IMPACT OF HOME-BASED PALLIATIVE CARE ON FAMILY CAREGIVERS

SHIFTING THE BURDEN:

THE IMPACT OF HOME-BASED PALLIATIVE CARE ON FAMILY CAREGIVERS

LIVING IN RURAL AREAS

By

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Abstract

Changes to the delivery of health care have resulted in increased reliance on family members to provide care in the home. This type of care is changing, becoming more complex and labour-intensive, and encompassing the provision of palliative and end-of-life (P/EOL) care. The demands of this care can be overwhelming, although access to support can mitigate burden and enhance the experience. In rural areas, access to services is fragmented and under-funded and the effect this has on family caregivers (FCGs) is not well-understood. Given the ageing population, the prevalence and necessity of P/EOL family caregiving is not going to abate. This research examined how family caregivers living in northern Ontario managed caring for their terminally-ill loved-ones in the home and how this affected their self-assessed health. A multiple case study design was used to explore the experiences. Data consisted primarily of semi-structured interviews, direct observations and documents. Conventional content analysis was used to develop themes from the data. The results revealed that FCGs in this area have limited access to support, through both the health care system and informal networks, and as such, experience high degrees of self-sacrifice and caregiver burden. A team approach to care with greater emphasis on the needs of FCGs is essential to maintaining caregiver health and well-being so that they may assist their loved-ones to die in their homes.

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In loving memory of my mother, Joyce Lorraine Aultman (1940-1992).

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Pulled in all Directions

Do I have strength to fight the pull
of days too short and bleary?
If I could find one minute more
of life yet not so weary;

Since all directions I must look
and every place must call
Everyone to whom I speak
on this whirling, twirling ball,

Is needing me, my life not mine
in sad and soothing care
I don't regret the time I spend
with one whose life I share.

Still, through my tired, grieving heart
I'm weighed against the hours
And minutes, seconds, days and weeks
no time to smell the ...

Patricia L. Scott

(Inspiration and editorial input by Rhonda M. Donovan)

Chapter One

Introduction and Review of the Literature

1.1 An Introduction to the Study

By choice or not, family caregivers (FCGs) have become a cornerstone in the health care system. In ever increasing numbers they are doing more than just picking up where the system leaves off; in some cases, they are *replacing* it. The reliance on FCGs in the delivery of health care represents a shift from institutional-based care systems to community and home-based care systems[1] and is just one result of massive restructuring undertaken by governments in most industrialised countries to reduce costs in health care spending. Homecare is a substitute for costly institutional care and is meant to provide supportive services that allow patients[2] to remain in their homes (Shapiro, 2002). This trend has been advanced as well by changing technologies that expand the type of care that can occur in the home (Shamian, 2006), such that FCGs are assuming responsibility for increasingly complex care. Homecare represents the fastest growing segment of the health care system (Romanow, 2002; Coyte & Young, 1997; Williams, 1996). It is predicated on the assumption that a willing and able family member (or friend) is available to assist with the care; the heaviest load tends to fall on those living with the person being cared for (Wiles, 2003). An emerging body of research is elucidating the dynamic nature of informal caregiving, including the individual, social and demographic factors that impact this experience. Given the extent of care that is being performed by FCGs, as discussed in Section 1.5, the demands of care often exceeds their capacity to cope.

Along with the move towards homecare has been the adoption of palliative and end-of-life (P/EOL) care.[3] One of the goals of P/EOL care is to support those who are dying in their homes. To do so there *must* be someone in the home (typically a family member or friend); this person is expected to and will provide the majority of this care. While the desire for dying (both the process of care and the death event) at home is quite significant, most deaths still take place in hospitals or other institutions (Wilson, Northcott, Truman, Smith, Anderson, Fainsinger, et al., 2001). This indicates that improvements must be made to better meet patient and family preferences; however, it obscures the fact that the majority of care has likely occurred in the home by a family member, with admission to the hospital occurring within just days or even hours before death (Rhodes & Shaw, 1999). The need to institutionalise the patient is usually the result of insufficient pain or symptom control and/or caregiver burn-out; sustaining FCGs in their role is therefore essential to meeting the goals of P/EOL.

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[1] The terms community care, home care and community-based services are often used interchangeably to refer to the range of services (social support, health promotion and home care) delivered outside of traditional institutions.

[2] The term patient(s) is used interchangeably with the term client(s) in the literature; throughout this paper, "loved-one" will be used to refer to the patient/client of health care.

[3] P/EOL care is a philosophy of care aimed at improving the quality of life for the dying. It is discussed thoroughly in the next section.

While the concept of P/EOL care as an ideal is not new, integrating it into the health care system in Canada, as both a policy and practice issue, has been slow. The development of a national strategy on P/EOL care is a major focus in health care policy and research (Carstairs, 2005). Supportive services[4] which can mitigate caregiver burden (such as palliative homecare services) are underdeveloped, fragmented and underfunded (Canadian Home Care Association [CHCA], 2004a; Romanow, 2002), making access difficult, if not impossible for both patients and FCGs. This is more pronounced in rural and remote areas, where the coordination and delivery of health care resources *in general* are constrained by geographic and logistical barriers (i.e. see Canadian Institute for Health Information, 2006; Kirby & LeBreton, 2002; Ministerial Advisory Council on Rural Health [MACRH], 2002). Often no services are available, reducing the likelihood for homecare or a home death and/or leaving FCGs in these areas at increased risk for caregiver burden, relative to their urban counterparts.

A tension exists for rural-dwelling FCGs who, recognising the adoption of the principles of P/EOL care within a geography characterised as having limited access to resources, face increased pressure to provide care in the home. Currently there is an urgent need to address health care issues in rural Canada from the perspectives of those living in rural areas (Kirby & LeBreton, 2002; MACRH, 2002; Romanow, 2002), including P/EOL care. P/EOL care in Canada is a relatively new phenomenon and not much is known about the experiences of FCGs, especially those living in rural and remote areas. Most of the work that has been done on rural P/EOL care is international in scope (Aoun, Kristjanson, Currow & Hudson, 2005; Hughes, Ingleton, Noble & Clark 2004; Evans, Stone & Elwyn, 2003) or specific to service provider perspectives (McRae, Caty, Nelder, & Picard; 2000), as is reviewed in the second half of this chapter. Given that the intensity of caregiving can change over time, there is a recognised need to examine how caregiving is experienced over time (Fast & Keating, 2000). The purpose of this study is to examine the experiences of FCGs living in rural areas over the caregiving process in order to understand: (a) how they manage the experience; and (b) its affect on their self-assessed health. Given that little research specific to palliative family caregiving in rural areas exists, this will fill a noted gap within the caregiving literature. This chapter provides the context for the study by first outlining the research questions and objectives, disciplinary context, and overview of the structure of the thesis. The second section of this chapter contains a review of the relevant literatures specific to the provision of P/EOL care and family caregiving.

1.1.2 Research Questions and Objectives

The research questions being explored in this study are:

1. How do FCGs who are living in rural areas manage home-based palliative care?
2. How does this experience affect their self-assessed health?

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[4] Supportive services refer to formal services that are provided through the health care system. Those that are providing such care are paid.

The objectives of this research are:

1. To understand and describe the palliative caregiving experiences of FCGs living in rural areas, including: the role of a caregiver; how are caregivers prepared for and supported throughout the process; and, their overall satisfaction with the experience.
2. To understand and describe the degree to which caregiver burden is experienced and how this affects their self-assessed health.

1.1.3 Disciplinary Context

This study is situated within the context of health geography. Health geographers are concerned with the relationships between people, health and the environment, with an emphasis on how place and space influence health and well-being. Health geography represents a shift from the largely *atheoretical* field of medical geography, with its primary focus on disease ecology and health services research using quantitative methods and spatial modelling (Kearns & Moon, 2002; Kearns, 1993). Health geographers have, through their engagement with social theory and the use of alternative methods of inquiry, produced a more place-centred understanding of health and health care – one that looks to and takes account of both the personal circumstances of the individual and the wider set of economic, social and political processes that shape place and the experience of health in place (Elliott, 1999; Kearns, 1993; Gesler, 1992).

This shift is reflective of the way in which health has been conceptualised. This was largely influenced by The World Health Organization (2004), who has defined health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (pp. 28). While this definition is difficult to operationalise (i.e. Evans & Stoddart, 1990), it has encouraged a more holistic understanding of health in which well-being has emerged as an important element. Contemporary philosophies of health now reject a purely biomedical model, with its focus on the treatment of illness and disease and espouse a view in which physical, social and individual factors are implicated in the experience and creation of health (Kearns, 1993). This has led to the widely adopted population health model which identifies a number of these factors or "determinants" (Public Health Agency of Canada, 2006; Evans & Stoddart, 1990). This model offers a framework through which to reduce inequities that contribute to ill-health while directing focus to health promotion and maintenance.

1.1.4 Structure of Thesis

This thesis is divided into five chapters. In the remainder of this chapter the foundation for the study is set via a review of the literature. First, the concept of P/EOL care is discussed to frame the review as, by definition, it imposes the role of caregiver on a family member of a terminally-ill person who wishes to die at home. This will then be situated within a discussion on the health care system, in relation to general trends in health care as well as those specific to rural populations. Finally, a review of the caregiving literature is presented to illustrate the scope of this role and its affect on caregiver health and well-being. Together these provide evidence as to the importance of the context for care (in the home and in rural areas) on the experience and health of palliative FCGs.

In **Chapter Two**, the research methodology and design are discussed, including a review of the research questions posed, as well as the strategies for data collection and analysis. A case study design was used to guide the research, with the data collected using primarily qualitative methods. Several amendments were made to the original design, particularly around issues of recruitment; this led to a delay in data collection, which affected the data sources used in analysis. These changes are explained, as are the challenges of conducting research with vulnerable populations. Doing research in collaboration with community organisations is also highlighted.

Chapter Three contains the case summaries for the FCG participants, where the unique circumstances and experiences of the FCG participants are described. Each summary begins with a reflective quotation from the FCG, followed by details concerning the context of care (caregiving arrangement and family structures) and the nature of caregiving (responsibilities and intensity of care) as it progressed over time.

In **Chapter Four**, the results of the cross-case analysis are presented. The overarching theme (suspension of self and time), along with three sub-themes around support, motivation, and health, are introduced and discussed. Rich examples from the data are presented to illustrate the themes. The results indicate that FCGs in rural areas lack access to support, both through the health care system and through informal networks. This, in turn, has significant implications for their health.

Finally, **Chapter Five** contains a discussion of the results and conclusions to the overall study. The importance of protecting health as a resource in caregiving is highlighted. The limitations of the study as well as recommendations for future research are indicated.

1.2 Putting the Research in Context: A Review of the Literature

The purpose of this section is to establish the context of palliative family caregiving. This is accomplished by: defining what P/EOL *means*; centring discussions concerning the provision of P/EOL care and relevant supportive services within the larger context of health care service delivery; and, examining how and why access to these services varies geographically. This section essentially provides a road map to illustrate the importance of this issue and is essential to understanding the effect on family members who become FCGs to their loved-ones at end-of-life.

1.2.1 Palliative and End-of-Life Care

Palliative Care (PC; also referred to as P/EOL care) is an approach to care that is dedicated to improving the quality of life of patients and their families from problems associated with a life-threatening illness, through the prevention and relief of suffering and the treatment of any physical, psychosocial and spiritual issues (World Health Organisation [WHO], 2007) This philosophy is rooted in the 1960s English hospice movement led by Cicely Saunders (Lattanzi-Licht & Connor, 1995:143), who advocated for total care of the patient and family as a unit to "maxmis[e] the potential the patient and family still have for activity, relationship and reconciliation" (Saunders, 2000; pp.11). In North America, the concept of hospice was adopted in the mid-1970s; the first program in the United States opened in New Haven, Connecticut in 1974 and in Canada, beginning in Montreal, Quebec in 1975 (Lattanzi-Licht & Connor, 1995). Originally dedicated to care for cancer patients, this philosophy gained momentum on a global scale and was expanded to include dying from non-terminal diseases following the First International Conference on Palliative Care of the Elderly in 1988 (Wilson, Justice, Sheps, Thomas, Reid, & Leibovici, 2006; Ley, 1989). This has shifted the concept from its philosophical ideal to one of political prominence; in fact, the World Health Organization recommended in 1990 that all governments make palliative care part of their health policies (Faull, Carter & Daniels, 2005).

Palliative care is holistic in its approach and is delivered by an interdisciplinary team, including: physicians; nurses; occupational therapists; social workers; pharmacists; homecare support workers; spiritual advisors; and, volunteers (Carstairs & Beaudoin, 2000). Based on the WHO definition, PC is not necessarily confined to care with patients who are no longer receiving treatment; in fact, it is suggested that PC is "applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life..." (WHO, 2007). It is, however, most often associated with end-of-life care, where "people should be helped not only to die peacefully, but to live until they die with their needs and their potential met as full as possible" (Saunders, 2000; pp.8). Palliative care services can be delivered in hospitals, long-term care facilities, hospices or the home, although it is primarily concerned with supporting people to die in their homes (Stajduhar & Davies, 1998). While health care policies vary, P/EOL services in Ontario are typically provided based on a physician's prognosis that the patient is not expected to survive beyond six months (Ontario Association of Community Care Access Centres [OACCAC], 2003).

Research indicates that the dying would prefer to be cared for and die in their homes or communities to sustain independence and family relationships and to retain normalcy (Brown, Davies & Martens, 1990; Stajduhar, 2003). Family members appear to want this as well because the circumstances of death are more intimate, peaceful and less distressing at home (Kinsella, Cooper, Picton & Murtagh, 2000; Grande, Addington-Hall, & Todd, 1998), and because the desired home experience of patients and families is linked to their notions of health and well-being (Roush & Cox, 2000). Research suggests that as many as 80% of dying people wish to die at home, although significantly fewer are able to do so (Burge, Lawson & Johnston, 2003; Carstairs, 2005). Deaths still occur most often in hospital or other institutions - although this number has dropped from 80.5% in 1994 to 75% in 1997 (Wilson et al, 2001). As more deaths are taking place outside of traditional institutions, and the preference for care and dying in the home at end-of-life is substantial, it has become evident that improving support of patients and families at end-of-life is critical (Carstairs & Beaudoin, 2000).

Currently, the provision of P/EOL care services in Canada is fragmented, resulting in varying degrees of access to EOL care, good quality care, and service costs resulting in varying out-of-pocket expenses for the patient. It is suggested that while there are more than 430 programs and services available in Canada, as few as

15% of Canadians (and only 3.3% of children) have access to hospice palliative care (Carstairs, 2005). Canada's ageing population will increase the demand for P/EOL care services and there is concern that the current health care system will not be able to manage (Quality End-of-Life Care Coalition of Canada, 2005). For example, it is expected that the composition of the population over the age of 65 will increase to 20% by year 2020 from its current rate of 12.5% (Health Canada, 2002) and that the number of deaths will increase by 40% over the same time (Carstairs, 2005). Approximately 160 000 Canadians could be expected to require palliative care in any given year (Kirby & LeBreton, 2002) and this will escalate as the population ages. Carstairs (2005) suggests that P/EOL care services should not stand as add-on programmes that may or may not be available in one's community but be integrated into the health care system (pp.1). Such integration requires national leadership to ensure the implementation and on-going monitoring and development of quality P/EOL care (Carstairs, 2005; Carstairs & Beaudoin, 2000).

The development of a national-level framework is complicated by the configuration of the health care system in Canada; this is affected by both the constitutive powers of the federal and provincial governments and the governing principles of the Canada Health Act. In terms of health care, both the provincial/territorial (P/T) and federal governments have different responsibilities. P/T governments are responsible for the management and delivery of health care whereas the federal government is responsible for specialised aspects of the system. This includes: primary health care to specific groups (First Nations/Inuit communities and military personnel, for example); health promotion and protection; health research; and financial support to the provinces (Anderson, 2002; Kirby & LeBreton, 2002). Of particular significance is the structure for the funding of health care services, whereby specific medically-necessary services, narrowly defined as those services delivered in-hospital and/or by physicians, are insured under the Act. As such, they are subject to dedicated funding by the federal government as long as certain criteria are met.[5] Provinces are not mandated to provide coverage for services that do not meet these criteria and their inclusion in provincial health insurance plans is discretionary (Williams, Barnsley, Leggat, Deber & Baranek, 1999). Many services are left unprotected by the Act, including extended care (i.e. long-term and homecare – including palliative care) and supplementary health services (i.e. prescription drugs, and chiropractic and dental care). Although homecare services are not technically insured under the Act (they qualify as an extended service), most P/T governments offer various degrees of support through their health insurance programmes; however, they differ widely in terms of eligibility restrictions, user fees, limits on services, and fees for drugs for post-hospital care (CHCA, 2004a; Romanow, 2002; Shapiro, 2002). As previously mentioned, community and homecare services are the fastest growing sector of the health care system (Romanow, 2002; Coyte & Young, 1997; Williams, 1996). For example, in 1975, homecare costs were estimated at $26 million; at $2.7

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[5] The Canada Health Act (1984) stipulates that health care is to be comprehensive (provincial health plans must cover all medically-necessary services provided in-hospital or by physicians); universal (equal access to all residents); accessible (reasonable access with no extra charges for the patient); portable (the services that one has under their own provincial health insurance plan is recognised when travelling outside their home province); and, publicly administered (administered by a not-for-profit organisation responsible to the provincial government) (Kirby & LeBreton, 2002).

billion in 2001 (Romanow, 2003) and at $3.4 billion in 2003/04 (Canadian Institute for Health Information, 2007). While substantial, this increase is paralleled with decreases to more expensive, medically-necessary services, such as hospital care (Romanow, 2003). With access to P/EOL care services so drastically uneven, it was recognised that they should be designated as core homecare services (CHCA; 2004a) and that the Canada Health Act be amended to include mandatory coverage for palliative homecare services (Romanow, 2002). To this end, commitment by the federal government for $3 billion dollars to improve homecare in key areas, including palliative care, was announced in June 2004 (CHCA, 2004b). Furthermore, the Ontario government announced it would provide up to $115.5 million to improve the end-of-life care strategy in Ontario (Ministry of Health and Long-term Care [MOHLTC], 2005). This money is targeted at CCACs, residential hospices and hospice volunteers to improve services at home and in the community (MOHLTC, 2005). Despite investment in homecare, it is still underfunded and differentially available, such that informal FCGs are assuming increasing responsibility for care. In addition to this investment in palliative home services, the need for FCGs to have protected leave from work to provide care has been recognised (Carstairs, 2005). One progressive policy that has been implemented in Canada is the recently created Compassionate Care Benefit (CCB). This is a form of employment insurance wherein caregivers (as designated by the patient) may apply for up to six weeks paid leave from their job to care for a gravely ill or dying family members (Service Canada, 2007).

1.2.2 Health Care Services

As discussed at the beginning of this chapter, the reorganisation of health care in most developed countries has seen the devolution of health care from traditional institutions - such as hospitals, to the community, and particularly to the home environment (Romanow, 2002; Chochinov & Kristjanson, 1998; Coyte & Young, 1997). Restructuring is part of a broader set of social, political and economic processes that began in Canada during the 1970s and dominated in the 1990s (Finkel, 2006). These processes were designed to reduce governments' role in the provision of social services through deep cuts to spending and increased reliance on markets to fill the gaps (Finkel, 2006). In addition to deinstitutionalisation, processes have included privatisation, regionalisation and the delisting of services once covered under the CHA. Increased wait times for services, hospital closures and user fees are now commonly experienced by consumers of health care.

The growth of homecare has been spurred by cost cutting measures, the need for continuing care outside of hospitals, and changing ideals for health care delivery and health prevention (CIHI, 2007). Homecare encompasses an assortment of services provided in the home and community setting, including:

> "health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration and support for the informal (family) caregiver" [emphasis added] (CHCA, 2004a; pp. 3)

In Ontario, community level services, including access to homecare, are delivered through local Community Care Access Centres (CCACs). Forty-three such centres were implemented in Ontario in 1996 to organise and deliver community-level health care services. They do not provide the services, but offer a single point of access to them (MOHLTC, 2007). Clients may be eligible to receive some of these services free of charge through the system while others may be subject to user fees. These services include: nursing; medical supplies and equipment; personal support and homemaking; and, therapy services (MOHLTC, 2007). Additionally, CCACs provide access to community support services, including: "meals on wheels" and "wheels to meals", security checks, and respite (in home, adult day programmes and short-stay respite). Community support services are most often subject to user fees (MOHLTC, 2007a). CCACs operate under a managed competition format, wherein both for-profit and not-for-profit (private/public) service providers bid for the opportunity to provide services. The goal of this system was to improve the quality of services through a competitive format. Prior to this, most services were provided by large, well-established non-profit organisations (such as the Victoria Order of Nurses) (Williams, 1996; 2006).

In an effort to better meet health care needs, the Ontario government recently undertook further restructuring. As of April 2007, the health districts in Ontario have been reorganised into 14 local health integration networks (LHINs) (MOHLTC, 2007b). According to the ministry website, LHINs will receive almost 2/3 of the Ontario health care budget to develop and fund services at their local levels. This includes control over: hospitals, CCACs, community support service organisations, mental health and addiction agencies, community health centres and long-term care homes (MOHLTC, 2007b). In northern Ontario, the seven districts that once comprised the northern Ontario health region have been collapsed into two LHINs: the North East and North West regions. The North East LHIN, where this study took place, encompasses five of the seven former districts of the northern-Ontario health region (MOHLTC, 2007; Bains, Dall, Hay, Pacey, Sarkella & Ward, n.d). CCACs have been reorganised to correspond with the LHINS, and the former area offices have been retained as branch offices across the LHIN.

1.2.3 Rural Health Care

Rural areas have been hard-hit by restructuring, as services that were typically offered at the community level have become centralised in large centres. Budget cuts and the managed competition format of long-term care in Ontario have compromised the delivery of care in rural areas by reducing or eliminating services (Cloutier-Fisher & Skinner, 2006; Williams, 2006; Cloutier-Fisher & Joseph, 2000; see also Abelson et al, 2004). For example, homecare workers face reduced hours, depressed wages and job elimination due to the bidding process of CCACs, which encourages provider agencies to deliver services as cheaply as possible. The above-noted work suggests that whereas clients may face discontinuity of services in urban areas, those living in rural areas may be subject to limited or no access.

