs of all concerned.

The recommendations that follow are grounded in my commitment to use

research as a way to influence practice, health care decision making, and policy

development. In keeping with my praxis orientation, the recommendations

presented here reflect my intent to explicate those factors that may contribute to

changes in the ways in which we conceptualize home-based palliative caregiving

and the directions we take in supporting family caregivers in the future. I begin by

discussing how promoting critical consciousness might provide a more enlightened

approach to care. From there, I consider the ways in which we might begin to think

about expanding the choices for caregivers. A set of recommendations for the

development of a comprehensive and coordinated system of palliative care is

presented, and directions for further research and for policy development are also

discussed.

Promoting Critical Consciousness

One of the most striking interpretations in this study was the way in which

taken-for-granted assumptions underpinned the provision of home-based palliative

care. For example, assumptions existed about the (a) "idealness" of the home

setting as the site for palliative care, (b) choices of caregivers, (c) equal access to

quality palliative care, and (d) influences of biomedicine. These operated, often simultaneously, to influence caregivers' experiences in important ways. These assumptions were embedded at an individual level, a system level, and a societal level. Therefore, it seems clear that if we are to enhance the care provided to family members in the future[111], there is a need to promote a critical consciousness in nurses[112], decision and policy makers, and the public.

I suggest that promoting critical consciousness is primarily an educative process[113] that applies equally to student and practicing nurses, decision and policy makers, and the public. The primary goal of consciousness raising is to expose hidden assumptions in order to make visible those beliefs and values that colour our perceptions of the world (in this case, home-based palliative care). In uncovering these assumptions, past actions and events can be reinterpreted from a new vantage point and new possibilities for how we conceptualize the world can be explored. Emanating from transformative learning theory, critical consciousness is primarily characterized by self-awareness and insight into the ideologies that sustain

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[111] In Chapter Three, I highlighted the problematic nature of engaging caregivers in a process to critically reflect on their positioning as caregivers. Similarly, I argue that engaging caregivers in a process to critically examine assumptions underlying their caregiving is not a morally neutral position. It is for this reason that I direct my recommendations at nurses, decision and policy makers, and the public.

[112] Given the interdisciplinarity of health care practice, it is important to recognize that all health professionals (e.g., physicians, counsellors, HSWs) could benefit from processes that promote critical consciousness. I focus here on nurses because nurses spend a large majority of time with families in palliative care. At the same time, the strategies proposed here could be applied to working with any discipline, acknowledging that each discipline has its own culture and context that would need to be considered in the application of these strategies.

[113] While I acknowledge that pedagogical efforts aimed at promoting critical consciousness can themselves become authoritarian instead of transformative and liberating (Lather, 1991), I believe such approaches have utility if educators are aware of these inherent risks. I also submit that critical consciousness be fostered in all nurses, whether they are front-line nurses, educators, administrators, academics, researchers, or policy analysts.

our thoughts and actions (Bevis & Watson, 1989; Diekelmann, 1988; Lather, 1991; Moccia, 1988b; Oiler Boyd, 1988). Therefore, the learning process emphasizes an active intent to move towards reflectivity, involving an enhanced awareness of one's beliefs and a critique of the assumptions underlying them (Daloz, 1986; Mezirow, 1981/1991). Clark (1993) contends that transformational learning processes produce lasting changes in the ways in which learners view the world indicating that people are "different afterward, in ways both they and others can recognize" (p. 47).

Because assumptions and beliefs are generally what we perceive in life as "truths" (Hoskins & Stypka, 1992), it would stand to reason that any educative encounter should be directed toward a critical questioning of our own beliefs and assumptions. Specifically, there is a need to engage student and practicing nurses, decision and policy makers, and the public in a process to (a) illuminate the assumptions underpinning home-based palliative care; (b) question the assumptions and the structures that support it; and (c) create new ways of thinking about end-of-life care at home. I argue that such ends can be accomplished by promoting processes such as critical thinking, questioning, and open dialogue about the issues.

Critical thinking is a "careful and deliberate determination of whether to accept, reject, or suspend judgment about a claim" (Moore & Parker, 1986, p. 4). Brookfield (1987) maintains that critical thinking involves identifying and challenging assumptions that are taken for granted, recognizing how context influences understandings and perceptions, imagining and exploring alternative ways of thinking, and engaging in reflective skepticism by questioning claims to universal truths or ultimate explanations. *Questioning* is an important part of critical thinking

as it invites a reconsideration of what has previously been observed, experienced, valued, or assumed. Through posing critical questions, we can invite "learners" to observe and reflect on experiences and taken-for-granteds, and to reconsider their perceptions, interpretations, and actions (Hoskins & Stypka, 1992). Facilitating *dialogue* opens the possibilities for familiar, everyday experiences and actions to be viewed from another's perspective. In addition, dialogue provides the opportunity for the processes of questioning and critical reflection to be expanded.

While the intended outcomes of this process are similar (e.g., to raise critical awareness), the strategies for working with each group (and sometimes with individuals within a group) differ. Indeed, promoting critical consciousness is not a straightforward endeavour. Ultimately, the context of the learning environment (i.e., nursing schools, health districts) influences how learning occurs and how it is enacted. In other words, even though the theory driving my recommendations is applicable to working with all groups, the strategies for working with these groups would differ. Therefore, I am organizing my recommendations here to first address nursing curricula and then educational programming for practicing nurses. I then discuss specific strategies for promoting critical consciousness in decision and policy makers and with the public.

Nursing Education and Nursing Practice

In order to enhance the care provided to family members in the future, there is a need for nurses to recognize the assumptions that underpin home-based palliative care, to understand the influence of those assumptions, and to consider the interests being served by dominant ideologies. Hayes (1997) argues that an

examination of those things we tend to take for granted is essential in informing the ways in which we work with and plan health care for families. Transformational learning involves shifting the focus of educative encounters from acquiring facts and skills to creating opportunities for learners to make meaning of particular experiences[114] (Hartrick, 1999). Purposeful self-reflection resulting in consciousness raising, however, does not take place without careful planning.

In educational settings, learning activities for *student nurses* could be designed to incorporate critical thinking, questioning, and open dialogue[115]. Several "experiential" activities could be incorporated into nursing curricula. For instance, students could complete a reflective writing exercise promoting self-examination and critical assessment of their own values and beliefs about home care for the dying. Then, case studies that present "disorienting dilemmas" (Hartrick, 1997, p. 20) in palliative home care could be used to invite students to reflect on the congruence between their espoused values and their values-in-use (Street, 1992). Learning activities, including the use of poststructural concepts of narrative and discourse,

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[114] I am not suggesting here that objective forms of knowledge be dismissed. The complexity of human experience requires the recognition that empirical, relational, and experiential knowledge forms can be enacted simultaneously (Stajduhar, Balneaves, & Thorne, 2001). Indeed, given what I have learned about home-based palliative caregiving through this research process, I believe that knowledge derived from scientific studies can play a central role in learning activities.