The restructuring of rural communities that has resulted from economic forces, such as globalisation, industrialisation and capitalism, has meant that fewer goods and services (including health services) are available locally to rural residents (Troughton, 1999). This creates an environment that forces residents to travel long distances (often facing harsh weather conditions or insufficient infrastructure) to seek health care, or to do without (Bull & Bane, 1993). In addition to the conditions of travel and the distance involved, travelling involves personal expenses, as well as time away from family, employment and social supports. The lack of resources has put increased pressure on families to provide care. These service changes are especially troublesome for those suffering from acute illnesses requiring sophisticated treatments (i.e. chemotherapies, dialysis, etc.), as well as for those who wish to remain and die at home. Arguably, access to resources is the largest contributor to the comparatively lower level health status of rural populations (CIHI, 2006; Kirby & LeBreton, 2002; MACRH, 2002; Romanow, 2002) when compared to their urban counterparts. Specific demographics in rural areas contribute to lower level health status, wherein rural populations in general are of lower socio-economic status due to higher unemployment rates and lower education levels (Kirby & LeBreton, 2002). This may affect both the propensity and ability to seek medical attention. Research indicates that rural residents will delay seeing a physician until symptoms are very severe because of the distance they must travel (Huttlinger, Schaller-Ayers, Lawson, Ayers, 2003). The comparatively lower level heath status has been noted along such indicators as shorter than average life expectancies, and higher mortality and infant mortality rates (CIHI, 2006; Kirby & LeBreton, 2002). According to a Statistics Canada report, rural and northern regions show higher levels of arthritis/rheumatism and depression, higher levels of obesity and high blood pressure and lower levels of self-reported functional health, self-assessed health status and health promoting behaviours (Mitura & Bollman, 2003; see also CIHI, 2006). Additionally, rural populations experience higher incidences of accidents, suicides and disability. Some of these disparities may be explained by the predominance of primary sector employment in rural areas. The noted disparities in health are generally found around the world (Strasser, 2003) and in this regard, it has been said that "geography is a determinant of health" (Romanow, 2002).

1.2.4 Social and Demographic Characteristics

In Canada, anywhere from 21% to 30% of the population is living in rural areas, depending on the definition used (du Plessis, Beshiri, & Bollman, 2002; MACRH, 2002). Rural areas have diverse cultural and demographic characteristics compared to their urban counterparts, including high proportions of elderly and children and low proportions of the working age. Rural areas also tend to have higher proportions of Aboriginal and fewer immigrant and visible minority populations (CIHI, 2006; MACRH, 2002).

The delivery of services is problematical in Ontario given that they are arranged for and delivered from one central area (through CCACs) and spread across broad geographic areas. While having one-point access is beneficial, clearly service availability will differ from one community to the next. The newly-created LHINs and corresponding CCACs are an improvement in this area to meet the needs of the population; however, the basic problems (i.e. physician shortages and the centralisation of resources) will continue to plague rural populations when accessing resources.

1.2.5 Palliative Care in Rural Areas

Specific to palliative care services, there is a sense that rural communities are unique in terms of the provision of support to their residents. Palliative care services are typically developed in urban areas and are applied to the population at large (Evans et al., 2003; Williams, 1996). Rural areas face challenges in delivering palliative care services because the population is thinly distributed over wide geographic areas; there are fewer specialists and there tends to be higher proportions of elderly populations with fewer family supports. Physician recruitment and retention are problematic and the high turnover of health care professionals in rural areas in general interrupts continuity of services and rapport with patients (Huttlinger et al, 2003). Additionally, service providers suggest they lack training and experience specific to palliative care (Kelley, Sellick & Linkewich, 2003). Improving the education of health care service providers in the area of palliative care has proven beneficial for delivery of palliative care services (Kelley, Habjan & Aegard, 2004; Kristjanson, Dudgeon, Nelson, Henteleff & Balneaves, 1997), where the knowledge learned has been applied and shared with other service providers. At the community level, there are fewer palliative care situations in which to develop knowledge and implement strategies to meet the needs of the dying and their families. Physician shortages in rural areas necessitate that health care providers such as nurses and social workers, as well as volunteers, play larger roles in the delivery of palliative care (Evans et al., 2003; Kelley, et al., 2003). Due to the fact that many of these non-physician service providers are generalists rather than palliative care specialists (Kelley et al, 2003; McRae et al, 2000; Community Care Access Centres for the Districts of Thunder Bay and Kenora and Rainy River [CCAC-TB/KRR], 2005), the quality of service is called into question. This is in contrast to large urban centres where patients and families are served by a long-established palliative homecare teams with all types of providers specialized in providing P/EOL care (Williams, 1996). Further, rural areas tend to lack organised volunteer programs designed to support patients and families at home and such programmes face issues surrounding liability and lack of remuneration for travelling expenses incurred by volunteers (CCAC-TB/KRR, 2005; Kelley et al, 2004, 2005). Despite increased palliative care education, barriers still exist; these include insufficient home care support, inadequate funding for supplies and equipment, lack of access to specialised care facilities, and problems with continued communication and coordination of services (Kelley et al., 2004; MacLean & Kelley, 2001). Numerous other gaps exist in services, including access to adequate respite services, dedicated palliative care beds, and specialised hospital services. As such, it is sometimes impossible to keep people in their communities to die.

1.2.6 Changing Demographics

Changes to the delivery of health care have resulted in increased demands on family members to provide care and this will increase as the population ages. Changing social and demographic structures complicate family member's ability to provide care (Fast & Keating, 2000). For example, women's increased involvement in the workforce and higher proportions of single-parent families will mean that fewer women will be available to provide care. Migration patterns affect rural populations leading to ageing-in-place (Bryant & Joseph, 2001). The out-migration of youth and the in-migration of elderly from urban centres in retirement impact population and contribute to higher than average rates of the elderly in rural areas. This can impact both the need for care and the availability of support networks to provide such care. The implications of these changes to the health care system and society in general are significant, especially for women, as care is most often provided by women (Keating, Fast, Frederick, Cranswick & Perrier, 1999; Martin, 2003; McKeever, 1999). It appears that at a time when the family structure is most vulnerable and least able to provide care, they are expected to do more.

1.2.7 Caregiving

A caregiver is anyone who provides a variety of support and services to those in need (Keating et al., 1999; Fast & Keating 2000; Pearlin, Mullan, Semple & Skaff, 1990); typically this refers to situations in which someone may suffer or even die (Baines, Evans & Neysmith, 1991). Caregivers are usually family members or close friends providing unpaid care in the home; they are not accountable to standards of conduct or practice (Graham, 1991). Recent statistics from the National Profile of Family Caregivers in Canada (2002) suggests that 4% of adult Canadians care for a family member who is frail, chronically-ill or has a physical or mental disability (Martin, 2003). Furthermore, an estimated 80-90% of care in the *home* – worth an estimated two billion hours of care per year - is provided by family members and friends (Romanow, 2002).

1.2.7.1 Components of Caregiving

Components of caregiving are distinguished as objective (the tasks involved) and subjective (the positive or negative experiences of caring) (Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt, & van den Bos, 1998). Caregiver burden is referred to as the financial, social, physical and temporal constraints of family caregiving (Gaugler, Hanna, Linder, Given, Tolbert & Kataria, et al., 2005; Nijboer, Triemstra, Tempelaar, Sanderman, van den Bos, 1999). Numerous factors contributing to caregiver burden (as noted below) are well documented in the literature and most studies have examined caregiver burden in relation to caring for patients with cancer (Haley, 2003) or with dementia diseases (Schulz, O'Brien, Bookwala, Fleissner, 1995). Studies specific to other diseases, such as HIV/AIDS (Clipp, Adinolfi, Forrest, & Bennett, 1995), heart disease and chronic obstructive pulmonary disease (COPD) are less represented (Exley, Field, Jones & Stokes, 2005). Many of the studies address the stresses of caregiving in general, and interest in caregiving at end-of-life has only recently intensified. Conceptualising the positive aspects of caregiving is receiving increased attention in an effort to produce a holistic account of the experience (Chappell & Reid, 2002). The remainder of this review summarises the work done in caregiving in general, with specific studies on palliative caregiving highlighted.

Caregiving is a complex and multi-dimensional process, affecting and influenced by a number of inter-related factors, with consequences to the health and well-being of caregivers (Haley, 2003; Hauser & Kramer, 2004). Caregivers become an active part of the caregiving team, often with little or no training, sometimes under sudden or extreme circumstances (Glajchen, Kornblith, Homel, Fraidin, Mauskop &

Portenoy, 2005), and usually with little choice (Stajduhar & Davies, 2005). Palliative caregiving is viewed as being unique to other types of caregiving in that it involves both actively caring for the patient and preparing for and grieving the impending death of a loved one (Rhodes & Shaw, 1999). Caregivers must stand by and witness the deterioration of their loved-one (Grbich, Parker & Maddocks, 2001), and have described the experience of caregiving as existing within a suspended and unreal world (Strang, Koop & Peden, 2002). As the majority of care takes place in the home prior to death, family members are providing *more* care for longer periods of time. The role of the caregiver is variable, depending on the condition of the patient, but involves medical and personal care, looking after household tasks, running errands/performing tasks outside of the home, managing finances, coordinating and taking the patient to appointments (Keating et al, 1999), assessing symptoms and making proxy decisions about end of life issues (Haley, 2003). Family members often balance the tasks of caregiving with other responsibilities, such as employment, maintaining a household, and caring for other dependents. Women are more often caregivers than men, although men are taking a more active role. Most recent figures estimate that about 60% of caregivers are women and 40% are men (Fast & Keating, 2000). Men and women perform different tasks in relation to caregiving; women typically provide hands-on and emotional care and men assist more with instrumental tasks, such as maintenance (Decima Research Inc., 2002; Fast & Keating, 2000). Additionally, men are more likely to make greater use of support and services than are women (Fast & Keating, 2000).

1.2.7.2 Health Impacts of Caregiving

FCGs report high levels of shock, disbelief, anxiety and depression (Emanuel, Fairclough, Slutsman & Emanuel, 2000; Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle, 2004; Prigerson, Cherlin, Chen, Kasl, Hurseler, & Bradley, 2003); this can be more pronounced in the caregivers than the patients themselves. A number of characteristics have been found to contribute to FCGs experiencing high levels of distress, including: perceptions of burden; perceived lack of support; balancing other responsibilities with caregiving; restrictions on personal activities due to caregiving; and, insufficient physician communication (Cameron, Franche, Cheung & Stewart, 2002; Emanuel et al, 2000; Goldstein, Concato, Fried, Kasl, Johnson-Hurzeler & Bradley, 2004; Kirk, Kirk, & Kristjanson, 2004). Often, the higher levels of psychological distress that are experienced as the patient's mobility decreases are due to *caregiver burden* rather than to the physical condition of the patient exclusively (Dumont, Turgeon, Allard, Gagnon, Charbonneau & Vezina, 2006). Women (especially younger caregivers) experience higher levels of psychological distress. This is likely due to their complex roles as that they normally balance caregiving with other household responsibilities (Dumont et al, 2006; Nijboer et al, 1998). Research indicates that caregivers who report mental or emotional strain have an increased risk for mortality than non-caregivers (Schulz & Beach, 1999). Some caregivers experience feelings of guilt and failure if they are unable to sustain care for their loved-one in the home (Stajduhar & Davies, 1998). Caregivers who lived alone with the patient experienced more distress than those living with other family members (Nijboer et al, 1998).

FCGs report having high information needs and often do not know what they need until they need it (Aoun, et al., 2005; Dunbrack, 2005; Kirk et al, 2004; Stajduhar, 2003; McCorkle & Pasacreta, 2001). Caregiver needs can generally be grouped into four types of care needs: patient comfort; caregiver information needs; practical care needs; and emotional support (Aoun et al., 2005). FCGs value getting the information in an easy-to-understand manner (Devery, Lennie & Cooney, 1999; Kirk, et al., 2005) and find that the ability to get information is empowering - giving them a sense of control in the situation (Wilkes, White & O'Riordan, 2000). Often information is provided as a form of crisis intervention, and those who appear to be coping are not assumed to have unmet needs (Aoun et al., 2005). Harding and Higginson (2001) found that caregivers experience high levels of stress, anxiety and need, but were ambivalent about seeking help for these needs. There are several reasons for non-disclosure, including: not wanting to put their needs ahead of the patient; not wanting to be judged as inadequate in their caring; and believing that the distress they are experiencing is a normal part of the process and cannot therefore be improved (Aoun et al., 2005). It is suggested, however, that if approached, most FCGs are willing to talk, but would prefer to do so in private, away from the patient.

FCGs appear to believe that physicians should be the primary source for information, for receiving details that are related to the disease, treatment and services available (Wilkes et al., 2000; Payne, Smith & Dean, 1999). FCGs feel frustrated and helpless when physicians are not available. In fact, most of the information received was from nurses; it was found that without nurses, FCGs would have been unable to manage.

A study that focused on the information of needs of FCGs in rural areas found that these needs tend to be similar to those FCGs in urban areas, although needs appear to be heightened for rural FCGs given the lack of support (including infrequent homecare visits) and the resultant increased requirement to care (Wilkes et al., 2000).

The impacts of caregiving on caregiver health are well documented in the literature and include: chronic fatigue, physical exhaustion, depression, sleeplessness/sleep deprivation, burnout, deterioration in health, increased susceptibility to illness, and increased risk for mortality (Goldstein et al, 2004 Grunfeld et al, 2004; Ladner & Cuellar, 2003; Prigerson et al, 2003; Carter & Chang, 2000; Emanuel et al, 2000; Schulz & Beach, 1999).

Many factors contribute to depression. It can, for example, be heightened by exposure to various distressing patient experiences that evoke feelings of fear and helplessness, including: witnessing pain, discomfort, delirium, confusion, choking, falling, and hopelessness (Prigerson et al, 2003). Additionally, depression may be attributed to feelings of overload and therefore being unable to meet personal obligations, or to the potential loss of a life partner (Ladner & Cuellar, 2003).

In addition to high levels of depression, caregivers suffer from sleep deprivation (Carter & Chang, 2000) which contributes to daytime dysfunction. Findings from Carter and Chang's study indicate that caregivers were often prescribed but reluctant to use sleep medications for fear of diminishing their capacity to care for the patient. To alleviate stress, FCGs often require breaks from the caregiving situation. FCGs tend to distinguish between mental (emotional) and physical breaks (Strang et al., 2002). Emotional breaks (referred to as 'respite'), were seen as freedom from the responsibility and worry of the caregiving situation and could be achieved in residence, whereas physical breaks (referred to as "taking a break"), involved separation from the caregiving environment. While caregivers recognised the need to get away from home, they were reluctant to do so, often experiencing anxiety and worry over what may transpire in their absence (Strang et al., 2002; Harding & Higginson, 2001). FCGs recognised that their role as a caregiver was limited in time, and that death was imminent. Respite was only beneficial if it contributed to managing the caregiving experience. Conversely, bereavement was described as very intense following the cessation of caregiving and the completion of the funeral, with caregivers often feeling the need to escape the home environment (Grbich et al, 2001). This was particularly prevalent for patients who experienced a home death compared to a hospital death.

Not all caregivers identify with their role and will often put their own needs on hold to care for the patient because they feel it is their duty (Harding & Higginson, 2001). FCGs seem to value self-reliance and independence; they are often reluctant to ask for help, especially from family friends (Payne et al., 1999).

Caregivers of lower socio-economic status are subjectively more overburdened (William, Forbes, Mitchell, Essar, & Corbett, 2003; Nijboer et al, 1998). They are found to provide more hours of care and report more negative consequences to their emotional, physical and financial health. They experience higher degrees of powerlessness, isolation and loneliness, likely attributable to the increased time spent in the caregiver role. Lower-income caregivers are more likely to engage in negative behaviours to alleviate stress (for example, use more caffeine and prescription medications) than higher income caregivers and, while they may have a stronger interest in utilising available services such as nurses and homecare support, they are less likely to do so because of a lack of awareness of the availability of services and and/or ability to access them. However, higher levels of self-esteem seem to be associated with caregivers with lower levels of education (Nijboer et al, 1998). It is postulated that caregivers of higher socio-economic status find their tasks less rewarding when compared with their professional roles and other intellectually-stimulating activities.

The financial impact of caregiving is complex, as it involves more than just out-of-pocket expenses that families incur over the process. It includes the loss of wages and potential wages, as caregivers may need to put career or employment opportunities on hold while they engage in caregiving (Wyatt, Friedman, Given, & Given, 1999). The economic impact of caring is higher for caregivers without extended health care coverage (Grunfeld et al, 2004) and for those families where the patient was the primary income earner. Furthermore, patients with high care needs experienced greater financial burden. Patients who are cared for at home may incur more expenses than those in institutions, including costs of nursing/home support (including respite), pharmaceuticals and equipment rental and/or purchase. In the home setting, the degree to which these are available to families varies, sometimes resulting in considerable expense (Chochinov & Kristjanson, 1998).

The experience of caregiving is also known to positively influence family caregivers psychologically while facilitating the bereavement process (Hauser & Kramer, 2004). Koop and Strang (2003) report on the effects of home-based palliative caregiving on bereavement and find that the pride caregivers felt as result of their accomplishments in caregiving contributed to a healthy bereavement; they further suggest that caregivers should be advised to contemplate the rewarding part of the experience while they are caregiving. Some caregivers describe the experience as life-enriching (Stajduhar, 2003). Themes that have been identified include: reciprocity (Cohen, Colantonio & Vernich, 2002), pride, self-efficacy, and self worth (Hauser & Kramer, 2004). Noon and Tennstedt (1997) suggest that meaning in caregiving, which is the positive beliefs of one's self *and* the caregiving experience that enables one to derive benefit from it, accounts for differences in depression and self-esteem. It is clear that, despite the stress inherent with caregiving, it can be a very rewarding experience if the support provided is adequate.

1.2.7.3 Rural Caregiving

There are comparatively fewer studies that exist on rural palliative care issues, especially in Canada; of those that do, the primary focus is on the perspectives of service providers and not FCGs (i.e. see Wilson, et al., 2006; Hughes et al,. 2004; Evans et al., 2003; McRae, et al., 2000). Furthermore, these studies do not typically focus on health as a component of the caregiving experience. Most significantly, there are fewer incidents of home-based palliative care in rural and remote communities - in some cases no incidents at all - because few services exist to support caregivers and meet patient needs (Wilson et al., 2006; CCAC-TB/KRR, 2005; Hughes et al., 2004; Evans et al., 2003). This is especially true in more remote areas (including First Nation communities), where those dying are often removed from their communities and families and, therefore, their traditional ways of life (Hotson, Macdonald, & Martin, 2004). Home death may be inhibited when FCGs are unable to purchase extra support (McRae, 2000). In addition to the lack of support, beliefs that home death is inappropriate or that care and/or the death cannot be handled at home are common (CCAC-TB/KRR, 2005). In some cases, death at home is not an option, even if family members want to provide care, because of the lack of support available. To access respite opportunities, it is often necessary to transport the patient to a facility located outside the community (CCAC-TB/KRR, 2005).

Studies suggest that FCGS are in general satisfied with the services they received at the local level; however, problems in terms of accessing tertiary care and quality of services received in hospitals have been noted (Hughes, et al., 2004; McCrae, 2000). It appears that, in addition to formal support, rural FCGs rely heavily the support of family and friends (Hughes, et al, 2004). Additionally, rural FCGs experience problems with transporting patients to various appointments (Thomas, Morris & Harman, 2002); long distances, difficult roads, the inconvenience of the hospital's location, as well as the discomfort experienced by the patient were cited. Additionally, many carers did not own or have access to a vehicle, making access problematic, while others felt burdened when they had to balance work or other commitments with travelling.

1.2.7.4 Caregiving and the Home Environment

There is a growing body of research, particularly in geography, that has expanded the understanding of caregiving in the home. Feminist geographers have challenged normalized ideas on home space and families, explicating how social and cultural discourses affect the relationships one has with home (see Dyck, 2001; Dyck et al, 2005; Williams, 2002). They suggest, for example, that as health care enters the home, it becomes a site of labour for both paid health service providers and unpaid FCGs. Furthermore, the meanings and activities that represent the lived home experience will be disturbed as care enters the home, especially when adaptive or medical services are involved (Dyck et al, 2005). Milligan (2000) regards the shift in care to the home as a blurring of boundaries between public and private space (pp. 56). She argues that community-based care may be better described as the institutionalisation of private space, as domestic space merges with public services to become a site for caring. Brown (2004), an American geographer, proposes that issues around hospice (Canada's equivalent to P/EOL care), including autonomy and freedom, are typically framed in discussions of justice for the *dying* and that home hospice is only possible through the surrender of autonomy and freedom on the part of the caregiver. He demonstrates how care in the home creates an increased *and* unequal division of labour to the disadvantage of women, and that such inequalities are "clouded behind the freedom one has to die at home" (Brown, 2004; pp.79).

The provision of palliative care in the home can affect the physical and social environments (Grbich et al., 2001; Milligan, 2000; Stajduhar, 2003; Williams, 2004) but, as yet, the home itself as a variable in the caregiving process has yet to be fully explored (Williams, 2002). The home is transformed physically by the addition of medical equipment, such as oxygen machines and pain pumps, and where possible, by aides such as lifts and bathroom accessories to facilitate care (Aoun et al, 2005; Williams, 2004). Other alterations may include the reconfiguration of certain rooms to become the "sick-room" along with the erection of spiritual alters or markers. For some caregivers and family members, the death of a loved-one in the home may change the attachment they feel towards it in general or to the room in which the patient died in particular (Williams, 1998; Koop & Strang, 2003). Some homes may not be conducive to adaptation; for example, the doorways are not wide enough to accommodate wheel chairs, or there is little room for the addition of lifts and hospital beds (Donovan & Williams, forthcoming; Williams, 2004). While caregiving in the home may produce feelings of pride, self-efficacy and self worth, it may also engender feelings of oppression, guilt, ambivalence and loss of personal identity (Hauser & Kramer, 2004; Koop & Strang, 2003; Williams, 2004; Stajduhar, 2003; Cohen et al, 2002; Harding & Higginson, 2001; Ramirez, Addington-Hall, & Richards, 1998). These feelings arise from the reaction to caregiving and the ability or inability to manage the caregiving situation and facilitate a home death (if that is what is desired). For example, some feel a loss of privacy as a result of the multiple health care professionals in and out of home. FCGs must renegotiate their identities and activities in relation to place as the nature of caregiving changes (Wiles, 2003). They may be unable to forgo employment to provide care, thereby experiencing greater stress which may lead to caregiver burn-out. Rousch and Cox (2000) and Williams (2004) point out that it is essential to allow clients (patients and FCGs) to maintain control over the home environment to empower them in the caregiving experience. Transformations to both the home environment and to life circumstances to provide care can impact health during and after caregiving (Williams, 2002).

1.3 Chapter Conclusions: Summary of the Research Problem

Changes to the delivery of health care have resulted in FCGs having to assume greater responsibility for care in the home; this includes the challenges of providing care for their terminally-ill loved-ones at end of life. FCGs may or may not wish to provide this care, but are impelled to do so if it is their loved-one's wish to die at home. Often the demands of this care are so overwhelming that they are unable to manage; if they do manage, it is generally with consequences to their own health and well-being. While supportive services can help mitigate against caregiver burden, access to such services are fragmented or non-existent; this is especially true of both formal and informal supports in rural areas.