[115] There are three approaches to death education that have been typically employed in nursing: integrating material throughout the curriculum; offering an elective course in palliative care; or, requiring "credit courses" (e.g., eight hours of palliative care instruction) as a compulsory component of a nursing program (Degner & Gow, 1988a). A longitudinal, quasiexperimental study conducted by Degner and Gow (1998b) indicated that nurses who were required to take a credit course had lower levels of death anxiety, were more comfortable in providing care to the dying, and had a better attitude about death and dying. These authors advocate for revisions to nursing curricula that include a required credit course in palliative care. I would agree with the authors in that I believe that an elective course and/or a credit course in palliative care should be provided as part of a comprehensive nursing education program. Some studies have indicated, for example, that student nurses (and practicing nurses I would suggest) feel inadequately prepared in caring for dying patients (Beck, 1997). Inevitably, most nurses will encounter dying and death in their practices. Thus, it seems reasonable to suggest that some focused education in this area would be helpful in preparing nurses for their practices with the dying and their families.

could be used to help students explore dominant ideologies shaping home-based palliative care. Of course, any learning activity that involves engaging students (and practicing nurses) in a process of critically questioning their own values, beliefs, and practices, has the potential to be anxiety producing, and may result in anger and resistance. For this reason, a safe classroom atmosphere must be created and clear lines for discussion must be established.

While the intent of these strategies (i.e., promoting critical consciousness) is the same regardless of the group at which the strategies are directed, the actual process of fostering critical consciousness in *practicing nurses* will be dependent on the organizational context in which they work. Many studies have documented the increasing demands placed on front-line nurses, including increased workloads and a concurrent reduction in continuing staff education (see, for example, Reimer-Kirkham, 2000; Rodney, 1997; Varcoe, 1997a). Current moves to contain health care costs, combined with the nursing shortage, certainly make it difficult to develop and implement comprehensive continuing education programs in the practice setting. At the same time, there is a pressing need to incorporate palliative care education into the practice setting, especially in light of caregivers' experiences with institutional care and with paternalistic and reductionistic health care practices in the home[116].

Both formal and informal strategies to promote critical consciousness are needed for practicing nurses. Educational sessions fostering open dialogue about

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[116] The strategies recommended here could be equally applied to HSWs. Although I have already mentioned this, I think it is important to re-emphasize the point because HSWs also play a key and ongoing role in interacting with family caregivers.

the challenges of home-based palliative care could provide opportunities for nurses to question current practices and develop an appreciation for the complexities and contradictions inherent in the provision of care at home. Workplace teleconferencing through professional nursing associations could provide nurses with opportunities to exchange "lessons learned" in their practices with families in palliative care. Facilitators must be well versed in using transformative learning strategies, be knowledgeable about the issues, and have the ability to create safe and open learning environments in order to initiate frank but respectful discussions. The facilitator must also be open to having his or her own assumptions challenged by learners.

Although I suggest these formal strategies, I believe that informal approaches have a much greater potential to promote critical consciousness. Based on my previous practice as a clinical nurse specialist, I find that "real time" practice issues provide an excellent opportunity for learning. The ability to engage with nurses in a problem solving process involving an actual situation that is relevant to their practice brings learning "to life" and almost always allows for discussion of the ways in which values, beliefs, and assumptions (including my own) influence nursing practice. Although I recognize that it is not always possible to be present when these "learning moments" occur, I believe that, with support from administrators, clinical educators and clinical nurse specialists can provide leadership in developing palliative care nursing "experts" in practice settings, experts who can work to foster ongoing critical consciousness with their peers.

For example, my approach as a clinical nurse specialist has been to spend a concentrated amount of time with a group of front-line nurses, gaining their respect and trust, and creating a non-threatening learning environment. Inevitably, most practice settings have informal "clinical nurse leaders" who are respected by their peers. I purposefully seek out these leaders, knowing that if I gain their trust and respect, I will have a greater likelihood of establishing effective relationships with their peers. In my experience, there have always been two or three nurses within a particular practice setting who are keenly interested in palliative care. I work with these nurses, helping them to develop palliative care "skills" and their capacity to promote critical consciousness[117]. Over time, I have found that I am slowly able to reduce the amount of involvement I have in that particular setting as the clinical leaders become more adept. My role then becomes secondary and takes on a maintenance function. I was once asked at a job interview what I thought was the most important role of the clinical nurse specialist. I responded by saying it was to "do myself out of a job". I have always held to this belief in my interactions with front-line nurses.

The process of involvement I have proposed through my example is not intended to suggest that this is the only way to promote critical consciousness in the practice setting, nor is it to suggest that these "steps" progress in a linear fashion. However, I believe there is an urgent need for front-line nurses to have this kind of

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[117] The ongoing development of my own critical consciousness has resulted from educational exposure to critical theoretical perspectives, and from my relationships with mentors who have challenged me to think in critical ways and have "role modeled" critical thinking, questioning, and dialogue. I use this learning as a way to role model critical consciousness in my interactions with front-line nurses.

concentrated, ongoing support. This could be facilitated in two ways. First, advanced nursing practice roles in palliative care must be expanded, particularly in light of the recent changes to the clinical nurse specialist role in the region where this study was conducted. Second, graduate education programs that prepare advanced practice nurses need to emphasize the knowledge and skills required to work with front-line nurses. Too often I have observed or heard about situations where the relationships between front-line nurses and clinical educators or specialists are marked by paternalistic and hierarchical approaches. If, as a profession, nursing desires to develop practitioners with critical thinking and reflection skills, it must begin to reconsider how to prepare advanced practice leaders. Advanced nursing practice programs have importantly focused on developing the knowledge needed for program planning and evaluation, and for consultant, clinical practice, and research roles (Barron, 1989; Glass, 1993; Hamric, 1992; Koetters, 1989; Naylor & Brooten, 1993; Sparacino & Cooper, 1990). However, in my experience, such education does not typically include explicit discussion on how to engage with front-line nurses. Yet, this element of the advanced nursing practice role is vital if nurse leaders are to effectively and respectfully foster critical consciousness. Working with nurses at the front-line is complex, requiring constant negotiation and re-negotiation of relationships. Graduate programs that prepare advanced practice nurses must not assume that all educators or specialists, by virtue of their previous nursing practice experience, will automatically know how to engage with front-line nurses in an effective and respectful manner.

At a broader level, any educational strategy designed to promote critical consciousness in student and practicing nurses must involve consciousness raising about the contexts in which health care is delivered. As demonstrated in this study, several factors, beyond the individual palliative care situation, influenced and shaped caregivers' experiences. Taking an individualistic view[118], divorced from the larger social contexts in which they are embedded, serves to decontextualize (Thorne, et al., 1998) caregivers' experiences. Thus, both the immediate environment in which health care is delivered and the larger social context must be considered (Varcoe, 1997b). An examination of the social, political, historical, and economic contexts of health care provision should be included in consciousness raising activities so that nurses working with families in palliative care can begin to critically examine and appreciate the contexts that influence their practices and the experiences of caregivers. Stevens (1989) submits that engaging in liberatory dialogue toward raising consciousness can set the stage for informed collective action towards change. Such an action approach is increasingly consistent with preparing nurses to

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[118] While individual attention is not in itself a problem, it does contribute to the tendency of society and the health care system to underutilize or misutilize professional nursing personnel (Chopoorian, 1986). As such, nurses are restricted from broader applications of their knowledge that may have the potential to influence social, political, and economic policies related to health. Additionally, an emphasis on individual-level concerns inhibits nurses from understanding the complexity of those forces that shape the behavior of populations, and provides little opportunity for nurses to understand the larger contexts that influence health and their role in facilitating change at a broader sociopolitical and economic level. Moreover, without this understanding, nurses may have difficulty promoting change in an effective and systematic manner (Butterfield, 1990). Without a broader view of the focus of nursing's concerns, nurses have little influence over social structures that may constrain a person's health (Chopoorian). Cummings (cited in Butterfield) reminds us that both individualistic approaches and social approaches are complementary. As such, I suggest that the individual and social mandates of nursing must be integrated.

enact the larger social practice mandate of nursing[119] (Moccia, 1988a; Starzomski &

Rodney, 1997; Williams, 1991).