The demands for P/EOL care in the home will increase as the population ages and rural areas are likely to face further challenges in terms of meeting patient/family needs given the effect of out-migration and ageing-in-place. The recent injection of funding by both levels of government into P/EOL care services suggests that the timing is optimal for research that can help provide evidence for the allocation of resources and the development and/or enhancement of appropriate services and programmes. It is imperative that this evidence base include the perspectives of FCGs providing care in the home, as home death would not be possible without them. Therefore, given that rural-dwelling FCGs lack access to supportive services, the purpose of this research is to examine how they manage caring for their loved-ones in the home and how this may affect their self-assessed health. A description of the research methodologies used in this study is presented in Chapter Two.

Chapter Two

Methodology

This section contains a description of the methodology used in the study, including the rationale for the paradigmatic approach and the methods employed, as well as evidence of scientific rigour. Additionally, the complexities of conducting sensitive research with vulnerable populations are highlighted, as are the benefits and challenges of corroborating with community organisations in the research process. The chapter begins with a prologue to highlight the research protocol and explains how the research design was adapted due to various challenges over the course of the study.

2.1 Prologue

This research was undertaken using a holistic case study design, relying on both qualitative and quantitative methods for data collection. This study took place in northern Ontario, Canada. Originally, the plan was to recruit participants through the CCAC in one specific health district, although due to problems with recruitment, this was expanded to encompass all CCACs in northern Ontario; in actuality, just two districts did participate. Five cases made up the sample; two FCGs resided within the catchment area of one CCAC district and three resided in the other. The sample was represented by one male and four female caregivers. To capture the process over time, a longitudinal approach was used, with FCGs interviewed an average of three times during caregiving and while in bereavement. The interviews with FCGs provided the primary source of data, and were used along with two types of surveys, direct observations, field notes, and other documents (as indicated in Table 2.1; attached as **Appendix One**). Significant difficulties were encountered over the course of the study, most notably in establishing a collaborative relationship with the originally-proposed CCAC and in recruiting participants; these problems led to delays in data collection. As a result, several design amendments were necessary to achieve the targeted sample. Due to the delays, data collection was not completed until late May 2007. Given the voluminous amounts of information gathered and the time limits in which to complete this study, it was not possible to undertake analysis on all of the data collected; for the purposes of this thesis, the survey data were excluded from analysis. The focus here is on the analysis of data collected through the interviews, direct observations, documents and field notes; however, the survey data was used as a confirmatory data source. The remainder of the chapter contains a detailed description of the entire research protocol, as originally proposed, with the changes that were made indicated where appropriate. The rationale for each of the design changes, all approved by the McMaster Research Ethics Board (MREB), is explained, in order of occurrence, in Section 2.6.

2.2 Research Paradigm

Given that there is little research evidence accounting for the perspectives of FCGs living in rural areas in Canada, qualitative methodologies were deemed most appropriate for this study. Methodology refers to "a set of rules and procedures which indicate[s] how research and argument are to be conducted" (Johnston, 1986; pp5).

These rules reflect a paradigm that is based on beliefs about what can be known (epistemology) and how it can be known (ontology). Qualitative research is a field of inquiry based on distinct methodological traditions that seeks to understand and explain phenomenon in their natural settings in terms of the meanings people bring to them (Denzin & Lincoln, 2000; Creswell, 1998). In contrast to quantitative approaches [that are primarily positivistic in nature and include, among their differences, the belief that reality "exists" and can be "studied, captured and understood" (Denzin & Lincoln, 2000; pp. 9)], qualitative research is premised on the understanding that there are multiple versions of reality. The findings of a qualitative study are primarily interpretive and the researcher is recognized as an instrument in this process. The aim of a qualitative study is to produce a complex and holistic picture of the phenomenon in question - as Merriam (1998) suggests, "[to] reveal how all the parts work together to form the whole" (pp. 6). This is in contrast to quantitative methods that commonly emphasise causal relationships between variables (Denzin & Lincoln, 2000; pp.8). Qualitative methods are appropriate to use to understand phenomenon that are not well-known or understood (Creswell, 1998) or for areas of research not amenable to quantitative methods (Pope and Mays, 1995).

Qualitative methods seek to explain phenomena in terms of the meaning people bring to them, while identifying (or considering) the importance of the *context* for these experiences; in health geography, this pertains to the relationships between people, their environments and health. Consistent with the shift from the largely *atheoretical* tradition of medical geography to the theoretically informed health geography (i.e. Kearns, 1993; Kearns & Moon, 2002) as discussed in Chapter One, qualitative research methods are increasingly being used to "produce place-sensitive and subject-centered analyses of the geographical dimensions of health and health care" (Dyck, 1999). Used on their own or in conjunction with quantitative methods, qualitative methods have influenced the way questions are framed and how experiences are conceptualised as they relate to illness, disability, health and health care (Dyck, 1999).

2.3 Research Design: Case Study

A case study design was used in this study to explore and understand the experiences of FCGs caring for their palliative loved-ones in the home. According to Yin (2003), a research design is "the logic that links the data to be collected (and the conclusions to be drawn) to the initial questions of study" (pp. 19). A case study "is an exploration of a "bounded system" or a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context" (Creswell, 1998; pp. 61). This strategy is often used to answer "how" and "why" questions, to understand complex phenomenon in their context and in situations when the researcher cannot manipulate the behaviour of those involved in the study (Yin, 2003). A major strength of the case study is that it facilitates the use of multiple sources of data, which should converge in a triangulating fashion (Yin, 2003). In other words, different sources can be selected and utilised because they are valuable in their own right and, when used together, offer a more robust understanding of the phenomenon. It was chosen here as an appropriate strategy to combine and analyse data collected (through both qualitative and quantitative methods) to best understand the experience. The case studies herein represent what Stake (2000) refers to as instrumental in nature; that is, it is not so much the case itself that is of interest as the issue the case represents. In this study, the focus is on the understanding of how FCGs manage the experience within the context of health care restructuring. A holistic[6] multiple-case study design (Yin, 2003) was used in this longitudinal study. Fast and Keating (2000) suggest that little is known concerning how the caregiving situation changes over time; in this regard, a longitudinal approach was used to better understand and potentially identify specific factors that may contribute to or mitigate caregiver burden over the caregiving process. Each FCG was treated as an individual case (see Section 2.3.3, Sample) primarily due to the longitudinal component of the study. As Yin (2003) states that:

> "[t]he theory of interest would likely specify how certain conditions change over time, and the desired time intervals to be selected would reflect the presumed stages at which the changes should reveal themselves." (pp. 42)

Therefore - and because each FCG represented "a" case - the decision was made to use a multiple-case study design, for "the single case study cannot be regarded as a complete study on its own" (Yin, 2003; pp. 42). The original design protocol is outlined herein with the changes that were made discussed in detail. First, the research propositions and research questions are reviewed; this is followed by the strategies used in the selection of the sample, recruitment, data collection and analysis. Ethical consideration, the role of the researcher in the research process, as well as the amendments made to the original protocol, complete the chapter.

2.3.1 Research Propositions

Propositions represent the theoretical orientation of the study (Yin, 2003). As such, they guide the researcher in meeting the objectives of the design through the collection and analysis of data. The propositions guiding this study were:

1. Access to support (both formal and informal) can minimise caregiver burden;
2. FCGs (engaging in P/EOL care) living in rural areas will experience high degrees of caregiver burden because they lack the support (formal and informal) that can sustain them in the caregiver role; and
3. High levels of burden will translate into decreased self-assessed health status.

2.3.2 Research Questions

Research questions help define both the *scope* of the study as well as the *type* of study to conduct (Yin, 2003). Given the limited understanding concerning the experiences of rural-dwelling FCGs providing home-based care to their palliative loved-ones, particularly in a Canadian context, along with the known challenges in

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[6] Yin (2003) defines a holistic study as one that encompasses the global nature of phenomenon and an embedded study as one that studies several units of analysis within the study. Given that the focus was on the experiences of FCGs, it was holistic in nature.

accessing rural health care resources (as discussed in the previous Chapter), the following two research questions were posed:

1. How do FCGs who are living in rural areas manage home-based palliative care?
2. How does this experience affect their self-assessed health?

Further, the objectives of this research were:

1. To understand and describe the palliative caregiving experiences of FCGs living in rural areas, including: the role of a caregiver; how caregivers are prepared for and supported throughout the process; and, their overall satisfaction with the experience;
2. To understand and describe the degree to which caregiver burden is experienced and how this affects their self-assessed health.

2.3.3 Sample

As suggested by Merriam (1998), two levels of sampling are necessary in qualitative case study research. The first level of sampling requires the selection of the case (criteria for case selection) and the second level involves selecting the sample within the case (who/what will be studied). Representing the first level of sampling, each case (also known as the unit of analysis) was defined (or bound) as the home-based palliative caregiving experience of a rural-dwelling FCG. Criteria (representing the 2nd level of sampling) that defined the case included:

- The FCG is the person identified by the patient (client on the CCAC caseload) as providing the majority of care;
- The *patient* is newly assigned to the palliative care (PC) caseload (to facilitate capturing the experience as early in the caregiving process as possible);
- The FCG resides within the catchment area of the participating CCAC (to ensure some degree of homogeneity in terms of formal health service provision);[7]
- Within this catchment area, the FCG's residence must meet the definition of rural; and
- The FCG is comfortable with the research process.

There were no restrictions in terms of age, sex, relationship to patient, and so on. This reflected a sampling strategy based on maximum variation (Patton, 1990), wherein a wide range of cases were sought to accrue as much variation as possible. Three to six cases were seen as an ideal number of cases to target in this study, given the amount of data to be collected and the time available in which to complete the study. This is also reflective of what Yin (2003) refers to as a replication logic, wherein each case is analogous to conducting an experiment. A greater number of cases provides "more compelling support for the initial propositions" (pp. 47). A few cases would be used

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[7] Given that the study was expanded to include other CCACs across the district, this criterion became less of an issue. However, the fact that only two CCACs participated and there were multiple FCGs from each district, it was possible to examine cases across districts on the basis of service provision.

to achieve literal replication - which predicts similar results across the cases. Four or more (ideally six or more) would be indicative of a theoretical replication, in which there may be conflicting results, but for predicatable reasons (Yin, 2003; pg 47). Theoretical replication was achieved in this study because, while the experiences of the FCGs did differ somewhat, the different results can be explained by the propositions in the study (as confirmed through examining a total of five cases). The final sample consisted of five FCGs: four female and one male. Four of the FCGs were Caucausian and one was of Aboriginal descent.

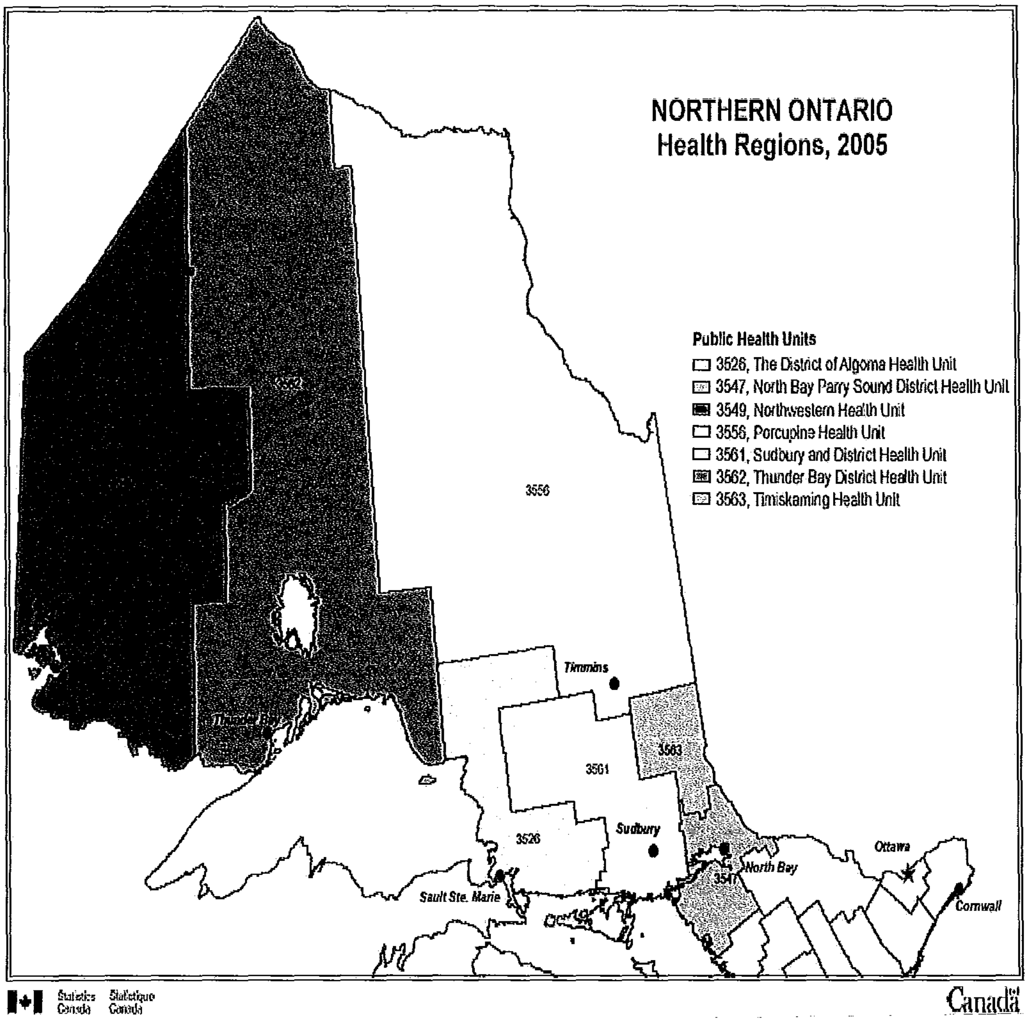
2.3.4 Data Sources

A number of data sources suggested by Yin (2003), were collected in this study, as defined in the original protocol. These sources include interviews (including surveys), direct observations, and documents. The types of data that were collected through these sources as well as the method of their collection are outlined in **Table 2.1 (attached as Appendix One)**. With the exception of the surveys (as mentioned), all of these data sources were used for analysis in this thesis. The value of these multiple sources of evidence contributed to building an in-depth picture of the study and to providing corroborating evidence in what is known as data triangulation (Creswell, 1998; Miles & Huberman, 1994; Patton, 1990), a critical element of research credibility (Baxter & Eyles, 1997).

2.3.5 Study Setting: Northern Ontario

The original protocol proposed that the research be conducted in rural communities situated in one of the seven medically-underserved health regions in northern Ontario represented by the CCACs. This was amended to include all CCACs across the Northern-Ontario health region, as displayed in Figure 2.3.1 [see Section 2.6.4) for details on this amendment]. Ultimately, two CCACs assisted with recruitment but are not named here to protect the anonymity of participants.

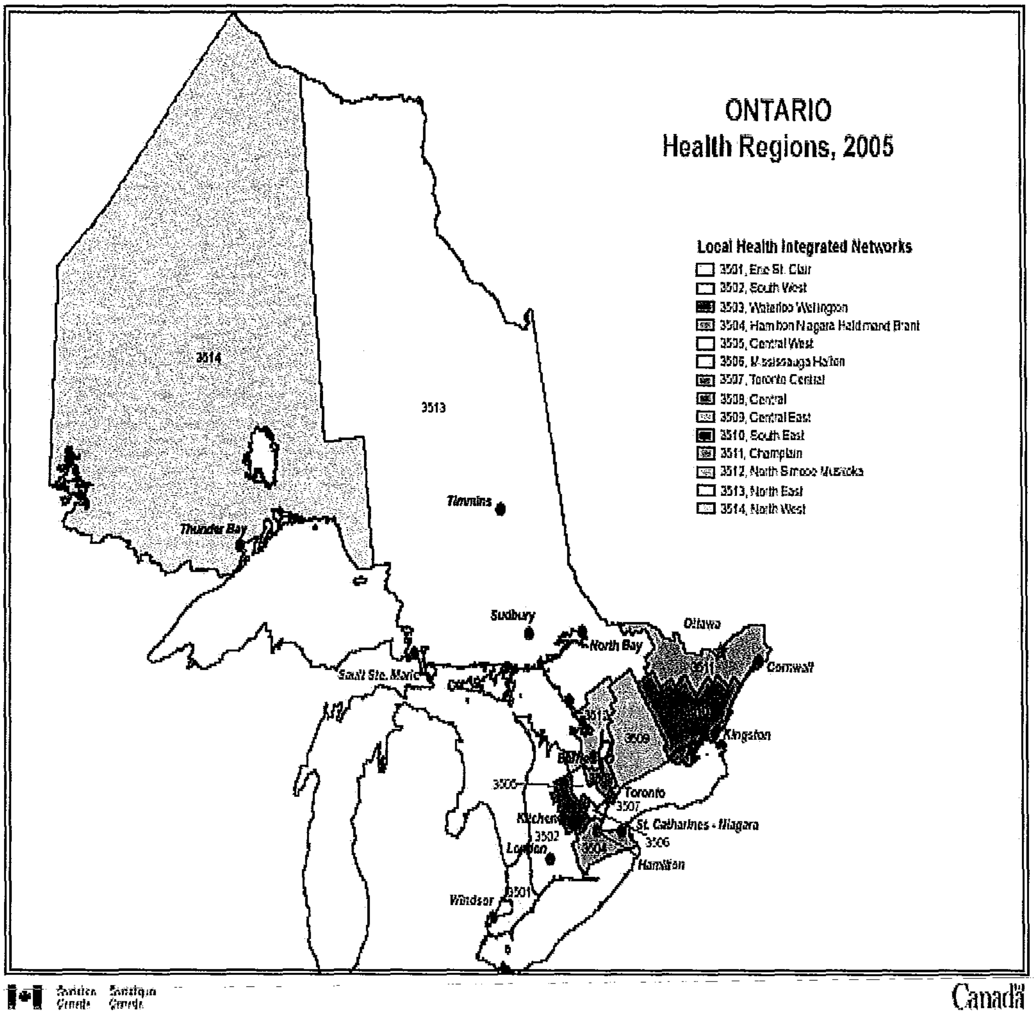
Figure 2.3.1: Northern Ontario Health Regions



Source: Statistics Canada, 2005 (www.statcan.ca)

There were 43 stand-alone CCACs in Ontario at the beginning of the study; however as discussed in Chapter One, both the health districts and the CCACs were restructured over the past year. Across Ontario, the health districts were amalgamated into 14 local health integration networks (LHINs) and in the north, this resulted in the collapse of the seven districts into two LHINs, as illustrated in Figure 2.3.2. The CCACs were reorganised to correspond with these LHINs; while there are now two regional-level CCACs in northern Ontario, the former districts continue to operate as boundaries for CCAC branch offices (OACCAC, 2007).

Figure 2.3.2 Local Health Integration Networks in Ontario



Source: Statistics Canada, 2007 (www.statcan.ca)

The North East LHIN is the region from which the sample was recruited. The following information was taken from the North East LHIN website to provide socio-demographic data specific to the region. This was prepared using Statistics Canada data, by Bains, Dall, Hay, Pacey, Sarkella & Ward (n.d). This area contains about 4.6% of Ontario's population; this figure has steadily declined at a rate of 0.6% per year since 1994. The majority of the population is concentrated in the south-east section of the region, around Sudbury, Sault Ste. Marie and North Bay. Relative to Ontario as a whole, there are higher than average proportions of elderly (15.3% to 12.8%); higher unemployment rates (9.8% to 6.2%) and lower participation rates in the labour force (60.0% to 67.3%). Education levels tend to be lower, with only 42.4% having completed post-secondary education, compared to 48.7% for the province. 8.0% of the population is of Aboriginal descent, compared to 1.7% for the province, and visible minority and immigrant populations account for 1.6% of the population, compared to Ontario's average of 23.9%. Life expectancy rates are significantly lower for both men and women. In this LHIN, females have a life expectancy of 80.5 years and males 75 years, compared to 82.1 and 77.5 years, respectively. In terms of health, the population has higher than average rates of arthritis, rheumatism, high blood pressure, diabetes and heart disease, and significantly lower levels of contact with doctors, than the provincial average (77.2% vs. 81.4%).

Rural was defined as "the population in communities with densities less than 150 people per square kilometre" by the Organization of Economic Co-operation and Development (OECD) (du Plessis et al., 2002). Each health district has one large urban centre and numerous dispersed communities that meet this definition of rural. While there are many ways to define rural (i.e. see Halfacree,1993; Williams & Cutchin, 2002, du Plessis et al., 2002), the OECD definition was chosen in this study because it operates as a common denominator to facilitate comparison within nations and at the international level (du Plessis et al., 2002). As indicated in Sections 2.6.2, the study area and the definition of rural were amended to include an urban/rural comparison within the region, with the entire region being designated as a rural, based on it being a medically-underserviced area.

2.3.6 Recruitment

Given that community-level health care services, including those provided in the home, are organised and delivered throughout the district by stand-alone branches of CCACs, the CCAC was seen as a logical source in which to recruit participants to the study. Participants were recruited to the study from the PC caseload with the assistance of representatives from the CCAC. These representatives were asked to introduce the study to the FCGs of patients on the PC caseload and, if interested, request permission to release their name and telephone number to the me. I contacted each FCG referred by the CCAC by telephone personally to arrange an appointment to go over all aspects of the study, answer any questions and read over the Letter of Information/Consent (attached as **Appendix Two**). Once certain that the FCG was consenting freely to the study, the form was signed and the interview began. This procedure of informed consent was followed at the beginning of each interview for each FCG (in all but one case, the interviews were conducted immediately after signing the form; in that one case, I returned a day later to conduct the interview). The recruitment strategy was amended throughout the study, as indicated in Sections 2.6.4. This included expanding the recruitment base to all CCACs in the region as well as to utilising the acute-care caseload of the CCACs and one visiting hopsice organisation.

Since access to the research site was proposed through CCACs, it was necessary to build and maintain a professional and collaborative relationship. Working with the original CCAC was quite challenging at first, as I had enormous difficulties in getting them to respond to my requests to meet and discuss the research. However, once initial contact was achieved (some three months later and through the intervention of a close friend), I was able to introduce the study and secure their assistance. This was done through justifying the purpose of the study and demonstrating how I was going to protect the rights of the participants.

The response with this CCAC was ambiguous at first – they agreed to help but saw little benefit for themselves, despite my attempt to address any questions/issues in which they were interested into the study. There was some discomfort with the study given their understanding that FCGs and patients are likely in crisis and would not want nor have the time to dedicate to the study. I felt as well that there was hesitation because I was a 'student' researcher; once I met face-to-face with CCAC representatives, they admitted to feeling much more comfortable with the study (the one time my age may have truly been an advantage!). I was aware of some concern on their part, particularly given their gatekeeping actions (Miller et al., 2003)[8] and that, as a result, not all potential participants were being approached. This led to a research design change, specific to recruitment (i.e. changing the terminology "home-based palliative care" to "caring for loved-ones who are facing a life-threatening illness"). This strategy was primarily implemented to increase the pool from which to recruit participants; I felt it also helped circumvent any discomfort the CCAC may have experienced in determining if a FCG was a suitable candidate for the study. For example, as mentioned in Section 2.6.3, not all families (both patients and FCGs) regarded the situation they were facing as *end-of-life*; therefore they were excluded from being invited to the study by the CCAC prior to this amendment.

Once entering the field, I maintained regular contact with CCAC representatives and found they became quite interested in how the study was proceeding and were looking forward to hearing the results of the study. The other CCAC did not express many concerns; while they wanted assurance regarding the ethical component of the study, they accepted my request for assistance immediately. Having only minimal evidence themselves concerning home-based palliative care from FCGs' perspectives, they were interested in expanding this to improve programme delivery. Both participating CCACs will receive a written copy of the report and have the findings presented to them formally, once the analysis is complete.

2.4 Data Collection Methods

2.4.1 Interview Data

The interviews provided the primary source of data. The goal was to meet with the FCGs up to four times over the caregiving process - three times while caregiving and once during bereavement. The first three interviews were targeted to coincide with Pattison's three clinical phases of living-dying: the acute crisis, chronic living-dying and terminal phases (Pattison, 1978).[9] Each phase is characterised by distinct

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[8] Gatekeeping refers to the influence people have on potential participants that may facilitate or inhibit recruitment.

[9] Pattison (1978) defines the three clinical phases of living-dying as:

a) Acute Crisis Phase: This stage begins with the crisis of knowledge of death. It would most closely approximate the time of referral to the Palliative Care case load, although patients who have experienced a long disease trajectory may be beyond this stage at referral. Essentially, this is the initial response to the knowledge of death and is a phase of extreme anxiety.

b) Chronic Living-Dying Phase: This stage is characterised as the time period that the patient faces fears and resolves issues of dying. During this phase, the priority is the management of the physical, emotional and psychological needs of the patient as they move toward the terminal phase.

levels of stress and crisis that require a response by the patient in order to move "appropriately" through the dying trajectory. It is expected that the needs of the patient will vary across these phases becoming more intense as the patient nears death. This may possibly increase the intensity and nature of caregiving for the FCGs. The final interview was to take place during Rando's (1995) first phase of uncomplicated grief and mourning, known as the avoidance phase.[10]

The initial protocol outlined that arrangements were to be made with the CCAC to monitor patients' status in order to help guide the interview process during caregiving; interviews would then be scheduled based on the patients' deteriorating status according to the phases as outline above. This protocol was later amended due to difficulties in recruiting participants; the interviews were scheduled at six week intervals instead, as outlined in Section 2.15(d). The bereavement interviews were arranged with the FCGs privately, without the assistance of the CCAC, and occurred approximately six weeks after the death of their loved-ones.

Given the difficulties in conducting research in palliative populations, including the uncertainties with the progression of the disease trajectory and the FCGs' time and ability to participate in the interviews, the collection points described above were considered "ideal". In actuality, FCGs participated on average in three interviews conducted at various stages along the dying trajectory. The bereavement interviews, conducted in three of the five cases in the sample, corresponded more closely with the accommodation stage (Rando, 1995)[11], although two of the FCGs suggested they had not yet grieved.

The interview schedules (attached as **Appendix Three**) were developed as a result of an extensive review of the literature. The semi-structured interview schedule provided a framework of themes to be covered, yet left the ability to be open to changes in question sequence and question form – in order to best follow-up the answers and stories given by the participants (Kvale, 1996). The first interview involved the one-time collection of data specific to residential history, family formation, and socio-demographics, as well as the locational history of the patient/caregiver. These data were collected to establish the context of the caregiving experience (see Part A of the interview schedules). The first interview also involved the collection of data representing the longitudinal component of the study (see Part B of interview schedules) around the following themes: (a) managing the caregiving experience [this section focused on the experience of caregiving (both positive and negative), including tasks involved, the time spent, new skills acquired and types of support (formal and informal) available]; (b) roles [this section focused on how the role affected the FCG, including balancing other responsibilities (other dependents, home, work, social activities, etc.) and their coping strategies]; (c) health status (this

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c) **Terminal Phase:** This stage is characterised as the time period immediately preceding death. The patient begins to physically and emotionally withdraw unto themselves in preparation of dying. This has been described as a type of "apathetic giving up" that accompanies a deterioration of the physical state of the person.

[10] Rando (1995) states that the avoidance phase encompasses the period of time in which the news of the death is received and shortly thereafter.

section examined the physical and mental health of the caregiver, both in terms of how it was affected by the caregiving experience and how the FCG attended to his/her own health needs over the process). The follow-up interviews focused on Part B (the longitudinal component) of the interview schedules, with emphasis on how the caregiving situation changed from one interview to the next. The bereavement interview (attached as **Appendix Four**), included: details of the death event; types of support FCGs received; responsibilities FCGs carried out (in terms of re-organising their homes and routines, and settling the estate); their satisfaction with the experience; and, their health.

The use of standardised interview schedules "allows for [interview] comparisons of emergent phenomena" (Baxter & Eyles, 1997; pp. 508). In fact, Miles and Huberman (1994) encourage the use of pre-structured interview schedules to focus the data being collected and to ensure continuity across cases in order to facilitate comparison. The interviews were designed to last no more than one hour but, in fact, they generally exceeded this time limit. Exceeding the time limit indicated the truly complex nature of the caregiving experience. As the researcher conducting the interviews, I felt the extended interview time also reflected that the FCGs participating in this study were in need of a good listener with whom they could describe their experience. This is expanded on Section 2.7 (Ethical Considerations for the Study), where the benefits of the study to the participants are discussed in greater detail. Additionally, I do not believe that the FCGs found the interview questions too invasive, as only one question (pertaining to household income) was not answered by one FCG. I had also planned on speaking directly with representatives from the CCAC regarding particular FCGs (i.e. to determine how services were arranged in the home) but later abandoned this idea as FCGs did not seem comfortable with it. Instead, I had had informal discussions with some CCAC representatives to better understand how the palliative programme works.

2.4.2 Surveys

Although not used in the analysis for this thesis, caregiver burden surveys were also implemented at each interview capture, excluding the bereavement interviews. The Caregiver Reaction Assessment (CRA) (Given et al, 1992) (**Appendix** Five) and the Self-Rated Burden Scale (van Exel, Scholte op Reimer, Brouwer, van den Berg, Koopmanschap, & van den Bos, (2004) (**Appendix Six**), both widely employed in caregiver research, were used. The CRA assesses five domains of caregiver burden (both positive and negative), related to self-esteem and family support, and the impact of caregiving on finances, personal schedules and health. (Njiboer et al, 1999). The SRB is a subjective rating of burden on a scale from 1 (low burden) to 100 (high burden) (van Exel et al, 2004). The inclusion of these surveys, representing a quantitative data source, is a method of triangulation to confirm and/or corroborate the qualitative components (Miles & Huberman, 1994). Although all FCGs took the time to complete these surveys, the completion of the surveys during the interviews was optional so as not to create undue burden for participants. This option was clearly specified verbally as well as in writing in the Letter of Information/Consent. As mentioned, the analysis of the results of the surveys are not included in this analysis, but will be examined at a later date. They were used, however, as a confirmatory data source; for example, to compare how FCGs rated their levels of burden from one interview to the next and to examine if those levels corresponded to the interview data. The survey data will be analysed descriptively to corroborate the information that was collected from the interviews and through observations to understand the impact of caregiving and predict burden. Consistent with *multiple* case study protocol, there are no plans to pool the surveys for analysis (Yin, 2003).

2.4.3 Direct Observations

Data concerning changes to the physical environment of the home (for example, changes such as the addition of medical equipment or the re-organisation of furniture or certain rooms to provide care) and non-verbal behaviours (body language, facial expressions, interaction with patient/household members where applicable) were also collected through direct observation. Yin (2003) differentiates direct observation from participant observation in that participant observation involves the active participation of the researcher in the setting (i.e. becoming a member of the group) whereas direct observation is the passive collection of data (such as the physical setting) as a result of the field visit. The data collected by direct observation (as recorded in the research field book) was profound in contextualising the caregiving experience in terms of the everyday world of the participating FCGs, as well as that of the patient and other family members occupying the home (although they are not the focus of this study).

2.4.4 Documents

The use of documents in the study primarily pertain first, to my field book, and second, to the collection of information regarding service provision and/or policy updates (across the two districts and at the provincial level). My research field book became integral to the study as a source to record thoughts, ideas, feelings and decisions made throughout the research process. By doing so, it was possible to keep track of and reflect upon my thoughts and decisions concerning the research design, my own observations, and emerging themes. This allowed me to control for personal biases, helped direct data collection and analysis, and facilitated my recall during analysis and write-up.

A second document type was information regarding service provision and policy. This included, for example, the review of websites specific to: The Ministry of Health and Long-term Care, the provincial and branch sites of the CCAC, and relevant volunteer and service providers. Further, various brochures relating to service delivery were collected. These information sources allowed me to gain an understanding of the context of the provision of palliative care services for comparison across CCAC districts, as well as to changes over the course of the study. While this could be viewed as essential information to establish the context of the case and thereby, not necessarily a data source, it is noted here to provide evidence that not all of the information obtained or mentioned in the analysis was acquired through the FCG participants. In addition to helping establish the local context of service delivery, this knowledge was beneficial in clarifying the information conveyed by the participants. For example, one participant suggested that she had the "{name withheld} Palliative Care coming in". If I was not knowledgeable about the services that were available in the area, I would not have known if this meant service providers - such as nurses, dispatched through the {name withheld} CCAC PC programme, or visiting volunteers through the {name withheld} Palliative Care *Network* (it was the former - she was just unsure of the different organisation names). This information was useful for me to have when FCG participants were not sure themselves as to what was available (i.e. bereavment services) and was, in fact, required by the MREB to ensure that I could recommend help if necessary so that FCGs were not left in a state of crisis.

Additionally, participants were given a journal to document their experiences. While not compulsory, they were offered to help FCGs keep track of any events, thoughts or feelings deemed important and to facilitate recall during the interviews. They did not, however, materialise as a data source as none of the FCGs had the time to use them.

2.5 Data Management

A vast amount of data was collected throughout the study, including: signed consent forms; field notes (from all interviews, observations and website scans); tape-recorded versions of interviews; and, completed participant surveys. All interview data were transcribed into computerised text documents and stored electronically. Hard copies were made as well, as both a safety precaution in the event of computer malfunction and for use in the analysis process. All participants were assigned a psuedonym and identification number to preserve anonymity. All names of participants, family members and communites of residence were removed from the transcripts. All participants had the opportunity to verify their statements during data collection. Tape recordings will be destroyed at the end of the study (once lay and professional reports are completed) but the written information will be kept for a period of five years for future analysis.

2.6 Data Analysis

In keeping with the iterative nature of qualitative research, analysis began in conjunction with data collection to help to organise the large amount of data collected, to direct on-going collection, and to identify gaps in the data (Miles & Huberman, 1994). Two techniques were used in analysis: classifying and describing (Creswell, 1998). To explain how FCGs managed the experience and identify the factors that contributed to this, content analysis was used to analyse the interview data. Content analysis represents a variety of approaches, either intuitive or structural, for analysing text data (Hsieh & Shannon, 2005). Often thought of as a quantitative approach, it is increasingly being used in qualitative studies, and in health studies in particular (Hsieh & Shannon, 2005). The focus is on "the characteristics of language as communication with attention to the content or contextual meaning of text" (Hsieh & Shannon, 2005; pp. 1278). It encompasses three approaches: conventional, directed and summative. The conventional approach was used here, given its appropriateness for describing a phenomenon when the existing knowledge base is limited. It appears similar to both grounded theory and phenomenology in terms of the approach to analysis, such as in the development of themes in the analysis; however, it should not be confused with the two. Grounded theory and phenomenology are both research traditions with distinct theoretical underpinnings (Creswell, 1998). Grounded theory seeks to generate a substantive theory while phenomenology seeks to find meaning in the experiences. Content analysis was used in conjunction with the case study approach as a means to increase the understanding of how (a) rural FCGs manage the experience; and, (b) its affect on their self-assessed health.

Hsieh and Shannon (2005) describe the process of analysis as involving the immersion in the data to develop codes that are categorised into clusters of meaning. The clusters are then reduced into a small number of categories and/or sub-categories as derived from either explicit (actual words used by the FCGs) or implied (through intuition or interpretation by the researcher) communication. The categories are presented (reported) along with examples from the data, with or without the identification of the relationship between the categories.

Data immersion began with data transcription; this was viewed as an ideal way to become familiar with the data. The transcripts were read numerous times, both while listening to the tapes and without (except in one case where the tape was damaged during transcription), to capture any nuances, such as the tone used or pauses in speech. Next, the initial coding began by reading over the transcripts again and looking for words that related to: (a) managing the caregiving experience; (b) caregiver health; and (c) caregiver burden, as well as identifying other significant themes. A number of codes emerged and these codes were refined (into seven themes with several sub-themes) and used to code the remaining transcripts. The cross-case analysis was completed in a similar fashion but the categories were clustered into four themes (which included one over-arching principle and three sub-themes). A record of the exact sources for each of the categories generated during the coding process was kept. Multiple sources of data, including the themes that emerged, were developed into the case summaries to provide an in-depth picture of each unique caregiving experience.

2.7 Ethical Considerations for the Study

While this section appears near the end of this commentary on the research process, it was, in fact, a guiding factor throughout the study, given that this research involved working with participants who were extremely vulnerable. The subject matter of this research was highly sensitive, where sensitive is broadly defined as "research which potentially poses a substantial threat to those who are or have been involved in it" (Lee, 1993 in Johnson & Clarke, 2003, pp.422). This threat is typically emotional for both the researcher and the researched, along practical and ethical grounds. It includes, for example, the following possibilities: that the nature of the research may make it difficult to recruit participants; that participants may become upset by reliving and/or sharing the experience; that it may be upsetting to the researcher and it may cause role conflict for the researcher in terms of relationships with participants (Johnson & Clarke, 2003).

Ethical approval for this study was obtained from the MREB for research involving human participants (behavioural/non-medical) prior to data collection. The original approval certificate and all amendment certificates are attached as **Appendix**

Seven. The MREB requires that all participants be fully aware as to what their involvement in the study entails. To this end, a Letter of Information/Consent (attached as **Appendix Two** as previously noted), was given, explained and signed by the participants prior to the collection of any data. As mentioned, I had participants complete this at the beginning of each interview to ensure they understood their rights in the study; it served as a good "ice breaker" before launching into the interview questions as well. The following section identifies ethical issues that were addressed during the study, including risks and benefits to participation and confidentiality.

2.7.1 Potential Risks to Participants

The following were identified as possible risks for the FCGs in the study by the researcher and/or the MREB: the time taken for the interviews could disrupt their routine; discussing the experience could make them feel upset or sad; they may feel uncomfortable revealing personal information about themselves or their loved-ones; they may not want the researcher to discuss any personal information with the CCAC; they may be concerned that participating or withdrawing from the study could impact service provision; and, they could be identified by various service providers/CCACs in written and verbal reports. An additional concern by the MREB was the longitudinal component of the study wherein they expressed concern that the number of interviews and their duration may be excessive for FCGs in light of the circumstances in which they provide this care. (For example, an option could have been to study the experiences with bereaved caregivers.) However, given the steps taken to minimise the risks (as outlined below) and the justification for a longitudinal approach this issue was resolved.

2.7.2 Minimising the Risks

Numerous steps were taken to minimise the risks, including: scheduling the interviews at times and places (usually the home) convenient for them; reassuring them that cancelling the interview (even with short-notice) was not an inconvenience to me; advising them that they would not have to answer questions in which they felt uncomfortable; and, that the interview could be paused, stopped and/or rescheduled if necessary (i.e. restraints on time, tend to loved-one, emotionally upset, etc). They were advised that they could withdraw from the study at any time and that their decision to participate (or withdraw) would not affect the services they were receiving. Additionally, I had a list of various resources that were available in their community in which to refer them if necessary, and I planned to stay with the FCGs for as long as necessary after the interview if they seemed upset.

2.7.3 Confidentiality

Several issues around confidentiality were addressed. This included altering FCGs names and the names of their loved-ones and any other family members. To further preserve anonymity, the overall study area was referred to as "one of seven health districts that comprise the Northern Ontario health region" (later amended to include the two areas) and specific names of communities were not revealed. Instead, the communities were identified by their approximate population and their distance in time (i.e. minutes/hours) from available services.

2.7.4 Benefits to Participants

There were no direct benefits to the participants as they were not compensated for their participation in the study. At the end of the study they were given a spring-blooming shrub (referred to as a "caregiver tree") as an expression of appreciation for their participation. FCGs did feel valued and relieved for having the opportunity to share their experiences. In fact, the interviews turned out to have enormous therapeutic value for the FCGs; while I expected this when approaching the study, the extent was still surprising. It appeared that FCGs just simply needed someone with whom to talk. They had given up so much of their social lives, and despite the support they did receive from families and friends, it was not enough. One thing that surely influenced this was the fact that I had experienced a palliative caregiving experience with my mother; for them, just knowing that I "really did understand" (Barb, Interview 1) was comforting, even though they were not aware of the circumstances of my own experience to begin with (but see Section 2.5). Additionally, I felt they appreciated knowing that the visit was for *them*, as their lives become so task and patient-focused. For the most part, they were willing to discuss their experiences openly and honestly and they believed in the value of the study. The interviews were comfortable and I believe they appreciated the non-judgemental nature of our conversations, although two FCGs appeared reluctant at first to focus on themselves. This may have been because it was difficult to put their needs ahead of their dying loved-one or because it appeared as though they were complaining. The first interview schedule provided a structure that focused on the "facts" (i.e. the actual tasks they were performing) and I found they soon felt more comfortable. The interviews provided the opportunity to be frank with someone outside their immediate family about what was involved and discuss how they were feeling about the situation. An unexpected "by-product", I believe, was the feeling of empowerment FCGs experienced through the research process. They were, for example, often able to come up with solutions or to rationalise the problems they were facing just through "talking it out" or finding out, through discussion, various options that were available (i.e. who to ask for certain types of assistance) - although in some cases, this was the result of conversations that were held off-record. In any event, in addition to "telling their stories", it is believed that in this study, the research process was of great benefit to the FCGs.

2.5 Researcher as Instrument

One characteristic of qualitative research is that the researcher is the primary instrument in the collection of data and analysis (Merriam, 1998); as such, the results are the researcher's interpretation of the meaning given to the experience by participants. Reflexivity is the acknowledgement of the researchers' biases, values and experiences on the research process, and should guide the researcher through all stages of the study (Creswell, 1998). The closeness to both the setting and the participants present challenges in terms of power relationships and ethical considerations. As a neophyte researcher, I was aware of my role in the research process, especially given the sensitive nature of the research. First and foremost, my concern was for those who would participate in the study. I was cognisant of the potential biases I might project onto the study as a result of my own experience in palliative care (and subsequent bereavement) with my mother, and was concerned with how undertaking this type of research would impact me, and therefore, the study. While the ethics section of the protocol addresses potential harms and benefits to the participants, together with the methods used to minimise the risks, my role in the research process as it pertains to qualitative inquiry broadly, and the nature of this research in particular, is explored in this section.

These challenges were tackled through journaling where I listed my reasons for becoming involved in the research, and described how I thought my past experience would affect the study, the participants and myself. In my journal I also considered how much information I would tell participants about my caregiving experience, thought about how my experience differed from what I was studying, and described how I would want to be treated if asked to participate in research during that time in my life. Once identified, I was able to address these issues and my needs throughout the course of the study. I did find I experienced a heightened sensitivity to the loss of my mother, especially during the bereavement interviews. As such I made opportunities to discuss this, normally with my husband and my supervisor.

However, through my experience (as well as through sharing the experiences of several very close friends who ironically, at young ages like me, lost parents and spouses), I understood how the circumstances around dying and death are unique, and furthermore, did not feel uncomfortable discussing these issues. The aversion to openly discussing dying and death still prevails in our culture and so there is a tendency to avoid doing so; often this is because they just do not know *what* to say. I recognise that some people want to talk about their situation or feelings, and others do not, and that recruitment would likely be difficult for this reason. I approached this study with the idea that FCGs (who were interested in participating) would share their experiences with someone who was comfortable listening but not necessarily trying to fix their "problems". I discovered that this was true; but sometimes they needed both and there was a clear distinction between the two. For example, there were instances during the interviews when the tape recorder was turned off because it was clear that they were just venting and/or they had asked that we talk "off the record". Whether or not this affected the research process is uncertain, but it demonstrated my respect for the integrity of the FCGs so that they did not feel exploited through their participation in the research.

I explained only enough of my own situation to the participants to let them know I had been through a similar experience and was motivated by it to become involved in this area of research, but answered any questions they had for me (about my experience, schooling, family life, etc.). As suggested by my supervisor, I undertook an extensive review of available literature and videos pertaining to dying, death, bereavement and grief as part of my training to assist me in developing knowledge and sensitivity. Additionally, I drew upon my previous work experience in interviewing and collecting sensitive data. I worked for the Ontario Legal Aid Plan for five years; part of this involved the application intake process where personal and confidential information relating to applicants' legal, financial and household situations were collected to assess eligibility. This included the collection of intimate details concerning their cases and/or previous criminal records. People were most always in a crisis state, as they were addressing significant and complex legal issues - in addition to being economically disadvantaged, or even incarcerated.

Given the ethical considerations that were built into the study design, along with consideration for my personal experience, I feel I made every attempt to control for researcher bias. I believe that my personal experience, together with the knowledge gained through research around dying, death and bereavement, increased my understanding as to the sensitivity of the research, while contributing to me feeling comfortable with approaching FCGs to participate in the study and to conducting the interviews in a thoughtful and respectful manner.

2.6 Amendments to Research Design

Amendments were made to the research design several times over the course of the study to address issues of recruitment. This was necessary, as despite being "in the field" since May 2006, there were no leads for participants by July 2006, and only one case study was completed by October 2006. Several strategies were implemented, as indictated here in the order they were presented to the MREB. As a result of the amendments, the minimum targeted sample size of three was attained by December 2006, and a total of five cases recruited by February, 2007.

2.6.1 Information Cards

I believed the original strategy of having the CCAC representatives informally leaving my information with interested FCGs lacked professionalism and was inconvenient. Following the model used by my supervisor, postcard-sized information cards containing a brief description of the study, along with my contact information were created and given to the CCAC representatives to hand out to interested FCGs. The overall recruitment strategy did not change and the postcards were not handed out indiscriminately nor left in an open place. They were only left with the FCGs who agreed to be contacted by me.