Working with Decision and Policy Makers

In the last decade there has been increasing interest by decision and policy

makers to use research findings as a way to inform health care decision making and

policy development (Usher, 1998). Rist (1994) maintains that research findings can

be a powerful tool to influence the decision-making and policy process. However, as

Jonathon Lomas (cited in Usher) contends, "the lack of communication between

policymakers and researchers, as well as a poor understanding of each others' work

environments, are key detriments to the effective use of research in health policy"

[and decision making] (p. 19-20). Therefore, if nurse researchers are to use

research findings to foster critical consciousness and influence decision making and

policy development, they must design appropriate communication strategies and

develop an understanding of the organizational contexts in which decision and policy

makers reside.

As a way to begin, nurse researchers could develop a theoretical

understanding of the processes used for health care decision making and policy

development. For example, understanding approaches to public policy and policy

formation and implementation (see, for example, Howlett & Ramesh, 1995) could

help nurse researchers understand the policy cycle and how their research findings

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[119] Moccia (1990) reminds us that "nursing enjoys a unique and privileged potential to bridge the patriarchal separations between the public and private worlds" (p. 74). In other words, by the nature of their close proximity to individuals who receive care, nurses are appropriately, effectively, and knowingly positioned to influence the larger social mechanisms that influence individual health.

might be used to influence the policy-making process[120]. Recognizing decision

making and policy development as an inherently political process imbued with

political agendas and competing interests (Fierlbeck, 1997; Zaidi, 1994), and

keeping abreast of the important health issues facing Canadians, will also assist

nurse researchers to gain credibility with decision and policy makers and facilitate

the use of their research findings to foster critical consciousness. Moreover, the

power of networking cannot be overemphasized. Involvement in regional, provincial,

and national committees, attendance and participation at health board meetings, and

developing relationships with key stakeholders, are strategies that nurse researchers

(and nurses in general for that matter) can use to educate decision and policy

makers and to create a critical awareness about ongoing issues related to home-

based palliative caregiving[121].

Nurse researchers concerned with influencing health care decision making

should also consider active involvement of decision and policy makers in their

programs of research. Decision and policy makers have unique perspectives to

bring to the research process. Most importantly, they bring a pragmatic perspective

to the research enterprise that contributes to ensuring research is relevant and

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[120] Drawing on critical theoretical perspectives to influence decision making and health policy development might necessitate challenging the conventional policy cycle in order to bring forward issues that are taken-for-granted (e.g., home-based palliative caregiving). I believe that bringing forward such issues requires a great deal of "political" skill. One way that nurses can learn these skills is to get involved with groups (e.g., The Canadian Coalition for Caregivers) that have experience in political advocacy. At the same time, I do believe that understanding the "conventional" policy cycle has merit.

[121] I argue that until recently, there have been few Canadian nurse researchers who have developed explicit mechanisms by which to interface with decision and policy makers. Yet, it seems to me that if research findings are to be applicable and relevant and used to inform health care decision making, then it is essential that collaborative working relationships be developed. While I acknowledge there are several factors that ultimately influence the extent of engagement between researchers and decision/policy makers, I nonetheless believe it is an important goal for researchers to pursue.

applicable to the decision and policy making world. Inviting decision and policy makers to be involved with research also provides opportunities to foster critical consciousness, facilitates "buy-in" to the research findings, and can expedite research transfer and uptake to decision and policy maker audiences.

Ultimately, ongoing interaction with decision and policy makers is key to fostering critical consciousness. However, this might not always be possible or appropriate. Alternate strategies for communicating are also needed to heighten awareness of the issues and to promote critical thinking. I believe that if investigators are committed to using research findings to raise consciousness and, ultimately, to inform health care decision making, they must find ways of disseminating their research findings to decision and policy makers beyond publication in scientific journals[122]. A survey commissioned by the Social Science and Humanities Research Council of Canada (cited in Canadian Health Services Research Foundation, 1988) found that only 6.7 percent of the average researcher's time is spent on communicating results outside of the academic community. Yet, it is paramount that communication and dissemination strategies be carefully planned if investigators are to reach decision and policy maker audiences. Alternate strategies for communicating with decision and policy makers could include: (a) publication in trade and administrative journals; (b) utilizing the internet to disseminate findings; (c) writing short executive summaries in language that is geared toward decision and policy makers; (d) attending and presenting at decision

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[122] I am not trivializing the importance of disseminating knowledge through publication in scientific journals. My point here is that additional strategies are required depending on the audience a researcher wishes to reach.

and policy maker related conferences; and (e) engaging the media in assisting to disseminate findings. Nurse researchers should also consider budgeting for a communications consultant to assist them in their communication and dissemination plans.

Expanding Public Perception

Strategies directed toward raising public consciousness are required in order to present a more realistic portrayal of home-based palliative caregiving. Since the media played a powerful role in shaping and reinforcing caregivers' assumptions, it would stand to reason that appropriate media messages in the form of broadcast media for public television (see, for example, Curtis & Symansky, 1997; Curtis, 1999) could be a useful strategy in promoting critical consciousness about home-based palliative caregiving. Of course, I am under no illusion that this strategy alone would suffice. Family caregiving is invisible and making the "invisible visible" is challenging, especially when many Canadian citizens do not see caregiving as an issue that is directly relevant to them (i.e., they are not currently caregivers) (Canadian Coalition for Caregivers, 2000). Nevertheless, the media can be a powerful tool if issues are reported accurately and sensitively. For example, a January 2000 edition of Maclean's magazine featured a compelling and well-reported lead story on family caregiving (Chisholm). Stories such as this, along with public forums, newspaper articles, and promotion of family caregiver support networks, can also be used as strategies to engage the public in a consciousness-raising process. However, any public awareness strategy must be particularly sensitive to palliative caregivers given the emotional repercussions that can

potentially result from pushing critical reflections (see Chapter Three). For instance, public forums are often an appropriate strategy for debating and critiquing health issues but, in palliative care, such a strategy must be carefully planned with due consideration given to including caregivers in the planning process[123]. I would re-emphasize that extreme sensitivity is required with these approaches. Instead of using a more confrontational learning activity as I suggested using with nurses, public awareness campaigns may be best directed toward promoting a well-balanced discussion of the benefits and burdens of home-based palliative care.

In summary, promoting critical consciousness is not a straightforward process and the implementation of the recommendations and strategies I have proposed requires careful planning, considerable effort, and astute political insight. Notwithstanding the challenges, what I have recommended here provides a place from which to start re-imagining the ways in which we conceptualize home-based palliative care. Identifying and challenging assumptions, and imagining and exploring avenues for new ways of thinking, have the potential to uncover and minimize hegemonic health care practices. Given that several hidden assumptions profoundly influence caregivers' experiences, it is increasingly important to seriously consider, and put into place, mechanisms to support nurses, decision and policy makers, and the public to gain a better understanding and critical awareness of the constraints imposed on family members when they provide palliative care at home.

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[123] As I suggested in Chapter Seven, many caregivers are often too exhausted or are unable to participate in such planning processes. However, I have also met some caregivers who have completed their caregiving and who are very active and vocal about the issues facing home-based palliative caregivers. These are the caregivers I suggest could be invited to participate in planning public awareness campaigns.