2.6.2 Urban/Rural Comparison

In an effort to recruit participants, the scope of the study was expanded to include an urban/rural comparison of FCG experiences within an overall rural context. This opened up the opportunity to recruit participants from larger centres within the CCAC catchment area(s) without compromising the integrity of the study. Conceptualising the region as rural is consistent with a holistic definition of rural that includes descriptive, socio-cultural and locality-based characteristics, as opposed to purely descriptive measures based on, for example, population density (Williams and Cutchin, 2002). In this case, it involved examining the context of health care provision – the problems with access to resources, including issues around physician and nurse recruitment and retention - within wider processes (i.e. globalisation, economic restructuring) that are impacting and shaping rural (or in this case, northern Ontario) communities. Given the shortages of health care services, the the districts that comprise the entire health region are, within the provincial context, areas that are medically under-serviced. This medically under-serviced area provided the "overall rural" context for the study. This change was implemented without changing the original criterion for defining rural communities (i.e. the OECD definition). In effect, this means that because only one community met this definition of rural, an urban/rural comparison was not actually achieved in the study.

2.6.3 Terminology

It was discovered that part of the trouble with recruitment was due to certain terminology being used. The FCGs were being recruited through the CCAC *Palliative Care* caseload. This proved problematic because of operational difficulties with the term *palliative care*, wherein the philosophical ideology of palliative care infers one definition and orientation to health care, but health care policy implies (and dictates) another. To illustrate, the World Health Organization (2007) defines palliative care as the total care of patients suffering a life-threatening illness. The goal is to ensure the best quality of life for patients and their families through pain and symptom management and psychological, social and spiritual support. Palliative care can be integrated at any stage along the course of illness, not just at end-of-life. Based on this definition, it was possible that someone could in fact "be palliative" but not actively dying. From a policy perspective, *access* to palliative care services was more or less based on an imminent or anticipated death (i.e. the patient is not expected to survive beyond six months); thus the patient is "actively dying" - from a clinical perspective. The status of the patient along the trajectory influenced which services were available, such that a palliative patient may have been assigned to either the long-term *or* palliative care caseload. It could be quite late in the trajectory before the patient was referred to the palliative programme (when they become actively dying, for example), if they were, in fact, referred at all. Conversely, a patient could be considered actively dying and referred to the palliative caseload, although the patient and family did not consider the status as "end-of-life" because they had not given up hope for recovery or a cure. Under those circumstances, their FCG could not be advised of the study because of the explicit focus on palliative/*end-of-life* care. Being referred to the palliative care caseload involved a judgment call based on an assessment of how long the patient was expected to live. In effect, that limited the number of cases assigned to the caseload and thereby, the number of participants available to recruit to the study. It also limited the ability to capture the experience "over time", as it could be (and was) quite late in the disease trajectory before patients were "palliative" from a programme perspective. Furthermore, the *dedicated* palliative care programme at the participating CCAC was relatively new (under one year old) compared to some other regions (i.e. the second CCAC's programme was about two years old); as such its integration into the community had not yet been fully developed, potentially affecting service uptake. Therefore, the focus shifted from *palliative/end-of-life* to studying "family members living in rural areas who are providing care in the home to a loved-one with a *life-threatening illness*". This opened up the opportunity to recruit participants who were providing palliative care in the home from both the palliative and acute care caseloads at various stages along the disease trajectory of a life-threatening illness.

2.6.4 Expanding Recruitment Base

At the same time, the recruitment base was expanded to include accessing the caseloads of *all seven CCACs* in the northern Ontario health region and the client base of one district's visiting volunteer organisation. This provided a much greater pool of potential participants. As mentioned, two CCACs ended up participating. The change in terminology and expansion for recruitment required that the data collection methods be amended as well. While the *desired* number of interviews remained the same (four), rather than targeting the interviews at times defined by Pattison's (1978) phases of dying, the interviews were scheduled at six week intervals instead. This time-frame was suggested by a well-known researcher in P/EOL care who has faced similar challenges in recruiting participants. Doing so eliminated the need to have the CCAC act as a go-between to confirm patient status and in doing so, helped to conceal the identity of FCGs during the study. FCGs were nonetheless advised that is was still possible for service providers to recognise the unique family combinations in the final reports.

This strategy seemed to work in general, as two more participants were recruited within weeks. It may just have been that the CCAC were more comfortable asking FCGs when the focus of the study was not on P/EOL care. A life-threatening illness is, of course, a serious situation, but it does not necessarily imply a judgement concerning the prognosis of the disease. There was some tension expressed in asking families who were in crisis to participate in the study; for example, the CCAC needed to be absolutely sure that the patient and family regarded the situation as end-of-life and that the FCG could (in their estimation) handle the extra commitment the study would entail. Protecting clients as such, referred to as gatekeeping, is a noted challenge to recruitment in home health care research (Aoun et al., 2005; Payne et al., 1999). While the amendment specific to terminology was approved, only one other CCAC agreed to participate and there was no success in accessing the client base of the acute care caseload or the visiting hospice volunteer organisation.

2.6.5 Remuneration

The final amendment included remuneration to the CCACs for their participation in recruitment. I requested this amendment to acknowledge the time that CCAC representatives were dedicating to the study. It is hoped that these funds will be applied towards an education fund specific to P/EOL care. The formula used was to assume that it took 15 minutes of the CCACs' time to approach a FCG and explain the study. CCAC representatives were aksed to keep track of how many participants were approached and this number was multiplied by 15 minutes. They would be paid a rate of $32/hour (their hourly rate). The total amount of $32.00 (two approaches; rounded off to one hour) was paid to one CCAC and $64.00 (five approaches; rounded off to two hours) to the other.

2.7 Scientific Rigour

"All research is concerned with producing valid and reliable knowledge in an ethical manner" (Merriam, 1998; pp.198); within the qualitative research paradigm, the evaluation of such research is referred to as rigour, or the trustworthiness of a study. There is no prescribed formula for doing so; however, the principles of credibility, transferability, dependability and confirmability are often used to evaluate qualitative research, similar to the tenets of validity, reliability, generalisability and objectivity that are used in quantitative research (Baxter & Eyles, 1997; pp. 521). Thus, as an evaluator of research, one is (broadly speaking, based on the use of specific strategies) looking to be able to: recognise the experience based on the descriptions (credibility), find meaning beyond the study situation (transferability), and follow the decision trail to replicate and produce similar findings based on the audit trail (dependability). Confirmability is reached when all three principles are present, with the researcher clearly demonstrating how decisions were made. There are numerous strategies that can be used in the design of a study to ensure its rigour and it is noted that these strategies may be used to address more than one component of trustworthiness (as suggested here) (Baxter & Eyles, 1997). The following section outlines the strategies used in this research to ensure rigour, some of which have already been made explicit, and others only alluded to, in the preceding discussion of the methods used in this study. As a note, this discussion is adapted from the work of Baxter & Eyles (1997); they have researched and referenced their work extensively and framed their discussion around interview data within the discipline of social geography.

After careful consideration for the best strategy in which to answer the research questions, a multiple case study design, using primarily qualitative methods, was chosen. Maximum variation, a strategy of purposeful sampling, was used to ensure a wide variety of cases were selected so as to give a voice to multiple subjects sharing a similar experience. I engaged in prolonged engagement in the field through the collection of the data longitudinally, having completed, on average, three in-depth interviews with each FCG. Given the nature of the study, I paid extreme attention to ethical issues (and/or made changes to address these and documented why and how these changes were made), including sensitivity (i.e. to the terminology used; to the time I was asking the FCGs to dedicate to the study), and to confidentiality (i.e. preserving the anonymity of participants, their loved-ones and family members; the communities in which they reside; and, the study area as a whole) in order to build trust and ensure the integrity of the participants. I was conscious of my role as researcher in this study and how it may have affected data collection and analysis (as a neophyte researcher and as the vehicle through which these experiences were constructed). As such, I used a field book extensively to record and monitor my thoughts and decisions over the course of the study. Triangulation (the use of multiple sources and methods) was used to confirm findings and produce a holistic description of the experience (i.e. Merriam, 1998; pp. 204). Member checking (having participants verify their statements); peer examination (discussions with my supervisor concerning the direction of the study, the analysis and emerging themes); and the recording of the design decisions were completed as part of an audit trail to explain how the findings were reached so that others can determine the transferability of this research to other situations. I used "thick description" to describe the research methods and the summaries of each case, and provided examples derived directly from the data to illustrate the themes.

2.8 Summary of Research Methods

A multiple case study design was used to explore the experiences of rural-dwelling FCGs who were caring for their terminally-ill loved ones in the home over the course of the caregiving process. Five participants were recruited to the study from two districts in the northern Ontario health region. Multiple sources of data were collected, with the primary source being the interview data (a qualitative data source). This data forms much of the foundation of the analysis in this thesis. Numerous challenges were experienced over the course of the study, particularly around community collaboration and participant recruitment, resulting in several amendments to the research design and a delay in data collection. As a result, one source of data was not analysed at the time of this writing. Major changes included opening the study to a rural/urban comparison, expanding the study area (from one district within the health region to the entire region) and changing the terminology (from "palliative/end-of-life" to "life-threatening illness") in order to increase the pool of potential participants. Changes to the design were documented and justified to ensure rigour and particular attention was paid to the ethical components of the study. Difficulties in both conducting research with vulnerable populations and in collaborating with community organisations were highlighted and substantiated by the need to amend the research design. The findings of the study are presented in the next two chapters; summaries of the cases are presented in Chapter Three and the results of the cross-case analysis follow in Chapter Four.

Chapter Three

Case Summaries

This section contains summaries of each of the five cases that comprise the study, highlighting the unique experiences of this cross-section of caregivers drawn from the catchment areas of the two participating CCACs. They represent but do not replace the within-case analysis and appear in order of recruitment to the study. For quick reference and comparison of caregiver demographics across cases, refer to **Table 3.1**. Names of participants, their family members and loved-ones have been altered and the communities in which they reside omitted.

Table 3.1

	Lisa	**Tom**	**Angela**	**Barb**	**Maddie**
Sex	Female	Male	Female	Female	Female
Age	50 Years	79 Years	38 Years	68 Years	53 Years
Marital Status	Married	Married	Married	Married	Married
Relationship to Patient	Daughter-in-Law	Spouse	Daughter	Spouse	Daughter
Age of Patient	75 Years	79 Years	71 Years	78 Years	79 Years
Other Dependents	None	None (One adult child)	Two children (Ages 4 & 9)	None	One (young adult)
Occupation	Developmental Worker	Electrician	Customer Service Rep	Homemaker	Business Women
Employment Status	Unemployed (quit to CG)	Retired	Unemployed (quit to CG)	Unemployed (senior)	Self- Employed
Residential Location	Rural TP Pop <1 500	Urban Pop <12 000	Urban Pop <55 000	Urban Pop <75 000	Urban Pop <55 000
Duration of Caregiving	16 months	12 years+	8 months	4 months+	8 months
Number of Interviews **C=while caregiving** **B=Bereavement**	C: 1 B: 2	C: 4	C: 3 B: 1	C: 2	C: 1 B: 1
Place of Death	Home	N/A	Home	N/A	Home

3.1: Cases

3.1.1: *Lisa and Rose*

> "I'm not a martyr, I can say that much. You do it [be]cause you care. Everybody keeps saying, 'oh, I don't know how you've done it.' But...don't make me up to be a martyr, I don't want to be. I am doing it because I care...I think most people that care enough do feel that way anyway." (Lisa, Interview 1)

Often times, the people who make the biggest difference are those who completely underestimate the value of 'what they do' simply because it is just part of "who they are". Such was the case with 50-year-old Lisa, who cared for her 79-year-old mother-in-law, Rose. However, while she self-consciously downplays the significance of the caregiving role to deflect any glory and normalise the process, her dedication was anything but average. Lisa was interviewed three times, once during caregiving (two weeks before Rose's death) and twice during bereavement (at two and nine months).

Lisa lived with her husband, Don, in a modest home in a rural township, located about 35 minutes from a large urban centre. Although they had no children of their own, they shared their lives and their home with their dog, a gentle giant named Kaelo. Lisa and Don resided in the community for about 13 years, having relocated from a city in southern Ontario. Both worked outside the home on a full-time basis and had a combined household income of approximately $100 000. No extended family on either side lived nearby although they had many friends in and around their community and kept in touch with close friends from their hometown.

The formal caregiving arrangement began in July 2005, when Rose moved into their home after becoming too ill to care for herself. Doctors diagnosed Rose with leukaemia 9½ years earlier and she had lived on her own in southern Ontario since the loss of her second husband (Don's stepfather) in 2003. During a visit to Lisa and Don's in 2005, Rose was hospitalised and doctors told her she would not be able to live on her own upon her release. She wanted to stay with Lisa and Don as opposed to placement in an institution but left the decision with them. It was a sudden but anticipated decision and they readily settled her affairs and moved her into their home. Prior to this formal arrangement, Lisa had spent time caring for Rose at her home in southern Ontario on several occasions over the course of her illness.

Although Don assisted in the care of his mother, Lisa was the primary caregiver. Given Rose's grave condition at the time, Lisa quit her job immediately in order to provide the level of care required. Influencing this decision was the fact the Don had the better paying job of the two and, although it resulted in a significant drop to the household income (from $100 000 to $60 000), Don's income, coupled with limited contributions from Rose through her pension, was sufficient. There were no regrets and Lisa embraced her role, although initially it was difficult adjusting to the demands of caregiving as well as to the isolation of being at home all of the time. A very outgoing and friendly person, Lisa enjoyed doing various crafts and was quite adept at folk art painting. She enjoyed her work and she loved spending time with her friends, shopping and participating in craft shows. No doubt, her outgoing personality contributed to her ability to adapt to the changing situation, get along with health service personnel that visited the home and develop an amiable relationship with Rose's physician. Additionally, her training as a developmental worker was beneficial to the role, providing her with infinite patience and compassion and having prepared her in various ways medically (monitoring patient status, making patient comfortable, etc.).

Lisa was responsible for all aspects of Rose's care, including monitoring and administering medications, personal hygiene (although she had daytime assistance with this through homecare), tending to household chores (for example, preparing meals, shopping, cleaning, laundry, running errands) along with coordinating and attending doctor and specialist appointments. Rose's health status changed over time, and during these peaks and valleys, the nature and intensity of caregiving changed as well. Lisa felt confident in her abilities and accepted new tasks as they came along. In addition to her caregiving tasks, Lisa spent a lot of social time with Rose trying to keep her active and her mind busy, as Rose had a difficult time adjusting to the prognosis and her own physical decline. Engaging Rose in conversation, crafts and hobbies in the home, along with local outings for bingo, dinner and a show - or for an ice cream treat, were integrated into their schedules to the extent that Rose could participate, given her health status. The activities outside the home were not ones in which Lisa would normally participate, but it brought great joy to Rose and strengthened their relationship. They turned trips out of town to specialists in Toronto and Sudbury into mini-vacations where possible to take full advantage of the time it was necessary to be away. Although sporadic, these excursions were beneficial for Lisa as she had few opportunities to get away from home other than to run household errands. In general, Lisa found the caregiving experience "surreal" (Interview One), it was not something she thought about, she just did it.

Homecare via the PC caseload through the area CCAC was in place upon Rose's discharge from the hospital and throughout the dying trajectory. It encompassed weekly nursing (both RN and RPN) and daily respite visits. The frequency of these visits increased as her condition deteriorated and, in fact, just before Rose passed away, the nurse was coming in daily. As a family unit, they were able to develop positive relationships with the health care providers coming into the home; the personalities of the health care personnel and the consistency to which they were present throughout Rose's placement on the caseload contributed to this. Additionally, while they were not PC specialists, they were knowledgeable and reliable and treated the family with a great deal of professionalism; Lisa especially valued the special relationships they developed with Rose over time. They were quick to provide information when needed, although Lisa and Don often relied on outside sources, such as the internet, to supplement this. Access to respiratory and occupational therapists and social workers was available as well on an as-needed basis. Only respiratory therapists were used (twice) over the course of caregiving, and were especially helpful when Rose was experiencing difficulties with her oxygen levels. In addition to the assistance through the homecare programme, Rose's family doctor was incredibly supportive. He frequently saw Rose in his office, made home visits when necessary and as possible, and was available by phone, anytime – day or night - if needed. He involved Lisa and Don fully in Rose's treatment as his general approach, recognising that the medication Rose was prescribed for pain impaired her ability to fully understand and accurately share treatment information with them. No other resources in the community were used during the caregiving period.

Rose was hospitalised two times over this period, once for five days and once for six hours, rendering virtually all of her care to the home space. Through assignment to the PC caseload, the nursing and PSWs were provided free of charge, as were many prescription medications (both through the palliative care programme and Rose's drug benefits through the Canada Pension Plan), some assistive equipment and limited supplies (i.e. soaker pads for the bed and Depends diapers). Personal expenses included non-prescription medications and certain pieces of assistive equipment, as well as the loss of Lisa's income while caregiving. A number of modifications were made to the home to facilitate care; these included: the addition of support rails, a commode and bath chair in the bathroom; a hospital bed in the living room, as well as a respirator, monitor, wheelchair, walker and trapeze. While the trapeze (lift) was too big for use in the home, these devises and their configuration therein promoted Rose's independence and increased family interaction. This, coupled with health care personnel in and out of the home, resulted in restricted used of personal space and a loss of privacy for Lisa and Don. Here again, Lisa did not dwell on this aspect of the experience, understanding its temporal nature and rationalising that it was part of the process. Following Rose's death, they had the equipment removed and returned the home to its original functioning status.

Lisa, Don and Rose lived several hours away from their family and close friends, thereby limiting the type and amount of support available outside the health care system. Don was an only child and Rose's stepchildren had very limited contact throughout her illness. Most support came through Lisa's family by way of regular telephone calls and frequent visits. Winter conditions made travel difficult – both to make and receive long-distance visits - but during the spring and summer months their home was filled with visitors every other weekend. It did tend to get overwhelming having to entertain on a regular basis but they enjoyed their company immensely and felt their support was phenomenal.

The relationship between Lisa and Rose was mainly positive throughout the caregiving situation, strained only by the effects of the disease. Lisa was reluctant to dwell on this aspect because they had become very close, but did acknowledge that at times Rose could be temperamental towards her in particular and withdrawn from them both in general at times. While it was easy to put this in perspective and understand that the disease and the medications were altering her personality, it did add stress to the situation, contributing to the depression Lisa was experiencing due to exhaustion and grief. The relationship between Lisa and Don was strong throughout the experience although challenged somewhat when the difficulties with Rose surfaced. It was difficult for Lisa to discuss these issues with Don (because it was his mother and because she did not want to appear as though she was complaining) so she avoided doing so. She also tried taking medication to control her depression. When these strategies did not work, she realised that dealing with the issues was more appropriate and conducive to her mental health and to the caregiving arrangement. As such, communicating with Don became an important goal and one that helped sustain them both emotionally for the duration of Rose's illness.

Lisa enjoyed relatively good health prior to caregiving; her main concerns included high blood pressure and bowel problems (similar to irritable bowel). She took medication to control her blood pressure and experienced 'flare-ups' with her bowels frequently due to stress and her diet. In fact, Lisa was hospitalised for five days while caregiving with one such attack. As mentioned, Lisa also experienced bouts of depression and exhaustion that she attributed to the stress of caregiving and to witnessing Rose's ongoing decline. Maintaining her health was important to her, and in addition to trying to eat properly, she took vitamins, glucosamine and calcium. Although she recognised the importance of proper rest, this was not always possible; she was up every couple of hours during the night, particularly near the end. Exhaustion did catch up with Lisa and she began to fall asleep "on the spot". On more than one occasion she fell asleep while sitting in conversation with PSWs in the home and, on one of the rare instances when she and Don got away together for a few hours, she fell asleep while riding on the back of his motorcycle. With the focus on Rose, Lisa did put her health needs on hold. The depression and exhaustion had subsided greatly two months following Rose's passing and her blood pressure returned to normal. She was then, surprisingly, diagnosed with diabetes. Untreated during caregiving, it likely also affected her body's response to the stress of the situation.

Just as open communication was an essential coping strategy, Lisa also discovered the importance of getting away from the caregiving situation to recharge. While Lisa did have the PSWs coming into the home on a daily basis during the week, she was somewhat restricted in terms of how she could use that time. A two-hour time limit four days a week prevented her from getting away from home given the distance/time to the nearest centre, while the four-hour block once per week was usually spent running errands. As the depression and exhaustion set in, Lisa recognised that she needed to use this time for herself for her own well-being and it was not until the last month of caregiving that she made an effort to do so. For example, she would go and pamper herself with a manicure or a pedicure, a treat given to her by Rose. Additionally, getting away together as a couple was normally not possible as the respite/homecare hours were schedule during the day – while Don was at work. With few people living nearby to step in and stay with Rose, they either had to get away separately or remain home. There was just one occasion over that 15-month period when they did get away together for a weekend; a friend, who had some medical experience, was able to come and stay with Rose. Lisa acknowledged, however, that one is "never really away" (Interview One). Both their minds were with Rose, always firmly planted at home, wondering and worrying.

Rose died in their home almost 15 months after the arrangement began. While it brought them both a great deal of joy to have granted Rose her wish to die in their home, they both found the events leading up to the death, and the death event itself, stressful. They questioned whether it would be better to place Rose in an institution, not only to ensure she was getting the best treatment and support, but to get some rest themselves. Rose suffered a stroke just five days before she died; she withdrew emotionally, became incontinent and endured great pain (having reduced her intake of pain medication to remain coherent). It was difficult to accept that the end was approaching, and even more difficult to witness the rapid decline. They relied a great deal on the family doctor at that point – calling him at his office and on his cell phone for advice and reassurance. The doctor, who sometimes suggested hospitalising Rose throughout her illness, supported them immensely at the end, encouraging them to keep her home and advising them what to watch for and what to do to keep her comfortable and make her passing as peaceful as possible. Armed with the knowledge that they did everything possible to make her last year the best they could, Lisa, Don, their dog, Kaelo, along with the RN and both PSWs, bid farewell to Rose just before noon on August 31, 2006. A short time after Rose's funeral, Lisa and Don threw a small party for the nurses and PSWs to celebrate Rose and thank them for the contribution they made to her quality of her life. In the spirit of Rose's generosity, they also gave them gift certificates as tokens of appreciation. Lisa has remained in touch most of the health care personnel and would often run into them in the community. Ironically, Lisa found herself back in the role of caregiver just eight months later, this time for Don following his near-death from a motorcycle accident. Interestingly, similar services - including the same personnel - were coming into the home; however accessing these services in their rural community was much more difficult this time. For example, the service provider for homecare was reluctant to provide them with PSWs because they lived so far out of town; they expected the nurse to provide personal care, such as bathing Don, instead. This was unacceptable to Lisa, who did not feel it was the responsibility of the nurse to provide such care. It appeared as though they expected Lisa to look after everything, with the exception of medical care, on her own.

The experience had a lasting effect on Lisa in several ways. First, she questioned whether she would attempt something similar in the future with, for example, her own ageing parents. Upon reflection, both Lisa *and* Don felt so relieved and proud at what they had been able to do with Rose's situation that they agreed when the time came, that they would embrace looking after Lisa's parents in the same manner. The experience led her to retire rather than return to work and she came to value her family and friends on a deeper level, and in time, she was able to accept that Rose was in "a better place" (Interview Two). Don paid tribute to Lisa and her vital role in caring for his Mom in the eulogy to his mother; although deeply touched by the sentiment, Lisa was extremely modest about caregiving. She did however acknowledge that she would not have been able to provide the level of care required had she worked outside the home.

3.1.2: *Tom and Mary*

> "I feel good about it, what I am doing - when she's in bed and all taken care of for the night, and I have my rest, put up my feet and I look back: another day is gone, everything went smooth, you know; I feel good about it." (Tom; Interview 1)

With that, Tom, 79, makes the responsibility associated with caring for his wife, Mary, also 79, appear simple. The truth is that it is has been anything but simple; such peace and reflection have come from more than a decade of experience caring for Mary at home as she has battled Alzheimer's disease. It has been a remarkable journey – one of frustration and joy; guilt and pride; tenderness and resentment; love and loneliness. Sadly, it is also one marred by a lack of support from the medical community to "keep" Mary in her home, despite Tom's complete devotion to her care. Although Tom had been caregiving for many years, the focus of data collection was specific to the palliative stage of Mary's illness. The history of the caregiving roles is included herein to the extent necessary to understand the current context. Tom participated in four interviews over the caregiving process at approximately six-week intervals.

Tom and Mary spent the past 50 years living and working in a small remote north-eastern Ontario community located roughly two hours from any major urban centres; 48 of those years were spent in their present large, two-storey home. The couple have one child, two grandchildren and two great-grandchildren, all of whom reside in southern Ontario. They were both retired; Tom, an electrician, retired in 1985 at the age of 58 years. The average household income was around $60 000.

Prior to Mary's illness, they had settled nicely into retirement, travelling abroad when possible and wintering in the south. Tom was an avid outdoor's man, spending most of his time gardening, fishing and at their family cottage near their home. He first noticed changes in Mary's personality in 1994 but due to difficulties with the health care system, was unable to have her formerly diagnosed with the disease until 1995. Tom made the decision to provide care for Mary in the home immediately following the diagnosis, despite suggestions from her doctors to place her in an institution. In fact, he never really considered institutionalisation as an option for care; she belonged at home and he would do whatever he could to keep her there as long as his health would permit. He believed, that despite the illness, she was "still a person"; for this, he would have to advocate strongly on her behalf. Although he had no previous experience with either the disease or caregiving, he had both the time and resources to dedicate to Mary's care; those, coupled with his strength and determination, were assets to the arrangement.

The nature and intensity of caregiving changed dramatically for Tom over the 12-year period, as the disease progressed and as Mary battled various other health conditions, including breast cancer, mini strokes and numerous urinary tract infections. Her mental decline was rapid; the first few years of the disease were marked by hallucinations and sun-downing (reversing day and night) and she was incontinent from the beginning. Those days were quite stressful for Tom, as he faced not just the mental health issues associated with the disease (i.e. oppositional, argumentative behaviour), but took responsibility for her physical health (i.e. eating, medications, hygiene) and safety as well. Her physical decline was steady but slow and she became bed-bound approximately three years ago; this marked a significant turn to this caregiving situation. It was, for example, easier for Tom to go about the tasks of caregiving, but the quantity and intensity changed as Mary lost physical capabilities and become more dependent on Tom. She remains completely incapacitated, with Tom being responsible for every aspect of her care and well-being (from personal hygiene to feeding).

Tom functioned for the first couple of years with limited assistance, in part by choice and in part limited by the resources that were available in the community (i.e.

medical knowledge of the disease, paid and unpaid home support). He joined a support group through his local chapter of the Alzheimer's Society in 1996 (he remains a member primarily to support new members) and was referred to the homecare programme with the CCAC by his family physician in 1997. While the degree (quantity) of support available in the community has been consistent, the quality has varied immensely over time and by provider; as a result, navigating the system has been challenging for Tom.

When first assigned to the caseload, Tom received limited assistance. This consisted of the support of a homemaker five hours per week and generally encompassed light housekeeping. At the time, however, he was also able to access additional support through the Alzheimer's Society (AS) for a nominal fee[12]. The homecare hours have peaked at 60 hours per month and he continues to receive the 40 hours through the AS for a total of 100 hours per month, on a use-them-or-lose-them-basis – they are not transferrable to the next month. This is the equivalent of approximately 3 hours of support daily, depending on how many days are in the month. Given Mary's condition and the level of support required, it requires a strategic approach to maximize the time allotted. Sometimes he ends up with limited or no help on weekends or evenings, meaning that he must manage the routine on his own. He has daily assistance from a PSW (two regulars during the week and other part-timers on weekends). Tom has perfected this routine over time, and because the PSWs are consistent, it is the model of efficiency. Each morning they get Mary cleaned up and ready for the day, transport her from the upstairs bedroom to the living room and feed her breakfast. Twice a week, Tom leaves to participate in a swimming programme for fitness and/or run errands. Additionally, Tom takes Mary to an assisted living (AL) centre to use the hydraulic bath facilities to bathe her, as he can no longer manage that part of her care at home. One day a week this routine is altered; the PSW comes for just an hour in the morning (to help get her ready for the day) but returns in the evening so that he gets out one night a week. In addition to the PSW, a nurse comes to the home once per month and is available by phone anytime, if needed. Other assistance in the home includes access to occupational and physical therapists as needed. Normally, there is a wait-list for these services as the providers are not confined to the community but spread out over the large district. Tom makes use of other resources in the community, including a wheel chair accessible transportation system and the day programme at the AL centre. Every three months Tom puts Mary in respite for two weeks and, although he is financially responsible for this much-needed break, he still goes in most everyday to feed and care for her. One advantage to this set up is that he can also send his PSW in to help as well. Once again, a strategic approach is required in coordinating her admission to the centre for respite; so as not lose homecare hours, he must use the last week of one month and the first week of the second. Interaction with doctors (family physician and those in hospital) has been difficult over time and across a broad range of circumstances. He attributes this to both a lack of knowledge (about the disease) and a lack of

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[12] This programme through the AS was dismantled with plans for restructuring; during this period, those using the programme were able to continue receiving the hours without charge until the new one was put in place. This has never been completed and all homecare hours are now provided through the CCAC. Tom is one of the few people who continue to receive these hours in addition to those provided by the CCAC, for a total of 100 hours per month.

consideration for her care (because of the disease) and, in some ways, he feels they have given up on Mary. For example (and there are many), Tom felt that Mary was given a sub-standard physical, as compared to what a "healthy" person (himself included) would receive. Additionally, because of Mary's incapacitation, Tom is no longer able to bring her to the doctor's office for care and must rely on home visits. These tend to be unreliable and at the mercy (or subject to) the doctor's availability. When physicians are not available to conduct a home visit, Tom has to call an ambulance and use the hospital emergency services if Mary requires care. Sometimes he is made to feel that the visits do not warrant a trip to the emergency department. Over the years, experiences with the hospital have been frustrating, causing him to feel mistrustful and disillusioned. Some complaints are typical of the health care system in general (i.e. long and unnecessary waits, bed shortages and pressure to discharge early). In other cases, the treatment has been appalling, for example, left in her urine-and-faeces soaked clothes and linens for hours; not provided liquids and/or intravenous feeding and not fed. Tom would always spend extra time with the nursing staff to explain Mary's condition because of her inability to speak (she can, for example, swallow food and liquids, but cannot feed herself); but even with this information, she was neglected.

Over the course of the interview process, Tom did experience a major shift in support from all levels in the health care system. Surprisingly, this occurred following Mary's admittance to the hospital with another mini-stroke. His home care hours were increased to guarantee him support every day, including weekends (so he never had to manage alone); his opinion was valued in the hospital and the decision for her discharge was left to him (he could discharge Mary when he was comfortable bringing her home) and the family doctor showed up unannounced for a home visit and committed to making weekly visits. The doctor did at this time discuss what Tom should do if Mary should pass in the home; although Tom was reluctant to hear this he understood that it was necessary. These changes in attitudes were likely a reflection of the recognition by the medical community that Mary was approaching the end, although none of the actions were explained to Tom. Additionally, when asked, Tom was at a loss to explain this sudden change; he quite honestly did not care why – he was just so pleased to have increased support to care for Mary and validation of his knowledge and role in her care. Mary's health status also changed at this point. She was starting to experience organ failure, was having more difficulty swallowing and could no longer bear any weight. This has resulted in an increase in the intensity of caregiving, both physically and emotionally; physically, the tasks and the effort required to complete them are increasing, while emotionally, he must contemplate the effects of her continuing declining status. He is not ready to accept 'the end'. He knows it is coming but still did not expect it this soon.

Tom has invested an enormous sum of money to facilitate care in the home. He has invested upwards of $60 000 on upgrades and equipment to accommodate her declining status, including: the addition of a bathroom on the main floor, an electric lift on the stairs, and a wheel chair ramp on the house exterior. He has two hospital beds (one in their upstairs bedroom and one in the main floor living room), as well as a reclining hospital chair, a Hoyer lift, a wheel chair and various bathroom equipment (i.e. commodes). Other costs have included: linens for the bed, blankets, gowns, garments, incontinent products (some of which are now covered through the CCAC), and additional services; Tom pays to have Mary bathed twice weekly ($80/wk) and pays for respite every three months at a cost of $500 per visit, for a two week period.

Tom has limited support outside of the health care system. No family members live nearby and relationships with friends in the community were severely limited, having eroded over time by the nature of Mary's illness and the intensifying caregiving situation. Tom and Mary's siblings live abroad; their only child and grandchildren live in southern Ontario and can only make it home on long weekends. When they do visit, they assist in whatever way they can and Tom is satisfied with the situation. Most of the couple's friends have not been able to cope with Mary's condition and do not visit or help out. Tom is highly organised, coordinating errands during his respite time; he would only ask for outside assistance in case of an emergency. Tom has cultivated "new" friendships through his support group with the AS and it would be from this circle that he would seek assistance. Tom acknowledged that Mary would have to be institutionalised should he become unable to care for her anymore. He realises that his family would not be in a position to dedicate the time necessary to provide the level of care required nor would they likely be able to handle the nature of the tasks involved (diapering etc) or likely handle doing what he does. For example, he mentioned how his daughter has commented to him that she did not know how he did it. He has financial arrangements in place to ensure that Mary receives the best possible care should anything happen to him.

At 79 years, Tom is in good health. Other than suffering from aches and pains associated with ageing, he feels healthy and strong. Serious health issues have been few, including a problem with kidney stones and treatment for a prostate problem. Unfortunately, his emotional health has been less stable over time. He was initially devastated; he had difficulty both accepting the disease and her decline, and was exhausted and stressed by the caregiver role. While he still experiences bouts of depression, they are less frequent. As a coping strategy, he allows himself time to brood but then moves on, realising that he is doing everything possible for Mary. Maintaining his health is very important and proper nutrition, regular exercise and medical check-ups, as well as time away from the caregiving situation, are essential components of his caregiving regime. He travels with a cell phone at all times but does not worry when he is away, as he trusts Mary's care completely to his regular PSWs.

Tom still has an incredibly difficult journey ahead. He remains optimistic, confident and dedicated to his caregiver role. This journey will be much easier now that he feels valued and respected by those with whom he interacts in the health care system.

3.1.3: *Angela and June*

> "I feel good that she is here and I am able to give her better quality of life than she would have had in a hospital bed or nursing home or trying to struggle on her own - back at home or whatever. I know I have prolonged her life by doing it. In August when I went and got her, they didn't even think she was going to make it – in that hospital, so… and then coming

> to Christmas - where they weren't sure if she was going to make it to Christmas, and now we're into the end of March, you know?" (Angela, Interview 3)

Angela's ability to make such meaning of her contribution to her mother's life is well-deserved, considering the sometimes formidable obstacles she has faced. In fact, while it is difficult (and perhaps unfair) to compare caregiving situations in that light, Angela's experience was likely the most challenging of all participants in the study. Her strength and resilience can be models for others who embrace the caregiver role. Angela completed four interviews during the study, three during caregiving (at approximately six week intervals) and one during bereavement.

Angela, 38, lived with her husband, Wes, and two children, Stephanie and Michael. They had lived in the community for 15 years and in their present home for six. They both worked outside the home on a full time basis and the annual household income was approximately $75 000. No extended family on either side lived nearby.

The formal caregiving arrangement began in August 2006, just two months after her mother, June, aged 71 and widowed for two years, was diagnosed with pulmonary fibrosis. Immediately following the diagnosis she remained in her own home in north-eastern Ontario and was assigned to the CCAC caseload. However, Angela discovered that June was: (a) not being monitored and, (b) that her condition was worsening. Despite being assigned to the homecare caseload and there being other family members living in June's immediate community, June had no support in the home. Angela expressed extreme regret, even suffered nightmares, from not being able to help more in the care of her dad when he was ill and she did not want her mother to face her illness alone. Angela and Wes invited June to live with them in their home. Doing so was an obvious decision for Angela and Wes because they had a great relationship; the children enjoyed having grandma living with them although they did not really understand or comprehend the extent of her illness. In addition to her care, Angela was also given the responsibility for looking after June's household bills and making arrangements to put June's house on the market. June was still somewhat mobile when she moved in; she could, for example, still get up to use the bathroom and access snacks on her own. They had the services of Carelink®, an emergency medical alarm system that links the patient to a communication centre and 911 in case of emergencies. While at work, Angela felt comfortable leaving June home with this service in place. There was no formal support coming into the home; Angela was responsible for her care, including preparing meals, assisting with personal hygiene, coordinating doctor's appointments, and administering medications. In October (after 2 months living with Angela's family), June was admitted to the hospital with pneumonia and the prognosis was dim upon release – she was not expected to survive beyond Christmas. From this point on, the nature of caregiving changed dramatically as June's condition deteriorated. By the end of October, Angela was feeling very overwhelmed with the responsibilities and reduced her employment to part-time. Balancing caregiving with paid work and raising a family was exceedingly difficult, and Angela experienced tremendous stress and exhaustion. By December, she quit her job completely. While this resulted in a significant drop to the household income (from $75 000 to $38 000), Angela found that the situation improved immensely. She started to feel somewhat rested and was enjoying being at home, for both her mother and her children. However, the demands from both sometimes collided, and she found herself having to put her children 'on hold' while she tended to her mother. Although not suffering pain, June's needs increased as she lacked lung capacity, became winded easily and became bed-bound. For Angela, simple tasks became ordeals, without assistance. For example, it took almost 45 minutes just to change June's Depends diaper because it was so difficult for June to exert any energy to assist without a rest. She worried how she would continue to manage the situation on her own if her mother could not move to help change the diaper. When she mentioned this concert to the nurses, they had no solutions for her.

Formal support was slow to come. Nursing support was first received in the home after June's release from hospital in October due to a bedsore she developed while there. It was not until December that homecare was offered and this was limited to four hours per week (one hour one day and three hours a second day). Two different workers covered the hours and there was no flexibility - the days and times were set by the system. She was uncomfortable leaving her mother at first (in part because June experienced anxiety when she was not there) but felt pressured to do so; they did adapt over time. She was encouraged to leave tasks for the PSWs to complete (i.e. the dishes) and felt a loss of privacy and control by the suggestion. Equally she felt this time should be spent with her mother. She noted how one PSW worker took more time in bathing and attending to her mother than the other. She also experienced a most unfortunate incident with a PSW which required that worker being replaced. She often used the time to run errands and having the PSW in the home did remove the stress of having to rush around or waiting until her husband was home from work. The only other service accessed in the home was the assistance of the respiratory therapist. Angela expressed concern about the possibility of germs being transferred into the home through health care providers. Interaction with the family doctor was very difficult, despite his agreeing to take June on as patient, given her condition. He was basically unsupportive, promising house calls but never appearing, failing to return phone calls and failing to refill prescriptions. Then at one point, he renewed the prescription for six months. Angela found this distressing as it implied he did not want to be bothered. Angela hesitated about collecting the CCB (Compassionate Care Benefit) and when she did apply, the doctor even delayed that by at first neglecting to complete the form, then checking the wrong category for leave (personal instead of compassionate) when he finally did. At times she felt she would need to make her own appointment herself to get his full attention. While he did treat June well when he did see her, he made it clear to Angela that he felt she should be in a hospital.

While she was extremely grateful for the assistance she did receive, she was very disappointed by the failure of the system to guide and assist her when her mother was in the last stages of dying. Worried, Angela called the doctor for support in the morning of the day before she died; but he did not return her call by the end of the day. She then called the nursing organisation responsible for homecare twice (once around dinner time and then again in the early hours of the morning); they refused to send a nurse suggesting that if one was sent, June would have to be hospitalised, so she spent the night alone. While both the doctor and the nurse showed up the next day just shortly before June died, she endured the last night of her mother's life in fear and uncertainty.

Modifications to the home were necessary to facilitate care. Angela's daughter gave up her bedroom for June, and a hospital bed and TV were set up in the room to make her comfortable. Other equipment was acquired, including: a wheel chair and respirator, along with a commode, shower seat, toilet support and hand rails in the bathroom. The living room furniture and TV were moved to the basement to keep the main floor area of the home quiet. Angela's biggest expense was the loss of income. The respirator was provided free and the commode was rented, but all other equipment was purchased by June. Except for a miscommunication for a couple of weeks involving the Depends diapers not being supplied, there were no expenses for medications or Depends diapers as these were covered by the CCAC.

Angela received virtually no support from her family, all of whom lived out of town. Except for the family gathering together in her home for Christmas, and sporadic weekend visits from one brother, her four siblings did nothing to help. In fact she did not have one day off from the time she began caregiving in August through to June's passing in April. The lack of family support extended beyond the direct caregiving, as they failed to assist with funeral preparations and the settlement of June's affairs (i.e. selling/emptying her home, settling estate). Angela's found this extremely stressful over the process and into bereavement, not only in terms of the sheer work it produced, but for the lack of consideration and respect it portrayed. The calls did become more frequent following June's death, but only to push for the settlement of the estate.

Angela had positive relationships with both her mother and husband and these were sustained throughout the caregiving process. She was grateful for the support her husband provided – helping out with her mom (with most tasks, except those relating to personal hygiene) or spending time with the children. She recognised that they shared few opportunities to get away as a couple or a family.

Fortunately, Angela enjoyed excellent physical health. She suffered from no serious illnesses but experienced seasonal colds. She did experience high levels of stress and exhaustion both through: (a) balancing the caregiving role with her many other demands and limited support and (b) witnessing her mother's decline. As a result of her mother's condition, she was not able to get enough rest, particularly when she was employed. As the disease progressed, sleep was interrupted due to June's coughing at night, together with her own worrying. She had relatively few outlets to cope; with little support, she was not able to get away from home very often. Further, time not spent in caregiving was often spent mothering. Angela reported gaining weight while caregiving, explaining that she was motivated to snack to reduce tension; additionally, she found that her feet were very sore from being on them all day.

June died in the home nine months after moving in and more than five months later than was prognosticated. It was a gift for Angela to have kept June at home to die, despite the challenges she faced. The hard feelings she felt towards her siblings impeded both her ability to provide care, as well as the time available to grieve the loss of her mother; six weeks after her passing she had still not addressed these difficult feelings. Although Angela and her husband worried about how their grandma's death in the home would affect the children, it turned out to be a healthy experience. Angela was deeply affected by the experience, deciding that she would make a career change and go into the nursing profession.

3.1.4: *Barb and Raymond*

> "I've got no complaints, you know; ...I would do the same, well, more – not do the same! ... I feel that it's my job to look after him; I would do it as long as I can; as long as I have my health!" (Barb, Interview 2)

Barb initially believed that she played a minimal role as caregiver to her husband Raymond. This was partially because of the degree of functioning he possessed, and because caring for him seemed less of a task and more of an obligation because of their relationship; separating out the things she did as a caregiver to him was difficult. Barb was interviewed twice while caregiving at approximately six week intervals; the caregiving situation ended when Raymond successfully reached a stage of remission, almost three months after joining the study.

Barb, 69, and Raymond, 79, lived in a modest home on the outskirts of an urban community for the past 46 years. Barb was a homemaker and Raymond had been retired for many years. The household income was not disclosed. They had no children of their own but did have siblings and their extended families living nearby.

Raymond was diagnosed with work-related lung cancer in 2005. He underwent chemotherapy, which was discontinued in the summer of 2006, and was hospitalised with pneumonia in October, 2006. His situation was considered very grave and he was not expected to live long. His lung capacity was very low and he required oxygen; however, other than the oxygen, he was not in need of other treatment and was released from the hospital two weeks after admission.

This was a big shock for Barb; she was scared of what was ahead for Raymond but relieved to have him at home so that she knew what was going on with him. Barb had always been a homemaker and was very independent; she enjoyed several activities outside the home, including shopping and volunteering at her local church. She had no previous experience caregiving, but was quick to embrace the role, although there were aspects of caring that she found uncomfortable. She suggested for example, that if she was required to give Raymond any type of needles, she likely would be unable to do so.

Barb looked after many aspects of Raymond's care, including helping with personal hygiene and dressing, coordinating and driving him to doctor's appointments, and monitoring/cleaning the oxygen machine. Additionally, she was responsible for all of the household chores and took over some of Raymond's duties, such as looking after the household finances and maintaining the wood stove that heated their home (stoking the fire, bringing in wood, etc.). She was very concerned with providing an environment free of dust, germs or bacteria for Raymond given his susceptibility to lung infections and was concerned that health care providers may unwittingly introduce germs into the home when they made their visits. Although she perceived the care she provided as limited, it was necessary for someone to be in the home at all times in case there were any problems with the oxygen machine (including a power failure). As such, she sacrificed taking time for herself and getting away from home. When she did get away, she often worried and found it difficult to relax.

Upon release from hospital, Raymond was placed on the PC caseload and daily nursing visits were put in place to check and clean his PIC (or PICC) lines,[13] monitor vitals, and test his lungs. A PSW was also provided for four hours per week (one hour one day and three the other). While initially scheduled over two days, Barb had these hours combined into one block of time, one day per week, to make better use of the time given to her. She was pleased with the support and felt that any of her concerns or questions would be met positively through the system. Except for the addition of the oxygen machine, no modifications were made to the home and no expenses were incurred.

As Raymond's condition improved, he regained functionality and could look after himself. He started to resume some of his normal household chores and Barb's caregiving role diminished. She was the able to resume her outside activities and worried less about him when away.

Although in close proximity of many relatives on both sides of the family, Barb tried to limit dependence on them. These relatives suffered from various health problems and had their own families to worry about. Barb could count on them for emotional support, via visits and telephone calls, and often this was enough. On a few occasions, she would have Raymond's sisters come and stay for a couple of hours so she could get away to run errands or take a break.

Barb enjoyed good health both before and after the caregiving process. While she did suffer from arthritis in her hands, neck and back, she engaged in self-care activities to minimise the effects. She recognised the need to be aware of her physical limitations and to get proper rest. Health maintenance was important to both of them and they maintained a healthy diet. Her mental health was quite fragile at the beginning of the caregiving experience; as Raymond's condition improved, so too did her spirits and she felt no long-term effects from the caregiving situation. She found that Raymond's attitude was changed by the experience (nearness to death) and noticed that he seemed to embrace life more fully.