Expanding Choices for Palliative Caregivers

One of the salient findings of this study was the extent to which family caregivers are able to "freely" choose to provide home-based palliative care. As I mentioned in Chapter Seven, there is a need to continue to search for the most appropriate ways in which to support caregivers who wish to provide home care. At the same time, there is also a need to appreciate, and take seriously, the limits of what can or should be expected from caregivers. Caregivers who participated in this study tended to report life-enriching experiences when their decisions were negotiated with the patient. Conversely, when the caregivers made snap and indifferent decisions, their experiences tended to be life-draining. Almost all of the caregivers made a promise to their dying loved one to provide care at home. This promise created a high degree of distress for many caregivers. Given the complexities inherent in the decision-making process, the factors that influenced caregivers' decision making, and the limited choices that caregivers had for alternatives for care, recommendations directed toward expanding the choices of caregivers are needed. Because the decision-making process is not a straightforward matter for most caregivers but, instead, is imbued with intense emotions and obligations, I begin by considering some possible routes to foster informed decision making as a way to broaden the choices for caregivers. From there, I propose some possible solutions for expanding the range of options for caregivers providing home-based palliative care.

Fostering Informed Decision Making

Making an informed decision and, therefore, an informed choice, implies that the recipients of health care have been given all of the necessary information upon which to base their decisions. In health care, the "evidence" for informed decision making is most typically represented by the documentation of consent. Obtaining patient consent has become a routine part of health care delivery and is the focus of many discussions in bioethics (Edwards & Graber, 1988; Katz, 1995; Thomas, 1983). However, in the area of family caregiving, there has been little discussion of whether family members consent or freely choose to provide care at home. More typically, consent is assumed because family members are already providing home care, even if they are doing so reluctantly.

Issues of informed consent, and therefore, informed decision making, must be considered as they relate to families in palliative home care[124]. Caregivers should be given opportunities to fully understand what home care entails before it can be said that their consent is fully informed. For example, discussions with caregivers should focus on the challenges they might face, the likely strains and stresses of providing home care, the possibility of having to forgo employment and other pursuits outside the home, the impact of health care provider visits on family privacy, and the financial repercussions resulting from home health care provision. I am not suggesting that the informed consent discussion dwell disproportionately on the possible burdens of caregiving but, rather, that discussions should provide a well-

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[124] I recognize that there are inherent problems with the concept of informed consent. I agree with Jaggar (1993) that it may be impossible to fully achieve real-life moral consensus that is fully informed and uncoerced. Like Jaggar, however, I believe that informed consent is a useful ideal and support active disciplinary dialogue aimed at pursing consensus on the issue.

balanced presentation of the likely benefits and burdens of home-based palliative care. At the same time, there is a need to critically consider what caregivers are able and willing to hear. Some of the caregivers who participated in this study, for example, reported that they would not have wanted advanced preparation, information, or discussion about what is involved with palliative home care. Other caregivers recommended advanced preparation and discussion. While research is clearly needed to determine the most appropriate time and ways to prepare and inform caregivers, the ideal of obtaining informed consent from caregivers has merit if approached in a sensitive manner that is respectful of caregivers' needs. Information should be presented and discussed in an honest but sensitive way, keeping in mind the potential for emotional repercussions based on such discussions. Both verbal discussion and written information should be offered to caregivers. For instance, just as some hospice programs give caregivers written information on what to expect when the patient is dying, similar "handouts" could be developed on what to expect as a home-based family caregiver.

In Chapter Seven, I alluded to the problematic nature of decision making and caregiver choice when patients' rights are privileged over caregivers' rights. Without wanting to minimize the rights of dying patients, consideration also must be given to the types of models that can guide health care providers in their attempts to assist families in making negotiated and ethically justifiable decisions. The incorporation of concepts from feminist ethics (see, for example, Sherwin, 1992a; Tong, 1997; Warren, 1992) into decision making discussions may be a starting point. At the very least, accommodation and mediation of all legitimate interests, rather than the

exclusionary pursuit of the patient's interests (Dubler, 1990; Dubler & Marcus, 1994),

ought to be considered when thinking about decisions regarding end-of-life care at

home. The interests of caregivers, who can experience substantial burdens and

who often put their lives on hold, must be taken into account. When caregivers'

legitimate interests conflict with the interests of patients, providers should seek some

mutually acceptable accommodation or compromise, possibly by mediating

discussions between the patients and caregivers. Of course, such mediation

requires extreme tact, skill, and sensitivity, and providers who work in palliative care

should be educated in mediation and conflict management approaches.

There will inevitably be situations in which agreeable accommodation cannot

be reached. I agree with Arras and Neveloff-Dubler (1995), who suggest that there

is

> … no reason why caregivers threatened with the near-extinction of their
> personal lives must always be sacrificed to the desires or best interests of the
> patient…. In a just society that insisted on the continuing care and treatment
> of [palliative care patients], families would not feel pressured or made to feel
> guilty for wishing to avoid what they reasonably anticipate to be an
> unsupportable burden (p. 21).

Family caregivers must also be given the right and choice to change their minds

about home-based caregiving, and should not be subjected to judgements from

providers or others for doing so. The decision to provide home care must be one

that is negotiated and re-negotiated, and providers should be encouraged to

continually assess both the needs of patients and caregivers. Indeed, discussions

with patients and caregivers should be initiated by providers early in the disease

trajectory to either prevent caregivers from making promises to patients or to

suggest to caregivers and patients that promises to care might change as the

disease progresses. In other words, patients and caregivers should be counselled at the outset that any arrangements for palliative home care should be considered provisional and that, even with support and encouragement from providers, it may not always be possible to maintain the dying person at home. This approach gives caregivers a kind of "moral escape hatch" (Arras & Neveloff-Dubler, p. 21) that may help in reducing the guilt associated with breaking the promise to provide palliative care at home. Therefore, decisions about palliative home care should be based on attempts to obtain genuinely informed consent from caregivers and should be explicitly renegotiable throughout the course of the patient's care.

Expanding the Range of Options for Palliative Caregivers

A central point of concern arising from this study was the lack of appropriate and available locations for palliative care provision beyond the home setting. Caregivers in this study essentially had two options beyond home care: care in acute care or care in an inpatient palliative care unit. However, as I have previously discussed, these care locations were not always appropriate nor were they always available. As such, the recommendations I propose relate to improving the care provided in acute care hospital settings and considering alternative options for care.

One of the major issues concerning caregivers in this study was their experiences with institutional care. Indeed, these experiences were a primary reason for caregivers' decisions to provide home-based palliative care. Characterized by paternalistic approaches, and a tendency to depersonalize and decontextualize the experiences of families in palliative care, hospital care was seen as a last resort for many caregivers in this study. In some cases, hospital care was

not viewed as an option at all, even when caregiving became disproportionately burdensome. The experiences that caregivers had with institutional care, particularly acute care, point to an urgent need to improve the care for the dying and their family members in hospital settings. Although I am not suggesting that acute care settings provide the most appropriate site for palliative care, it must be recognized that a large proportion of Canadians die and will continue to receive end-of-life care in hospital settings (Heyland, et al., 2000).