Thinking to the future, Barb expressed that she would not want to place the burden for her care onto others; she believes that she would want to be put in an institution if that happened. While Raymond did recover and the cancer went into remission, the future is not far from her mind. Her philosophy is to take each day as it comes – she has rediscovered the value of the life they do have together and puts her trust in God's hands.

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[13] PIC (Percutaneous Intravenous Catheter) or PICC (Peripherally Inserted Central Catheter) lines refer to tubes that feed fluids or medications intravenously (Wikipedia, 2007; University of Iowa Health Care, 2007).

3.1.5: *Maddie and Nancy*

> "Her just getting up in the morning still alive is rewarding! I can't really see anything rewarding to it; well, it makes me feel good that I've done the right thing... it makes me feel good that I have done everything I possibly can for her. I will not feel guilty." (Maddie, Interview 1)

The ability to derive meaning from a difficult situation is often an effective coping strategy, although it does not necessarily equate with satisfaction; as Maddie hints, the meaning appears as a consolation prize. Maddie participated in two interviews, both outside the home: one during caregiving and one during bereavement.

Maddie, 53, lived with her husband, Brian, and adult daughter, Brianna. They had resided in the community for more than 30 years, spending six years in the current home. She had two other adult children and three grandchildren nearby. Maddie had no other family except for a brother who lived in southern Ontario. Both Maddie and Brian worked fulltime outside the home; Maddie owned and operated her own retail business in the community with part-time assistance from her husband. They had a combined household income of approximately $60 000.

The formal caregiving arrangement began in November 2006, when Maddie moved her 79 year old mother, Nancy, into the family home. Nancy lived alone having been widowed six years earlier. Maddie had been caring for her mother extensively prior to bringing her into the home, given that her current cancer relapse was the third in 10 years. The limited homecare Nancy was receiving in her home was not sufficient, so Maddie spent every night and weekends with her, cooking meals, tending to her house, and keeping her company. It finally reached the point where it was easier to bring Nancy into their home so as to allow Maddie to manage her home and retain some sense of her own routine. She was committed to caring for Nancy in the home both to honour a promise to her father and to respect Nancy's wishes to avoid institutionalisation. Although Maddie and Brian had offered to move into Nancy's home, Nancy preferred to move into Maddie's home because she had so many happy memories there.

While Maddie was the primary caregiver she had assistance from her husband, Brian. As well as working, Maddie enjoyed many social activities including volunteering extensively in the community, spending time with friends and exercising. As her mother's condition worsened, she found she had to give up her outside activities, but continued working. Working served as a coping strategy, offering her the chance to get away from the caregiving situation, although she had to close the shop a couple of times to take her mother to specialist appointments out of town. Additionally, she found that due to the caregiving arrangement, she was taking longer to meet customer needs; for example, orders that could be filled overnight often took three days or more to turn around.

Typically, for the first few months, Maddie would leave for work in the morning and return around 5pm; Brian worked shift work so he was able to help with the morning routine (i.e. feed breakfast and get medications) before leaving for work around noon. This routine ensured that Nancy was never alone for more than a few hours each day. In addition to regular housekeeping responsibilities, Maddie monitored and administered her medications, assisted with personal hygiene, and coordinated and attended doctor's appointments. Nancy gradually required a modified diet and experienced a decrease in the ability to perform routine activities (i.e. going to the bathroom). Though she loved her mother dearly, Maddie found her rather demanding and difficult to deal with. For example, she had enormous difficulty in getting her mother to bathe and was frustrated by her demands to be with her in the bedroom when she was not at work. The frustration made her feel guilty and both (frustration and guilt) added stress to the arrangement.

Maddie managed with little assistance through the health care system for many months; the only services going into the home were daily nursing visits. As Nancy's condition worsened and she became bed-bound, it was necessary to increase the support to include daily homecare. In the final month, she was never alone. Brian was relieved by a PSW around noon each day; the PSW stayed until Maddie returned home from work around five and Maddie was with her until she left for work the following morning. The number of nursing visits was increased substantially as well, reaching as many as three or four times a day. This became necessary to monitor and treat Nancy's pain, as only nurses can control the dosage of medication administered through a pain pump. Nancy had reached the capacity of pain medication that could be given in the home and, had she survived, it would have likely been necessary to hospitalise her. Most support came through the nursing staff and there was very little interaction with the family doctor. Modifications to the home were limited, consisting mainly of equipment in the bathroom and the addition of a hospital bed. Her mother was in a position to contribute financially to any expenses not covered through the CCAC, although Maddie had increased food costs and hydro expenses, and a loss of income when her shop had to be closed (this was perceived as minimal).

Nancy was hospitalised once and Maddie was discouraged by the treatment she received in the emergency department. The hospital staff on duty was aware that Nancy was a palliative patient but still prevented Maddie from participating in the treatment, despite Nancy's obvious disorientation. As a result, Nancy was unable to answer the questions properly and gave incorrect information. About ten hours had elapsed before Maddie was able to connect with Nancy, and this happened only through the interference of a friend who was a nurse in the department. Nancy was admitted and remained in hospital for a week but was very angry about being there. She was not very pleasant to the staff and was not eating or drinking properly, so Maddie ended up having her discharged.

Maddie had limited informal support as well. Although her adult children were nearby, they provided little help. Her brother, although living at a distance in southern Ontario, provided no support whatsoever. No friends helped out with the physical tasks of caregiving and some of their emotional support was lost when Maddie reduced her social activities.

Maddie enjoyed relatively good health in general but suffered from arthritis in her knees and neck, back and shoulder pain from a fall she suffered two years earlier. She saw a chiropractor regularly to treat her back injuries and had engaged in an exercise routine to deal with the arthritis. While she was unable to continue with the exercise regime, she was sure to integrate a great deal of walking into her day (i.e. to walk to work). She battled an inner ear problem that caused dizziness and always had difficulty 'turning off her brain' to get proper rest. She suffered exhaustion due to worrying about her mother and through attending to her throughout the night as her condition deteriorated. Financially, working was necessary but it also became a refuge, offering a much needed break. The problem with working was that Maddie was always afraid that her mother would die and she would not be there for her.

Anticipating the death event was stressful; while she thought it would be a blessing given the pain Nancy was in, both knowing what to expect and what to do when it happened weighed heavily on her mind. She feared being alone in the house when it happened, with her husband working shift work and her daughter always out. On the evening she died, Maddie had just happened to call a friend over to visit; just minutes after her friend arrived, Nancy died. Maddie believed that her mother had waited until she had someone with her when she died so it was not quite as distressing.

Following the death, Maddie was responsible to arrange the funeral and settle the estate. Once again her brother did not help and, in fact, removed items from the home before the estate was settled. This was very upsetting, further straining the relationship. As a result of dealing with the funeral, estate and family dynamics, she had not really had a chance to grieve, even six weeks later.

Maddie discussed finding few positive elements to the experience as a whole, although she felt very good about being able to honour her father's and mother's wishes to keep Nancy at home to die. She believed she was successful as a result of being a strong-willed woman, but questioned how much longer she would have been able to continue in the caregiver role. She recognised that caregiving was not something that she would do again, except for her husband. The experience with Nancy has left her completely traumatized about dying. The impact of her mother's death was strong - with both parents gone and a strained relationship with her brother, she feels very alone.

3.2 Summary of Cases

The caregivers in this study represent a diverse set of individuals who have dedicated themselves to caring for their loved-ones. Their situations are unique, reflecting different family structures, disease trajectories and lengths of time in the caregiver role. Individually, they faced various challenges and had varying degrees of support, both through the health care system and through informal networks. Collectively, they demonstrate how they attempted to find meaning and turn what many view as a tragic event into a personal triumph.

Chapter Four

Results

While it is clear from the case summaries that great diversity existed between the experiences of the participants in the study, the longitudinal approach to the study revealed many similarities as well. This chapter contains the analysis of the interview data across cases. The results point to a high degree of personal satisfaction in fulfilling the caregiver role, but with numerous challenges and many accommodations along the way, all of which have consequences on caregivers' health. The findings are arranged around one organizing principle, *suspension of self and time*, and three sub-themes, relating to *support*, *motivation* and *health*. *Suspension of self and time* reflects the extent to which FCGs put their lives on hold in order to provide care in the home, while the sub-themes represent factors that influenced the degree to which it was necessary.

4.1 Overview of Cases

The study consisted of five participants, four female and one male caregiver. This highly gendered sample is typical of caregiving in general, as discussed earlier. Three of the five cases involved adult-children carers which, in the caregiving literature, appears less common than spousal arrangements (Hauser & Kramer, 2004); however, that they were the daughters or daughter-in-law is consistent as more women than men provide care. They varied in age from 38 to 79 years and were in relatively good health approaching the caregiving situation. The length of time in caregiving varied from 12 years to four months and various diseases were represented [(cancer (three); AD (one); lung disease (1)]. Three of the five cases ended in home death; of the other two, one remains in caregiving as the disease continues to progress and one ended with the loved-one going into remission.

4.2. Themes

4.2.1 Suspension of Self and Time

An organizing principle that distinctly emerged from the data is the fact that the FCGs in this study literally had to put their lives on hold to provide the level of care necessary to keep their loved-ones at home. This *suspension of self and time* can be referred to as a period of liminality, a transitional stage of in-betweeness (Shields, 1991 in Winchester, et al, 1999). Although not previously used in the P/EOL caregiving literature to describe the experiences of FCGs in particular (i.e. see Hallman, 1999), this term aptly captures the "discontinuity" between "culturally-defined stages in the life-cycle" (Winchester, et al, 1999, pp. 60). Identities are altered as family members make initial accommodations to provide care; these identities continue to erode - slowly or quickly depending on the disease progression and the personal circumstances and support networks of the caregiver - until they are virtually engulfed in the caregiver role. The death marks the end; no longer a caregiver they emerge, affected by the loss and changed by the experience, to pick up the pieces of their lives and make decisions about the future. While these distinct facets of palliative family caregiving (for example, the changes to routines and living arrangements and the effect of the disease trajectory on the intensity of caregiving) are not new (i.e. Rhodes & Shaw, 1999), conceptualising them in this manner is new because it best captures the response by FCGs to a role that is largely socially imposed but not well-supported. The theme of suspension is illustrated through the loss of personal time, as evidenced by the nature and scope of the caregiving role.

This suspension affected different aspects of the FCGs lives. As previously indicated, two of the FCGs were retired and of the remaining three, two had to quit work to provide care; they all had to significantly decrease, if not practically eliminate, their social activities - including volunteer work, hobbies and exercise regimes. For those retired, the transition to care may have been easier, but it was found that caregiving was restricting to some degree in all cases; even for Barb who felt her role was not that significant. Reflecting on the experience during the second interview she realised this:

> "Before I had to make sure that there was someone with him; now I can just get ready and go if I have to go out; or if I want to go to a movie or shopping in the evening – you know, I can just go."
>
> (Barb, Interview 2)

In addition to the degrees of restriction they felt, they often approached the situation with limited knowledge – of what to do and what to expect; much of what was involved was learned along the way, as Maddie suggests:

> "You can't even dream of what you are getting into."
>
> (Maddie, Interview Two)

Equally, they realised how the intensity changes over time; and that relationships and roles change as well, with role reversals especially noticeable in the adult-child/parent caregiving situations. FCGs are quick to discover how caregiving changes across settings and how this stands to affect them:

> "If someone is in the hospital, and they need medication, you're there as a family member, you're there to hold their hand...you know, just be there for them. So if they need medication, the nurses do that, you know? You are 'in between' the medical. But when you are at home, you are responsible for everything. Nurses come, but I mean when they're not here, you're responsible for every need...every need."
>
> (Angela, Interview 4)

Time virtually became irrelevant as they assumed the caregiver role and set about attending to the needs of their loved-ones; despite the time involved in the tasks, this would normally take priority over everything else. For example, they would often have to stop in the middle of what they were doing – whether it be sleeping, trying to relax, doing chores - to tend to their loved-ones' needs or check their status (breathing, coughing). Sometimes simple tasks would take considerable amounts of time, causing FCGs to either prioritise their time (i.e. Angela teaching her children to wait until she was finished) or to rush through various tasks to play catch up. To illustrate, Angela, spent upwards of 45 minutes alone to change her mother's Depend diaper. Caregiving required considerable flexibility and patience on the part of the FCG, and other household members as well. The need to do so and the value of doing so were never lost on the FCGs, but as time went on, meeting the demands with few opportunities to get away from the caregiving situation became overwhelming. Quite simply, as Maddie states:

> "It had been going on for five months and you can only do so much before you start going bananas."
>
> (Maddie, Interview Two)

Often the decision to provide care was the result of situational factors; certain factors were necessary in order to both contemplate the arrangement and to put it in place. For example, leaving employment to care was possible when another household member, the spouse, was working. Employment was part of the FCGs "normal" routine and identity; but deciding how much of oneself to give up in order to provide care was related to their ability to balance these social roles, as contrasted here with Maddie and Angela. In both cases, it resulted in different levels of suspension. Maddie was self-employed, so had comparatively fewer options in general, given that she could not afford to hire a full-time replacement; she remained working for other reasons as well:

> "I think my work is my lifesaver kind of thing; because if I had to stay at home 24/7 and watch my mom the way she is, I think I would be a basket case. But I think being able to go to work ...even though it makes me busier, *mentally*, it's a place where I don't have to think about my mother, and I don't have to, you know, worry – well, I worry, but I don't have time to think of her and I don't have time to think of the situation because I am so busy at work. And I think that is what helps. If I didn't have a job, it would be...I don't think I could...I'd be having a social worker..."
>
> (Maddie, Interview 1)

So by continuing to work, she was able to retain some of her identity and cope with the caregiver role. Angela, however, found that to cope she had to leave her job; in doing so she lost some of her own identity and became tied to the caregiver role:

> "But it was hard, oh, that's one of the reasons I can't do this anymore – I can't work. Finally, I was starting to feel really...like I don't know if I could do this anymore because of that; now that I've made the decision not to work it's getting better. Rundown; I wanted to just run away sometimes. I had enough of this I couldn't do anything anymore; I just want to run away. I wanted to just scream..."
>
> (Angela, Interview 1)

The provision of the CCB was not utilised in leaving work in these cases and, for Maddie, was not even a possibility given that she was self-employed. This loss of income was in part balanced by the contribution of the parent/patient to their household (in a limited manner) and to their health costs, such as the purchase of the various supports and equipment to provide care in the home. The ability to adapt the home (through the addition of equipment, rearrangement of rooms, etc.) to care also made the arrangement possible. All of these factors discussed above contributed to the context for caregiving.

P/EOL care is immensely rewarding, but it is brutally demanding as well; the ability to balance the two is affected, in part, by the services and support to which caregivers have access to manage the care, and by their personal motivation and capacity to care. The following themes speak to the influences on caregiving arrangements, highlighting both aggravating and mediating factors that contribute to the degree of *suspension of self and time* experienced.

4.2.2 Gaps, Cracks and Obstacles: Services and Supports

This theme refers to the support available to FCGs and the effect of this support on their role as caregivers; it clearly contributed to and mediated against the degree of suspension experienced by the FCGs. Three sub-themes emerged: (a) geographical access, (b) formal supports, and (c) informal supports.

4.2.2.1 Geographical Access

For economic reasons, health care services in rural areas are often centralized in larger centres. While many larger communities have hospital services, specialty services in north-eastern Ontario - including oncologists, neurologists and equipment (i.e. MRIs), are concentrated in three cities: Sudbury, Sault Ste. Marie and Timmins. Cancer specialists can be found in Sudbury and Sault Ste. Marie in this health region (LHIN).

Geography explained how services differed *across* space as well as the implications *of* space in accessing various resources. In general, the FCGs in the study illustrated perceived satisfaction with the type of support that was available in their communities. All of the communities in which FCGs resided with their loved-ones had hospitals and all of the participants and their loved-ones 'had' family physicians. Nonetheless, certain limitations did stand out.

The types of services and how they were made available varied across communities and between districts. For example, all communities had access to palliative home-care services, but not all service providers were PC specialists, unlike those in urban centres. The assignment of homecare hours differed across districts and between caregiving situations. For example, Tom received 100 hours of homecare per month through 'his' CCAC as compared to the 24 hours received by Angela, despite the fact that both their family members (Mary and June) were afflicted with similar degrees of incapacitation. To take this comparison a step further, Tom had no other dependents in the home but Angela had two small children and her spouse worked fulltime. In this light, Tom's hours are perfectly justified given his situation, yet Angela receives a mere fraction.

Further, not all services were available in all communities. Tom, for example, had access to a bathing facility at the AL living centre in his community while the others did not. The benefit for Tom was that he could offer Mary more than just daily sponge baths. The larger communities had wheelchair accessible transportation systems, but no other options existed for those who could not be moved by wheel chair in non-emergency situations (except for ambulances, which are more commonly used in emergencies). This affected caregivers' ability to take their loved-ones out of the home, for whatever reason. For example, Angela could not take advantage of a respite opportunity, an adult day care programme, because her mother was unable to be transported in a wheelchair. Tom was also facing challenges in transferring Mary to the AL facility for her baths as she could no longer sit upright in her wheel chair. Fortunately, Tom had purchased a reclining hospital chair which could be used instead. It appeared that there was a difference in the flexibility with which FCGs could access services across districts. For example, where Barb was able to change the homecare hours to better suit her needs, Angela and Lisa were bound by the times allotted by the CCAC. As such, they were restricted in how they could use their "own" time and with whom it could be spent. Both Angela and Lisa's spouses worked during the day – the same time the CCAC hours were scheduled. Therefore, this free time could rarely be spent as much-needed 'couple-time'.

Accessing specialty services (i.e. oncology centres, certain equipment and testing facilities) was problematic due to the centralisation of these services in larger centres. It was often not the distance that bothered FCGs necessarily, as they tended to normalise this, but it was how travelling affected the loved-one, especially if they were particularly ill. This produced a helpless feeling because FCGs often had to do it on their own. If travelling was unmanageable, it really did affect whether or not services were accessed:

> "Well, I had to bring her to a specialist in Sudbury but she's just too weak to go; ...I talked to the doctor about that because I told him, after the pneumonia that was when she was really ill – really weaker, how am I supposed to get her to your office now? ...he wanted her to see a specialist in Sudbury - how am I supposed to get her there? Because I would have to do it on my own. Both myself and my husband can't take time off work, it's either or – so if I bring her to appointments like that I'm just with her by myself. There is no hospital between *community* and Sudbury. And in her state? She couldn't get from her bed to her wheelchair. I told them I really don't think she can go by car, so he had told me 'well, I'll try to make some arrangements where I can admit her and have her sent by ambulance' but he hasn't followed up on that."
>
> (Angela, Interview 1)

Lisa faced more challenges accessing health care services than the other FCGs in the study. This was because there were literally no services in her community and she was 35 minutes from the nearest centre where services could be accessed. In her case, a number of challenges were experienced to a greater extent than the other caregivers in the study, including: travelling to doctor's appointments; dealing with weather and night-time conditions (i.e. animals; winter driving conditions, dirt roads); having to pick up prescriptions as opposed to having them delivered; and travelling back and forth to the hospital when Rose was admitted.

Geography explains how services differ across areas and how access to them could be difficult. The fact that it did not materialise as a bigger issue in the study was likely twofold: first, FCGs perceived satisfaction with services is likely due to having minimal expectations of the system, given that they have normalised to the problematic service access issues in place. Additionally, and paradoxically, their ability to adapt their lives to the caregiving situation (i.e. through a reduction in their personal activities), ensured that they did not require as many services. Secondly the FCGs resided in, or were in close proximity to, urban centres where the needed services were located.

4.2.2.2 Formal Support

Formal support refers to services, supplies and human resources that are paid for through the health care system. As discussed in Chapter One, these services are organized and provided through CCACs in Ontario. The research findings presented herein are centred on the availability and quality of these services. The three most predominant members of the health care team were physicians, nurses and PSWs and are the focus herein. Also present, but with less prolific roles, were: physician specialists, occupational and physio-therapists, respiratory therapists, pharmacists, and clergy members.

Home-based PC was delivered and administered primarily through the CCAC PC programme, and case managers basically coordinated all of the services that went into the home. From the FCGs perspectives, they relied on *everyone* within the system to manage the experience, including: doctors, nurses, PSWs, case managers, social workers, respiratory, physical and occupational therapists - many of whom do not have specialised training in P/EOL care. In the aggregate, caregivers' needs were tremendous. For example, they needed to know *which* services were available in the community and how to access them. They required information concerning the disease and its trajectory, the dying process and what to do as death occurs. For example, Maddie had been caring for her mother for several months and still did not know what to expect or how to handle the death when it occurred:

> "Right now, I need to know what to expect when she actually dies. If she dies in my bed, what do I...how do I know that it's close? When do I call the nurse? When do I pick up the phone and call [services provider name]? When she stops breathing or when she's...what? That is the only thing...that's the one question that my husband and I want to know.
>
> (Maddie, Interview 1)

Not only do FCGs want some type of indication that death is imminent, but they need to know what to do when it happens. In fact, certain protocols exist in which to deal with a planned home death as there are legal ramifications otherwise. For example, FCGs in both areas are advised not to call 911 or an ambulance because the police would become involved. In one area, the protocol (as put in place by the CCAC) was to call the nurse in order to have the patient pronounced dead and then call the funeral home to have the deceased's body transferred. The doctor would sign the death certificate at the funeral home. In the other area, the doctor was to be called to pronounce the death but no options were given if the doctor happened be away at the time.

FCGs also needed guidance in performing specific tasks (i.e. treating sores and monitoring patient status), particularly around handling and administering medications:

> "Well, you know, with all the different medications that she is on, I was worried about mixing, right? I didn't want to overdose her because that is kind of scary...So I had the nurse sit down with me with all the medications and say what can I [give]...if I give her this, how long before can I give her *this* ...And they just informed me that because they are so low dose that it doesn't matter, the only thing is that she'll just be... some days if I give her the pill under the tongue which calms her, and then she needs something for pain, she'll just go to sleep more...that's all; it won't hurt her."
>
> (Angela, Interview 3)

Pharmacists, who would clearly have an important role to play here as well, were not always forthcoming with this information. Maddie, for example, could not get the pharmacist to even discuss the medications she was picking up for her mother (and responsible for administering at home) without bringing in her mother's power-of-attorney. Only one FCG was given a chart of some type to keep track of medications; otherwise, they were left to coordinate the administration schedules on their own.