Common recommendations for improving care for the dying in hospital settings include providing palliative care education to hospital staff (Ajemian, 1992; Barnes, Barrett, Weintraub, Holowacz, Chan, & Leblanc, 1993), and advocating for compulsory palliative care education in all health care professional schools (Scott, 1992). Palliative care education has been shown to be a useful mechanism for improving hospital-based care for the dying, particularly in regard to the management of symptoms such as pain (Ferrell, Grant, Ritchey, Ropchan, & Rivera, 1993). Innovative strategies such as computerized education modules, internet web site learning, and distance certificate programs have also greatly enhanced access to palliative care education for hospital staff (Stajduhar & Davies, 1998b). While these strategies have likely helped to improve care for the dying, educational programming and strategies are not a universal remedy. After almost three decades of focused palliative care educational efforts in many health regions across Canada, the care provided to the dying in hospital continues to be problematic. Presumably, health care reform and the nursing shortage have had a major impact on how palliative care is provided in the hospital setting. A better understanding of how

these shifts influence hospital care is desperately needed to determine the most appropriate ways in which to enhance end-of-life care in hospitals. Until research studies such as these are conducted, however, there is a need to consider and implement strategies that have potential to improve hospital-based palliative care.

As I recommended earlier, a clinical nurse specialist, whose sole focus is palliative care, is needed. However, given the regionalization process and the amalgamation of hospital sites in many regions across the country, it may not be feasible for clinical nurse specialists to provide consultation and clinical support in all acute care settings. For this reason, I agree with the recommendation of the Capital Health Region Palliative Care Review Steering Committee (1998a) to implement a palliative care consultation team. Palliative care consultation teams are generally made up of a physician, clinical nurse specialist, and counsellor, each of whom work with health care providers on a consultative basis to minimize the physical distress associated with dying, and to attend to the psychosocial and spiritual needs of palliative care patients and their families (Francke, 2000). Consultation teams in palliative care have been touted for bringing the principles of specialized, integrated palliative care to patients/family members in the hospital at an early stage in the disease trajectory and for reducing in-patient length of stay, thereby reducing health care costs (Bates, Hoy, Clarke, & Laird, 1981; Bromberg & Higginson, 1996; O'Neill, O'Connor, & Latimer, 1992). Such a team approach offers support to front-line providers that is necessary to enhance continuity of care and to improve the care provided to palliative care patients and their families in the acute care setting.

At the same time, I recognize that research conducted on the utility of palliative care teams has been contradictory and that the evaluative studies available suffer from some serious methodological flaws (Francke, 2000). Therefore, any move to design and implement a consultative team approach in acute care must include careful attention to developing an evaluative component. Furthermore, it is unlikely that the strategies I have recommended would be feasible for smaller and rural settings that often do not have the same resources as larger urban centres and that may not have the palliative care population to justify implementation of either an advanced nursing practice role or a consultation team. A centralized telephone "hot-line" that providers can access for expert advice might be one strategy to consider. Clearly though, research is needed to determine strategies that would best meet the needs of smaller and rural communities.

For a number of reasons already alluded to throughout this dissertation, the provision of palliative care in acute care settings may not always be most appropriate. As such, consideration must be given to developing alternative care settings for patients if caregivers exercise their right to not provide palliative home care or if they become too overburdened. Indeed, home care may sometimes pose larger threats to autonomy and privacy than well-designed alternative care settings. Many caregivers in this study indicated that they and the patient would have considered an alternate care setting had it been available to them and if they could be assured the care provided would be sensitive, personalized, and respectful. Thus, apart from improving the care for the dying in acute care hospitals, serious thought should be given to investigating the feasibility of establishing new

institutional structures that serve as an intermediary between the hospital and home. For example, small, free-standing hospice facilities, capable of providing all of the necessary support while looking and feeling more like a home, might provide a meaningful alternative to home care or acute care. Caregivers who lack any decent alternatives between the hospital and home are presently forced to opt for home care even if it seriously compromises their personal lives and their homes. As the findings from this study demonstrate, the choice to provide palliative home care is often reached because of a force of circumstances, such as hospital bed shortages and swift discharge from hospital, or because of the obligations caregivers feel to maintain their promise to patients.

The Capital Health Region Palliative Care Review Steering Committee (1998a) highlighted the need for more inpatient beds for palliative care that are distributed geographically throughout the health region. While I strongly support this direction, simply increasing beds will not likely result in remarkable improvements to the care of the dying (although it will increase choices for caregivers) without the structural backing to support effective and comprehensive palliative care. Furthermore, if the philosophy and principles that drive palliative care are not incorporated into a strategy that proposes bed expansion, it is unlikely that caregivers and patients will consider these beds as an appropriate alternative to home. Accordingly, any plan to increase palliative care beds must have a concurrent plan to ensure that the physical, psychosocial, and spiritual needs of patients and families are adequately met.

To summarize, there is clearly a need to expand the choices for family members providing palliative care. The recommendations presented here suggest strategies for how to begin considering ways to help caregivers to make negotiated, informed decisions about palliative home care while respecting their individual needs. Additionally, I have suggested that care for the dying must be improved in the acute care setting and alternatives for care ought to be considered. Although these approaches are not simple or straightforward, they are, I would suggest, necessary to ensure that the rights and choices of caregivers are respected in a way that best serves human needs and the needs of a compassionate but prudent society.

Towards the Development of a Comprehensive Continuum of Palliative Care

According to the Canadian Health Services Research Foundation (1998), continuity of care is a major issue facing health care systems across Canada. Continuity of care arose as a point of concern for participants in this study. Bureaucratic structures, underutilized and inefficient information systems, multiple care providers, a perceived lack of an overall "coordinator" of care, and ineffective discharge planning were all factors that contributed to discontinuity. Health care planners in the region where this study was conducted recognized the problems with continuity and were planning ways to improve it. At the same time, study findings suggest that long-standing historical issues among health care organizations have created tensions that have inhibited the development of a comprehensive system of palliative care. The recommendations presented here propose strategies for how to

minimize these tensions. On this basis, I then offer suggestions for how continuity of care could be enhanced.

Transcending Organizational Tensions

Chapter Five provided a detailed discussion of how long-standing organizational tensions have inhibited the progression of palliative care development in the health region. Because the effective delivery of palliative care depends, to a large extent, on collaboration among various agencies, it is vitally important that these agencies share and be committed to a similar vision for palliative care and establish respectful working relationships. Although the tensions existing among organizations may be gradually resolving, I suggest there is still a need to understand and address these tensions in order to advance the development of a truly comprehensive continuum of palliative care that will benefit dying patients and their family members.

As a starting point, the historical issues plaguing health care organizations need to be explicitly recognized and honestly discussed among all relevant stakeholders. Doing this in a safe and non-threatening manner that transcends "political correctness" will ultimately assist in getting the issues "out on the table" where they can be acknowledged, respected, remembered, but put aside so that working relationships can improve[125]. Many of the tensions among organizations reported by participants in this study resulted from philosophical divisions and approaches to palliative care delivery. Opportunities for facilitated and continuing

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[125] I am not suggesting here that the relationships between various stakeholders in the organizations are adverse. However, they could be improved as a way to foster a greater understanding of each other.

discussions, preferably with an arm's length facilitator, are needed to assist stakeholders in the various organizations to develop an appreciation and understanding for each other's perspectives. It is inevitable that organizations will conceptualize palliative care delivery in different ways. Agencies mandated to provide only palliative care will understandably have a more focused approach, whereas organizations responsible for delivering health care to a broader population will have competing demands that may not allow them to focus exclusively on palliative care. These differences need to be acknowledged, understood, and discussed in a frank and open manner. Furthermore, strategies to reduce "turf wars" among organizations need to be considered; it must be acknowledged that no one agency "owns" palliative care or "owns" families in palliative care.

One of the factors contributing to tensions among organizations in this study related to the use of palliative care donations, particularly for professional continuing education. Thus, one way to improve organizational relationships would be to establish a "community" education fund. Providers working for agencies other than hospice organizations and who provide a large proportion of community-based palliative care (e.g., HCNs, HSWs) could access this fund, within specified guidelines. Such a strategy would acknowledge the valuable contributions that all providers make to the delivery of home-based palliative care.

Finally, there is an urgent need to recognize and understand the incongruencies and tensions between the biomedical model and the hospice ideal. Such an understanding could facilitate open discussion regarding the directions of

palliative care development. These discussions are needed now, more than ever, to ensure the founding ideals of hospice and palliative care are sustained. Canadian leaders in palliative care need to seriously examine the direction of palliative care development. The philosophies and principles underpinning palliative care have long been upheld as the quintessential elements for delivering comprehensive and effective care for the dying. Without initiatives to engage in a national dialogue about the future of palliative care, the ideals originally proposed by Cicely Saunders (du Boulay, 1984), the founder of the modern hospice and palliative care movement, are likely to continue to erode.

Enhancing Continuity of Care

The complex nature of care for persons with life-threatening illnesses means that patients (and caregivers) see an ever-expanding array of providers in a variety of organizations and places. Connecting care into a coherent whole is increasingly difficult (Haggerty, Reid, McGrail, & McKendry, 2001). Although an exact definition of continuity of care remains elusive, it is widely considered an essential ingredient for improving the health care system and for enhancing patient and family care. Based on a comprehensive literature review, Haggerty and colleagues identified several elements that seem to underpin continuity of care, including: a coherent linking of care over time; a consistent approach to care, with clear goals and a suitable management plan; the effective transfer and use of information, both personal knowledge accumulated about the patient and family and records shared among providers; and, the establishment of relationships between patients/caregivers and a provider or a team of providers that span and connect

separate components of the health experience (p. ii). These elements (some more than others) were reported by caregivers and providers in this study to be seriously lacking. Therefore, strategies directed toward enhancing continuity of care are offered here.

One of the major problems the caregivers had with home care provision was the number of different providers they encountered. The caregivers reported they were often asked the same questions from each provider, were unaware of who to contact when they required help with care planning, and were beleaguered with bureacratic structures and rules that prevented continuous care. Clearly, a streamlining of services is needed to reduce the numbers of providers entering the home. Yet, this is challenging because, with home support, for example, union seniority regulations drive care delivery. However, I suggest that we need to challenge such regulations, working with unions to design systems of care that accommodate the needs of all parties. Ultimately, there must be some measure of continuity between providers if home-based palliative care is to improve. In addition, consideration should be given to specialized case management roles in palliative care. Caregivers need help with navigating the health care system and they require a single contact for this purpose. Although I agree with the providers who recommended that a re-emphasis on the HCN as the coordinator of care is needed, I do not believe that this strategy alone will suffice. Specialized case management roles in palliative care have the potential to enhance continuity of care by: (a) reducing the caregivers' feelings of abandonment by the health care system; (b) assisting in mediating relationships between care agencies and care providers; (c)

ensuring discharge plans from hospital are well organized; and, (d) serving as a consistent point of contact for families in palliative care throughout the disease trajectory.

At the same time, it is inevitable that caregivers will encounter different providers throughout the course of their caregiving experience, acknowledging that providers will necessarily change because of time off, vacation, and so on. Accordingly, it is critical that information and communication systems be improved so that caregivers are not faced with a repeated barrage of questions and assessments. To begin, providers must make greater efforts to use the communication systems that currently exist (e.g., in-home chart, "talking" to each other). They must also begin to trust one another so that assessments are not duplicated unnecessarily. Currently, planning for implementation of an electronic health record is underway in the health region where I conducted the study. Although the implementation date is still far off, consideration could be given to pilot-testing this record with providers working with families in palliative care as a way to improve communications between providers both within and between organizations. Because data on the delivery and costs of home-based palliative care services is extremely limited at a regional, provincial, and national level, and because this type of information is critical to the design of effective and comprehensive palliative home care programs, databases (with controlled access) should be established and linked to the electronic record. For example, client files that contain assessment and reassessment data, and the costs of services, could be recorded thus allowing researchers and decision makers to analyze aggregated data to identify outcomes

by client group (e.g., are outcomes different when caregivers provide care to patients with cancer and non-malignant diseases?) and to measure cost effectiveness. A national database could also be established to which regional data files would be linked. This would permit interregional comparisons, both for client groups as well as for different service delivery models.

Promoting continuity of care throughout a person's interactions with the health care system is a significant issue facing health planners. Systems of care that are discontinuous create many challenges for caregivers, some of whom are already overburdened by their obligations to care. In order to create a comprehensive continuum of palliative care, the tensions and turf wars existing among organizations must be surpassed. Health care systems and those who work in them must continually strive towards continuity, designing and implementing processes to enhance care. The development of a comprehensive continuum of palliative care is not an effortless endeavour. But, if the patient and family are kept at the centre of health care planning and their needs drive the planning process, the ultimate outcome will be one that will have a greater potential to improve the care to those at the end-of-life and their family caregivers.

Directions for Research

The impact of providing health care in the home is a relatively under-researched area (Alcock, et al., 1998). Yet, it is evident that shifting health care closer to home influences and shapes the experiences of palliative caregivers in important ways. The research conducted to date has provided us with a solid understanding of some of the individual experiences of caregivers. This study has

extended these understandings by situating caregivers' experiences within a broader social context. Thus, I have begun the project of developing knowledge toward a deeper and more contextualized understanding of home-based palliative caregiving. Like many researchers though, I am left with several unanswered questions from the findings of this study. It is in these questions that I find directions for future research.

Findings from this study suggest there is a need to better understand the decision-making process of caregivers, to assess the congruency between patients' and caregivers' desires for home-based palliative care, and to determine the extent to which these desires stay constant over time. Given that a patient's decision to die at home has many implications for caregivers, such research could clarify the exact nature of decision making, determine the extent to which patients' and caregivers' desires are congruent, and help pave the way to developing valid and reliable ways of assessing patients' and caregivers' preferences for place of dying and death. This type of information could help clinicians better understand the processes caregivers experience when making difficult decisions about care and could help to expand the repertoire of therapeutic interventions for health professionals working with caregivers. Such studies could also help determine if and why preferences for home-based palliative care change over time, and would extend understandings of the intricate nature of patient-family caregiver relationships, helping to determine those factors that tend to facilitate negotiated decision making between patients and caregivers. Similar studies, using the "family" as the unit of analysis, would help to ascertain how family functioning influences the decision-making process.

Some authors have hypothesized that the provision of care at home can complicate and prolong caregiver bereavement (Addington-Hall & Karlsen, 2000). Findings from this study suggest that this may well be the case in home-based palliative care. However, longitudinal studies are needed to fully understand the long term consequences to home-based caregivers; they would help to determine those factors that are more likely to contribute to prolonged grief, changes in physical and mental health over time, and changes in family relationships following the death of a loved one. This type of research could help clarify why some caregivers tend to cope better with home care than others and findings could be used to develop measures to predict which families are more likely to cope better with home care. Additionally, this type of information would assist health planners in knowing where to direct resources and target programs and services to "at risk" caregivers, and would alert clinicians to those conditions that might necessitate focused intervention. Moreover, longitudinal studies could be designed to carefully track not only long-term health consequences but also economic burdens and costs resulting from home-based palliative care. These under-described aspects of family caregiving could influence policy in more equitable directions. As McKeever suggests (1996), "although accurate data alone will not impel social change, without them, policy makers can invoke their absence as an excuse for inaction, and efforts to understand and eliminate inequities will remain seriously undermined" (p. 204).

There is also a need to better understand the palliative care needs of socially marginalized groups. The findings from this study suggest that marginalized people may have limited access to palliative care, may be judged harshly by providers, and

may have unique circumstances that render mainstream health care systems unsuitable for meeting their needs. However, these findings are based on interviews with a small number of providers. Qualitative studies, seeking the perspectives of marginalized people, could extend our understandings of their experiences and provide the information needed to design strategies and health care programs that may be more suited to meeting their needs. As the incidence and prevalence of life-threatening diseases such as AIDS and hepatitis continue to rise in marginalized populations (Archibald, Remis, & Williams, 1997; Millar, 1998), and as more people require palliative care, the need for research in this area will be increasingly urgent.

Findings from this study suggest that dominant discourses played a role in perpetuating and sustaining taken-for-granted assumptions about dying at home. Media discourses, societal discourses, discourses reproduced in professional texts, and discourses among health care providers, and between providers and caregivers all seemed to work together to influence caregivers' perceptions about home-based palliative care. Therefore, studies using research techniques such as critical discourse analysis are needed to document and verify the links between textual and oral communication, and their relation to reproducing and preserving dominant ideologies. Such a critical examination could help to explore how discursive practices, events, and texts arise out of and are ideologically shaped by relations of power and how such factors act to secure power and hegemony (Fairclough, 1993). This examination could also further explain the differences between caregivers' and providers' constructions of home-based palliative care.

The influence of health care reform on home-based palliative caregiving cannot be overemphasized. At the same time, there is currently a lack of evidence concerning the impact of reforms on health care delivery systems. While politically and economically driven policy decisions might benefit the interests of the system, such motivations may not be sufficient to constitute just or sound public policy. For this reason, there is an urgent need to conduct evaluative studies to determine, at a minimum, the impact and outcomes of regional reforms on caregivers. For example, evaluative studies should be planned with any major policy change that might influence caregivers (e.g., reduction of allocable home support hours). Studies that evaluate the outcomes of home-based palliative care are also required. While the findings from this study suggest that some caregivers were satisfied with the care received, others had significant difficulty, particularly when the biomedical imperative was operating. Studies evaluating the outcomes of home care could extend understandings about the extent to which biomedical models influence care and could provide direction for needed changes in the ways in which professional care provision is enacted in the home. Specific studies designed to examine the organization and delivery of home support services are also needed as such services play a pivotal role in supporting caregivers at home and can significantly effect the experiences of palliative caregivers.

At a broader level, it must be acknowledged that findings from this study are based on the experiences of caregivers in one health region in Western Canada. The organization of health care services, the available resources, and historical influences and contexts will, to some extent, influence caregivers' experiences.

Shapiro (2000) points out that research in home care has tended to ignore that health care systems across the country differ, and therefore, influence the generalizability of research findings. As such, replication studies are needed to determine the extent to which caregivers' experiences are fully represented across settings and provinces. Furthermore, interdisciplinary research agendas that are designed with policy goals and consequences in mind are needed to increase the likelihood that studies will yield information that could be used persuasively to influence health policy development (McKeever, 1996). And, given the demographic shifts in the population and the burden of caregiving, the capacity for family members to continue to provide care needs to be examined. Such information could assist decision makers in planning for the future and help them to assess the potential impact of workload on the formal care system if family members are unable to provide care. Given the anticipated growth of home care services, understanding human resource needs in this sector is critical (O'Brien-Pallas, Baumann, Birch, Tomblin-Murphy, 2000).

Finally, as McKeever (1994) aptly points out, most home care research continues to be driven by anti-institutional themes. As such, research findings tend to rationalize the need for expanded home care with little recognition of the impact on family caregivers who provide the majority of home-based care. While continued exploration of the benefits of home-based palliative care would be helpful, the assumption that home care is "better" can colour the research questions that are asked, the ways in which data are interpreted, and the overall outcomes of research findings. Nurse researchers interested in investigating the shift to providing health

care closer to home must re-think their allegiance to the concept of home care and recognize the potential consequences to caregivers when palliative care is provided in the home setting. This recognition will help to minimize the extent to which nurse researchers contribute to retrenchment practices and will ultimately promote the development of evidence that assists in crystallizing the directions that are taken to support family caregivers in the future.

Directions for Policy Development

One of the dominant issues facing decision and policy makers is the lack of evidence available to guide home care policy development. Often decision and policy makers are left to grapple with political changes proposed or enacted and, in home care, such a reality is made even more problematic because there simply is not enough information on home care to make informed and sound policy decisions (Anderson & Parent, 1999). The findings from this study provide some direction for policy development in the area of home-based palliative care. Some of these directions have already been implied and discussed throughout this dissertation. Here, I will briefly tease out a few more practical directions I think are needed to improve the situation for family members providing end-of-life care at home.

First, many of the caregivers in this study were overwhelmed by the constant barrage of health care providers entering their homes and often found the help provided did not meet their unique needs, particularly with home support. Some of the caregivers indicated that they would have preferred to organize and coordinate their own home help (e.g., HSWs) but were unable to do so because the government bureaucracy moved too slowly to accommodate their needs. Given the

difficulties that caregivers face, policy directions that give caregivers greater flexibility and control should be considered. Programs that provide funds to family members to organize and coordinate their own home support, such as the Community Support for Independent Living Program in B.C., should be reviewed with the aim of developing policies to allow caregivers to rapidly access funds to organize health care in a way that best suits their needs. Moreover, consideration should be given to developing policies that give caregivers greater flexibility in how these funds are utilized. Currently, caregivers who access such programs are restricted to using funds for health workers to provide personal care, respite care, and so on. However, for some caregivers and patients, there may be greater benefit to using these funds to assist with other tasks (e.g., house cleaning, yard maintenance) that may be equally burdensome. Offering this type of flexibility would recognize and respect the unique needs of caregivers and give them greater choice and control in how home-based services are provided.

Second, for caregivers who desire to provide home care but suffer financial repercussions as a result, consideration should be given to remunerating family members who provide care. The current B.C. government policy does not support hiring family caregivers but the government has said it will review this policy because of a recent human rights complaint placed before the B.C. Human Rights Commission by several family caregivers (Young, 2001). At the same time, there has been considerable debate in the literature regarding the implications of such a policy direction (see, for example, Adamek, 1992; Arling & McAuley, 1983; Blaser, 1998; Keefe & Fancey, 1997; 1998; Stone & Keigher, 1994). The issue of hiring

caregivers to provide full-time care is complex. Any policy option that is discussed and put forward must reflect this complexity and demonstrate consideration of the impact on, and implications for, family caregivers should remuneration as a full-time care provider become a viable policy option. At the very least, a number of questions should be considered in any policy review of this issue. For example, what should be fair and equitable remuneration to maintain a decent standard of living for family caregivers? If family caregivers terminate their employment to provide care, how will benefits (e.g., sick time, vacation time, and so on) be arranged? What mechanisms would need to be in place to support caregivers and how would quality assurance be maintained? What are the social impacts of such a policy direction? While I ultimately support the choice and self-determination of caregivers and believe financial remuneration is one option, I do think these and other questions need serious and thoughtful consideration before any policy decisions are made. Additionally, as I discussed in detail in Chapter Seven, the policies guiding the B.C. Palliative Care Benefits Program also need to be reviewed and the inclusion criteria expanded.

Third, policy changes must be made to ensure that caregivers are part of the formal family assessment process. Policies that direct providers to privilege patients' needs, at the expense of caregivers' equally important and legitimate needs, fail to recognize the social, emotional, and health impact that home-based palliative care has on many caregivers. Policies should direct providers to assess not only the availability of caregivers but also their willingness to provide care. These types of changes are necessary to support real family-focused care. For example, policy

changes are needed to allow caregivers to also be the recipients of care rather than limiting services to the ill person alone. Even though an individual person has the disease, family caregivers and whole families experience illness (Brown & Stetz, 1999).

Finally, because HSWs spend a substantial amount of time in the homes of families in palliative care, and because it is inevitable that relationships will develop, policies that inhibit relationships between HSWs and families in palliative care also need to be revisited. Instead of policies directing HSWs to limit their relationships with family caregivers, consideration should be given to educating and mentoring HSWs to establish therapeutic but professional relationships. Furthermore, policies must be developed to ensure that caregivers have a safe avenue to resolve disputes with home support agencies and to appeal decisions made by health authorities that limit the amount of support they are allotted from the health care system. Without such policies, caregivers are left at the mercy of the health care system and have no recourse (beyond hiring private care) if they are dissatisfied with care provision or decisions.

In summary, the policy directions recommended here are but a few of the possible options to be considered in effecting better support for family members providing end-of-life care at home. Enacting such directions will require a concerted effort from health care providers and advocates concerned with family caregiving issues. Health care providers can catalyze policy change by participating in family caregiver advocacy groups, supporting initiatives to promote family caregiver protection, and working with their professional organizations to promote legislative

change that supports family caregiving. Advocating for changes to the ways in which health care is provided to family caregivers will require that nurses and other health care professionals critically examine how larger structures and processes within the health care system play a role in overburdening family caregivers. Nurses and others involved with family caregiving issues must also understand the role they play in creating and supporting the larger social structures and systems that lead to inequities in the health care system (Drevdahl, 1995). With this knowledge, nurses will be much better prepared to identify methods to facilitate policy change at both micro and macro levels.

In conclusion, this study has explored the social context of home-based palliative caregiving. The findings illuminate the complex and multi-layered nature of palliative care when it is provided in the home setting and demonstrate how organizational and societal contexts mediate and profoundly shape caregivers' experiences. While many of the caregivers in this study reported on the benefits of providing palliative care at home, almost all of the caregivers also found the experience to be challenging. The findings from this study indicate that there is a need to re-think the ways in which home care for the dying is conceptualized and to explore how our own assumptions influence, and sometimes dominate, the provision of health care at home. Such awareness will ultimately pave the way toward a health care system and society that genuinely respects and honours the obligations, choices, and needs of family members who provide palliative care at home.

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Appendix A

Definition of Palliative Care

Definition of Palliative Care

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

Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.

While many service providers may be able to deliver some of the therapies that provide comfort and support, the services of a specialized palliative care program may be required as the degree of distress, discomfort and dysfunction increases.

Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing.

Appendix B

Letter of Invitation to Participate: Health Care Providers

Appendix C

Letter of Invitation to Participate: Family Caregivers

Appendix D

**Letter of Invitation to Participate:
Health Care Administrators
Lobbyists for the Assisted Suicide Movement**

Appendix E

Fieldwork Calendar

Fieldwork Calendar

PHASE	DATE	ACTIVITY
Preparatory Phase of Fieldwork	January 4, 1999	Funding Grant Proposal Submitted
	April 1, 1999	Funding Grant Proposal Approved
	May 27, 1999	Successfully defended Dissertation Proposal to UBC Committee
	June 24, 1999	Health Region Ethics Approval
	June 25, 1999	University Ethics Approval
	September, 1999	Release of Research Project Funds
First Phase of Fieldwork	October 1999 - January 2000	• Interviews and/or observations with 5 active caregivers • Interviews with 15 previous caregivers • Data analysis
	January 2000 - February 2000	• Data analysis • Development of a conceptual schema
Second Phase of Fieldwork	March 2000 - July 2000	• Interviews and/or observations with 8 active caregivers • Interviews with 32 previous caregivers • In-depth and focus group interviews with health care providers (28 participants) • In-depth interviews with health care administrators/lobbyists for the assisted suicide movement (10) • Data analysis • Revisions to conceptual schema
TOTAL FIELDWORK HOURS: 130		
Analysis	August 2000 - December 2000 January 2001 - July 2001 May 2001 - July 2001	In-depth Analysis Data Analysis and Writing Final Revisions to Dissertation
Disseminate Findings	September 2001 - ongoing Oct. 2001 - December 2001	Conference Presentations Disseminate findings to community groups, study participants, etc.

Appendix F

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
     ☐ PhD
     ☐ 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: _____

Notes:

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:

CAREGIVERS

1. Caregiver relationship to dying person:

❏ Friend   ❏ Partner   ❏ Spouse

❏ Parent   ➡   ❏ Mother   ❏ Father

❏ Sibling   ➡   ❏ Sister   ❏ Brother

❏ Adult
Child   ➡   ❏ Daughter ❏ Son

❏ InLaw   ➡   ❏ Daughter ❏ Son

Other: _____

2. Location of death:

❏ Loved one <u>currently</u> dying at home
❏ Loved one <u>has already</u> 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   ❏ $40,000 - $50,000
❏ $10,00 - $20,000   ❏ $50,000 - $60,000
❏ $20,000 - $30,000   ❏ $60,000 - $70,000
❏ $30,000 - $40,000   ❏ > $70,000

Appendix G

Confidentiality Agreement: Transcriptionist and Research Assistants

Appendix H

Interview Guide: Family Caregivers, Health Care Providers, Administrators

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?

Questions for Health Care Providers

- Tell me about your experience in working with families providing palliative care at home.
- What do you think are the benefits to family caregivers in providing home-based palliative care? Can you give me an example(s)?
- What do you think are the challenges to caregivers in providing home-based palliative care? Can you give me an example(s)?
- To what degree does the health care system, as it is currently structured, influence the provision of palliative care at home? What works well with the current system? What does not work so well? Can you give me an example(s)?
- What health care policies or systems influence your provision of palliative care at home?
- Why do you think there is an increasing interest from the public around issues of assisted suicide?
- What influence, if any, has home-based caregiving had on the assisted suicide movement? Can you give me an example(s)?
- Is there anything else that you would like to add that we haven't talked about?

Questions for Administrators

- Can you tell me about your background in health care.
- Can you tell me your understanding of how health services are organized to support palliative care at home in this community?
- What are your thoughts about having people die at home?
- What types of barriers exist for caregivers in accessing home health care services? What do you think could be done to minimize these barriers?
- Can you tell me what you know about some of the provincial and national initiatives that are in place related to family caregiver issues?
- What do you think needs to happen at a provincial and national level to support family caregivers? What do you think is most important and why?
- How do you think that the health care system could be improved to better support family caregivers?
- Why do you think there is an increasing interest from the public around issues of assisted suicide?
- What influence, if any, has home-based caregiving had on the assisted suicide movement? Can you give me an example(s)?
- Is there anything else that you would like to add that we haven't talked about?

Prompts

Can you tell me more …
Can you provide an example …
What I hear you saying is …
What was that like for you …
The experience was …
You felt like …

Appendix I: Consent Forms