FCGs had to be proactive in the search for information or their needs could be left unmet:

> "They are not going to volunteer something that is, like you said, taboo. Unless you ask that question they are not going to tell you things that are... that are negative. Or negative to them, even though you have to go through it. And I'm not one to wait around to find out, so I'll ask and you prepare yourself. I think that was one of my ways preparing myself for what was going to happen. Knowing what she was *going* to go through."
>
> (Lisa, Interview 2)

In addition to the practical needs for this information, the FCGs believed that having this information was essential in order to cope, as difficult as it may be to receive the needed information:

> "When I ask the questions I expect an answer – it's not always what I want to hear, you know, but at least they'll be honest with me.
>
> (Tom, Interview 2)

Knowing who to approach was often problematic as evidenced by the lack of a team approach. For the most part, case managers and nurses were used as sources of information; they were also most responsive to FCGs needs:

> "I know that anything I need, or anything I ask, I will get or get the answer to... they are constantly saying to me, you need anything Maddie, you call. So I have no qualms with them. [What I value] the most is knowing that I have all the answers that I need at my finger tips, and the fact that I trust their judgement and I trust their care to

> my mother. The nurse will call with questions at my place of work. If she [nurse] doesn't have the answer she will get it."
>
> (Maddie, Interview 1)

Nurses provided most of the care, including monitoring patient status. This is consistent with other research, which suggests the majority of care is provided by non-physicians (Kelley et al, 2003). Overall, FCGs were very pleased with the level of support they received from the nurses and felt respected in this arrangement. However, they often had to reach out for help and it is clear that their expectations were low in general:

> "Actually, the nurses are very good – I can ask them and they tell me, they show me, you know, if I need anything [or] they need to show [me] something ... that's kind of like <u>a comfort thing</u>, that the medical profession is coming in everyday, you know, just assessing her."
>
> (Angela, Interview 1)

PSWs were very valuable and, because they were coming into the home regularly, provided continuity and trust:

> "You have to understand I cannot do this alone – I have help and over time, I was able to get the best of help - what's available in our area – and it's personal support workers (PSWs); at one time they were called home makers; we have good ones and we have not so good ones; and over time I was able to pick the good ones."
>
> (Tom, Interview 1)

The remaining FCGs had few problems with the PSWs coming into their home. In one case, a PSW was replaced due to poor treatment. Any issues with PSWs were dealt with by the PC-CMs. According to the CCAC, the hours for this type of assistance were determined by the status of the patient to provide limited support for FCGs. Their assistance created valuable opportunities to get away, but as previously mentioned, there was little flexibility in how the hours were arranged.

In general, physicians were not very supportive of the patient being cared for at home, and in several instances, this was overt. As was indicated in the case summaries, this was reflected in a number of ways, including: an insensitivity to the patient's condition; failing to provide information as needed; failing to show up for home visits as promised; and, simply failing to renew prescriptions:

> "No, I just can't pick up the phone. She needed a prescription renewal, and I called, she needed it today actually [Saturday]. I called Monday *(the Monday before Saturday when the medication was needed)* and talked with the nurse [receptionist] – asked if they can phone it in; 'ya, I'll leave a note.' So Monday evening I called the pharmacist to see if the prescription was called in – nope, okay. Tuesday I called, said there's no prescription called in – 'oh, I'll leave another notice', okay. [I asked] 'Will you call me and let me know if you've called it in or not?' 'Well, I'm usually not here when he does that.' Okay, so I'll just wait until after 6 and call. Thursday...again not there; and then Friday, I call Friday morning -

> still nothing – so she doesn't have her medication that she was supposed to have today."
>
> (Angela, Interview 1)

Ultimately, Angela's doctor renewed the prescription for six months. Angela found this very distressing because it indicated to her that he did not want to be bothered; related to this, Angela felt that her mother was not being monitored properly. While this example is extreme, problems with prescription renewals were common across a number of cases; as a result, the FCGs often relied on the nurses to get prescriptions refilled because it was just easier. Conversely, one physician went above and beyond – making home visits and random phone calls, as well as providing the FCGs with his cell phone number so they could call, day or night. This reassurance was essential to the caregiver situation:

> "One of the things that [the] doctor always said to us was that 'you've got my cell number'; he said if anything goes wrong - he said 'please call me'...we did call it quite a bit when we were upset and he'd say 'take her to the hospital', or do this; and at the end he said just don't –' just keep her at home and keep her comfortable, turn up the oxygen'; so he was really good, informative... we depended on him".
>
> (Lisa, Interview 2)

While Angela experienced the same degree of insecurity as Lisa when her mother approached death, she could not get any assistance - either physician or nursing - into the home for almost 24 hours. This inconsistency is contrasted between cases: both Maddie and Lisa had numerous nursing visits to the home *each day*, whereas Angela had nursing twice a *week*. The difference was that Angela's mother was not being treated for pain. The night before June died, Angela was told that if the nurse went to the home, her mother would be hospitalised. While it was possible that the doctor was too busy to respond or did not receive the message until the next day, it would appear that there is more sensitivity towards clients who are experiencing pain, as opposed to equal consideration for other disease trajectories and/or caregiver distress.

To summarise the issue of formal support, for FCGs, it was about the quality of the care providers; it was their attention, knowledge, compassion and honesty that made the caregiving situation easier. While the people and personalities that serviced FCGs were - for the most part - of good quality, each worked in a very isolated manner, lacking little integration. Each service provider group appeared to be working in peripheral to the other, with the doctors being on the furthermost margins. Underestimating the extent to which FCGs require this integrated, seamless support is detrimental and a team approach could eliminate incongruence between providers while minimising caregiver burden. PC case managers were the common thread linking clients (patients) to services, but no protocols existed in terms of how supports were arranged. Generally, the level of support that went into the home was determined by the status of the patient, not the needs of the FCG (except for perhaps Tom), suggesting that rather than holistic in approach, palliative care situations are still very much patient and disease focused.

4.2.2.3 Informal Support

Informal support refers to those people who are not paid for the support they provide; this includes family members, friends and volunteers. The notion that there are strong networks of support in rural areas to assist with caregiving (Keating 1991, cited in Fast & Keating, 2000) was not evident in this study. In fact, except for Barb, none of the FCGs had relatives even living in the same community. On the one hand, families were geographically divided:

> "We are living just by ourselves – my wife and I; my family – I just have one daughter, two grand-daughters and two great grand-daughters; but unfortunately they all moved away – they are not living close by – they are all living in southern Ontario."
>
> (Tom, Interview 1)

The separation of extended family members severely limited the type and amount of support FCGs could expect to receive from their families. Tom's family would visit only on long weekends because of work obligations and the distance involved, whereas Lisa had a great deal of company, when travelling conditions were favourable. As a result, much of the support FCGs received was emotional in nature, not task related. As Barb indicates however, this support was important:

> "Even that alone is...you know – when somebody calls – they want to know how we are...that gives you a lift; people are interested in what you're going through."
>
> (Barb, Interview 1)

Additionally, family dynamics played a role in how the family handled the caregiving responsibilities. Angela and Maddie both assumed the role of primary caregiver, receiving no assistance from their siblings. This became a very serious issue, as Angela illustrates:

> "Here I am, I changed my whole life to do this and that I want this for her – I changed my children's life, my husband's life – and they have not once said or, do a little change in their life... I am not asking anyone: quit your job, move up here, you know? Help me out – once a month, a weekend, or just come so I can do stuff, you know?"
>
> (Angela, Interview 3)

Even when family members were dispersed, their inability to provide support was understood by FCGs when it was clear that an effort was being made, as in the case of Tom's daughter. However, when there was little or no effort put forth to assist, either physically or emotionally, tensions were created and the demands of caregiving alone became overwhelming. This situation was upsetting for their loved-ones as well, because not only were family members not coming around to help, but they were not coming around to visit either.

The FCGs in one community had access to a visiting volunteer organisation and although used only in a few circumstances, the FCGs were pleased with the services. The volunteers were trained specifically to deal with P/EOL care situations and were often nursing students or retired nurses. There were a number of limitations to the service, including the fact that arrangements had to be made several days in advance, and restrictions were in place in terms of when the services were provided (i.e. not overnight). Although certain restrictions are expected when working with volunteer organisations, FCGs at end-of-life are not always able to make or keep plans too far in advance. For example, Angela often had to change plans at the last minute, depending on her mother's health status that day; this often meant foregoing plans for herself and/or her children's activities.

This theme, *gaps, cracks and obstacles,* illustrates the variation that FCGs had with respect to support. To some degree, albeit perceived as minimal in this study, FCGs are limited spatially to services. Structurally, there is a high a degree of compassion on the part of the formal care providers, yet services are targeted more around the patient than the FCGs. Outside the health care system, few informal networks of support exist, save for that of an emotional nature. The significance then, was the quality of the services provided: feeling respected and having information needs met were invaluable to the FCGs in this study. In general, the lack of support contributed to the degree of suspension of self and time insofar as tying them to the caregiver role. If they had increased support, they could maintain some aspects of their normal routines and/or activities and alleviate some of the caregiver burden being carried.

4.2.3 The Drive Within – the Drive Behind: Motivations for Continuing the Role

This theme refers to how FCGs were motivated to care and to continue caring when faced with adversity. It was found that both internal and external factors contributed to these decisions to continue, creating what can be referred to as a 'culture of caregiving'. The "drive within" represents internal motivators - factors specific to the FCGs themselves - that contributed to the decision, while the "drive behind" represents external factors – both positive and negative - that were influencing decisions to continue.

A number of internal motivators were at play. FCGs were often motivated to care out of feelings of love and respect towards their loved-one:

> "To be quite honest, I had no idea where I [was] going from [t]here – from [that] point on. But one thing I was determined – we'd been married for such a long time and I found it is there - you don't just let go."
>
> (Tom, Interview 1)

Additionally, FCGs were motivated by the fact that they sensed that it was the right thing to do:

> "I just do it; take what comes...I don't want him to be sick but I do it [give care] because he is my husband."
>
> (Barb, Interview 1)

Doing so evoked a sense of pride - one that even carried over into the bereavement process. In some cases, these feelings also had the power to motivate future actions:

> "If I had to do it again for someone I really care about, I would do it again."
>
> (Angela, Interview 1)

External motivators (drive behind) were the more prevalent of the two motivators. In all cases, the FCGs found that caring for their loved-one was much easier and more desirable at home. As a result, they did not have to travel to an institution to spend time with their loved-ones and they were better able to balance their responsibilities and retain some semblance of routine in their lives. Additionally, dissatisfaction with hospitals and long-term care facilities and the level of care received (in terms of personal attention and general cleanliness), permeated FCGs thoughts. This enabled them to empathise with their loved-ones preference to avoid being institutionalised, as well as to providing strong incentives to keep them home:

> "The decision [was] very easy to make, if you have insight into those homes. No matter what they provide and what they say they would do, it does not come close to what you do at home."
>
> (Tom, Interview 1)

By far, Tom and Mary faced the worst treatment in hospital; but Lisa experienced this first-hand as well. Beyond Lisa's mother-in-law's unhappiness with the thoughts of staying in a hospital or home, she had her own:

> "I was there every day [at the hospital] with my father-in-law ... I would take him in the afternoon. One of the things I [the staff in the hospital neglected]: they never bathed her in ten days. So we were going in changing her sheets, bathing her –her niece [and I]; there was two or three of us that were doing it. I couldn't believe [it]...I was just furious because they couldn't even change her sheets and she was having accidents... it was awful... "
>
> (Lisa interview 1)

The most significant external motivator was the wish of the patient to be cared for and to die at home. Adult-children carers did not want their parents to be alone, and often they were the only option for care, given family relationships and structures. For example, Don was an only child, whereas both Angela and Maddie knew their siblings would not step in. Angela suggests:

> "My mom would be in a home or whatever; they [her siblings] wouldn't do it."
>
> (Angela, Interview 3)

This motivator reflected the sense of obligation FCGs felt towards their loved-ones - particularly in the three home deaths. In these cases, the FCGs knew how important dying at home was to their loved-one:

> "She doesn't want the options, and I [have] to respect her wishes; where she wants to be is here. She knows she is dying, and she want[s] it to be with us. And that was the only decision that we could have made. Let me tell you, it was hard, because we thought last night about taking her to the hospital and at least being able to sleep at night."
>
> (Lisa, Interview 1)

Given this duty to their parents, Maddie illustrates the great lengths FCGs like herself would go to make this happen:

> "So in February the nurse was going to send her again [to the hospital] and I said no, because they will not let her out. She would be in there and that would be it. And I said no; I said 'is there anything we can do here?' And she said 'just keep forcing liquids into her'. And I said 'okay, that's what I will do'."
>
> (Maddie, Interview 2)

The pressure felt by FCGs to manage in the home was, at times, overwhelming:

> "It was kind of...because there was [sic] times I thought well, I wonder if I can't handle it anymore. What happens if she is really... [I] was really scared – I don't know if I could handle it. What is going to happen...would she be really mad at me for backing out? Because she was so adamant, she really was, but...There were times I walked down[stairs]...I don't know if I can do this...but then I would go away and just sit and think or cry or stuff, and come back and say okay, 'do it again. I'll give it another try'."
>
> (Angela, Interview 4)

Dealing with the many tensions that accompanied providing care at home was a constant struggle:

> "You know you're getting emotional; you're getting tired your getting a little depressed, so those things were irritating me, and it wasn't on purpose, but.."
>
> (Lisa, Interview 1)

Add to this the known issues of providing P/EOL at home, including: the lack of both informal and formal support; the loss of privacy; the inability to get away from the caregiving situation; and, dealing with the impending loss. Clearly, staying committed to the caregiver role was a tough test for the FCGs *and* a testament of the deep respect they felt for their loved-one; honouring their loved one's wishes to be cared for and to die at home was a powerful influence in their success in sustaining their FCG role.

Both the internal and external motivators suggest that a culture of caregiving influences the decisions for family members to care and continue caring regardless of the challenging circumstances that are presented. While FCGs may 'want' to care for their loved-ones at home, this study shows that they are doing so under very extraordinary circumstances. Similar to other research (i.e. Wells & Kendig, 1996), these results suggest that there are different motivators between spousal and adult-children caregivers. Spousal caregivers are likely to be motivated internally, through their sense of what is right, likely because of the nature of the relationship. Adult-children are more likely to be motivated externally, out of a sense of obligation and the desire to please their parents. This may affect the potential for success for both caregiving at home and ultimately, a home death. Additionally, and importantly, while the FCGs felt good about the experience in general (especially where a home death occurred), the results imply that the demands of caregiving are excessive. It is suggested that the FCGs in this study lacked adequate support and a sense of duty to care forced them to push themselves beyond reasonable and healthy limits. To give up is a failure - not just to them, but to their loved-ones as well; bearing the guilt that would follow as a result of giving up was perceived to be too large a burden to manage. Pushing on though, contributed to the *suspension of self and time*, by tying them to the caregiver role, despite a lack of support, both formally and informally, and resulting in increased stress, as discussed in the next section.

4.2.4 Going the Distance – Prioritising Health Maintenance

FCG health, as a theme, is trickier to classify, in part because it was anticipated as an *outcome* of the caregiving experience in the research design (i.e. to be explored through the second research question). In fact, health materialised as significant in two ways: one because of its relevance to the caregiving situation, and two, because of its impact by the caregiving situation. In this first regard, FCGs discussed their health in terms of its value to help sustain them in their role. In this second regard, FCGs discussed health with respect to the overall effects of caregiving on their physical and emotional health.

Physical and emotional health emerged as separate issues; however, they seemed to reinforce each other. Generally speaking, the physical health of the FCGs remained stable over the caregiving process; however, FCGs tended to rate it lower during bereavement. They suffered mainly from minor aches and pains as a result of the physical demands of caregiving, previous health status and age. None of the FCGs experienced any type of injuries as a result of caregiving and did not appear to have increased susceptibility to other illnesses. The most prevalent complaint was exhaustion – both physical and mental - which contributed greatly to caregiver burden. Physical exhaustion was exacerbated by the intensity of caregiving coupled with a lack of sleep; while FCGs recognised the importance of getting adequate rest, this was often not possible. For example, sleep disruptions were common, often the result of worry:

> "So she kept trying to get out of bed on her own and she fell and they think she did something to her leg. But, they weren't going to do anything. I kept saying 'you can't get out of bed.' So my nights were spent awake most of the time; every time I heard a noise I would think she was getting out of bed so I would get up and go in and see if she was alright. So for that one month I probably got about three hours sleep a night because of that."
>
> Maddie, Interview Two

For Lisa, such worry resulted in her sleeping right beside her mother-in-law in the living room. The lack of sleep affected daytime functioning, leading to increased levels of stress and decreased patience. Angela, for example, who is normally very soft-spoken, found herself getting edgy with her children. Lisa quite literally fell asleep on the spot – once while riding on the back of her husband's motorcycle. Another time, earlier in the caregiving process, she was involved in a minor car accident because she was over-tired and distracted. The exhaustion for all FCGs intensified over the caregiving process; this was clearly a combination of their loved-ones' deteriorating status (increased intensity of caregiving), as well as the lack of support. The extent of this exhaustion was still evident even six weeks after the death of their loved-one.

FCGs were motivated to stay healthy to sustain the caregiver role. For Tom and Barb, there was no one else in the home to take over should they become incapacitated; as Tom states, "if I go to the hospital, she [Mary] goes to the hospital." But this was equally important to adult-children caregivers as well; given the family structures and dynamics involved, either there was no one available or no one willing to step in. In addition to much needed sleep, maintaining health included eating properly, staying active (exercising) and taking time for themselves – all of which, to some degree, were difficult - if not impossible - to achieve given the demands of caregiving. Proper nutrition was important and all FCGs made it a point to eat well, but the ability to prepare healthy meals sometimes became diminished, compromising both their values (in terms of what comprises a healthy meal) and their health more broadly (given what was substituted):

> "Sometimes you just run out, I find that more – because 'oh, let's have McDonalds'; before it was like 'no, I will just make supper'.... And now it's oh, I'll give in because it - I just don't want to [cook]...at the end of the day, if I had a rough day kind of thing, then it's... it's easier; one less thing to think about."
>
> (Angela, Interview 3)

FCGs experienced high levels of stress as a result of the caregiving arrangements (and lack of support) and the witnessing of their loved-ones' decline. This often led to depression. Family dynamics contributed to the stress experienced, both while caregiving and during bereavement, preventing them from being able to grieve. While advised that bereavement support was available, it was not used by these participants.

Mental health was impacted by the culmination of physical exhaustion, stress (family dynamics, witnessing the decline of their loved-one, and dealing with difficult personalities), and few opportunities for "self-care"[14]. Tom clearly recognised both the need to get away from the situation and the value in doing so. He also felt the most comfortable leaving as he had been able to establish a wonderful relationship with his PSW and trusted her completely with Mary's care. With the exception of

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[14] Self-care is used here to refer to strategies that are designed to reduce stress and tension; they may include getting away from the situation for periods of time, engaging in activities that bring pleasure and/or expressing feelings.

Barb, FCGs in this study recognised, often too late, that they needed to get away more often and that they needed to take full advantage of the opportunities that existed to do so. As Maddie suggests:

> "The only other thing I would suggest is to get out more. Use the palliative care people for the time that you are given free – use them. Get out more."
>
> Maddie, Interview Two

Although recognised as the most significant strategy for self-care, getting away was the most difficult. Obviously, the lack of support available contributed to their inability to get away more often, but other factors influenced this as well - some of which have been touched on already. For example, one could make plans to go out, but they could be changed suddenly if their loved-one's condition changed. The hours of support that were provided did not necessarily correspond with times FCGs wanted or needed to be away either. Additionally, it was distressing to be away because FCGs were worried about their loved-ones when they were not with them. The inability to get away was also due, in part, to their loved-ones' reluctance for them to leave; FCGs felt guilty leaving them, whether alone or with someone else. Thus, they felt more confined in this role and as a result, experienced a great deal of stress. Again, Maddie expressed this feeling best:

> "...trying to believe that you do have a life and you have to take it...you HAVE to take time for yourself. So, you know, probably the largest challenging thing was believing that I wasn't doing anything wrong – that was probably the most challenging."
>
> Maddie, Interview Two

As Angela put it, having someone "that can help you... guide you, I guess – where you need to be emotionally" (Interview Four) was essential to relieve the stress; thus support was necessary for more than getting away. Doctors were not seen as the most appropriate option, normally offering medication to help the FCGs "deal" with the stress and or lack of sleep; but no other service providers were consulted.

Mental health was impacted positively by the experience as well, contributing to overall health and well-being. The FCGs in this study were very proud of what they did, and despite the challenges, had no regrets in doing so. Pride eliminated any feelings of guilt they could potentially experience afterwards, as it was rewarding to have provided improved quality and quantity of life to their loved-ones. This greatly reduced the grief they experienced during bereavement.

As can be seen in this study, health was both impacted by the caregiving role and impacted the caregiving role. Supportive services in particular have an important impact on how the FCGs handle the situation, both in terms of providing opportunities to relieve stress through discussing the feelings they had towards caregiving (and dying and death), as well as providing opportunities to get away from the situation and minimise burden. The experience of health was highly contingent upon: the degree of suspension, the support available, and the motivations for care. These contingent elements highlight the link between the context of care to health outcomes for FCGs.

This theme clearly illustrates the need for a more 'caregiver-centric' perspective to P/EOL care in the home.

4.3 Conclusion

The FCGs in this study assumed the caregiving role under a variety of circumstances and with no real clear conception of what was ahead for them or their loved-ones. The adoption of this role was in addition to other social roles which, in time, were adapted to respond to the intensity of care. This resulted in a *suspension of self*, as mediated and aggravated by access to support, both through the health care system and through informal networks. FCGs experienced high levels of stress and exhaustion as a result caregiving; this impacted their health, their ability to provide care, and the experience of the caregiving situation. It appears that the FCGs in this study face extraordinary challenges in managing the caregiver role and meeting their loved-ones' wishes to remain and die at home. In general, however, FCGs were pleased with their decision to provide care and with their (cap)abilities in meeting the responsibilities required. Additionally, there was perceived satisfaction with the support they had, although this most often reflected the relationship to those with whom they had direct contact (i.e. formal care providers) and was relative to the adaptations they made to their lives, and for some, their families who shared their homes.

Chapter Five

Discussion and Conclusions

The purpose of this research was to examine the experiences of FCGs living in rural areas to understand how they manage palliative and end-of-life caregiving in the home setting, and how it affects their self-assessed health. In this final chapter, the lessons learned, as illustrated through the themes *suspension of self, support, motivation and health,* are discussed. The results of this study point to the need to adopt a more caregiver-centric approach to P/EOL care, especially when such care takes place in the home. Of particular concern is the impact that caregiving has on FCG health; it is demonstrated here that greater attention to health as a resource for facilitating caregiving is critical. A discussion of the value and limitations of the study is provided and recommendations for future research are suggested.

5.1 Discussion

The label of caregiver is imposed: it is socially constructed, assigned and assumed, largely through processes of restructuring that are driven by the quest for fiscal efficiency. Community-level care has been one of the primary mechanisms of health care reform (Barenek, Deber & Williams, 1998; Williams, 1996). Community-level services are precluded from mandatory coverage under the CHA, leaving provincial and territorial governments to make their own decisions regarding the provision [and distribution] of publically-funded services (Williams et al., 1999). Because it is generally more cost- effective to deliver care in the home (Hayward, Davies, Robb, Denton & Auton, 2004; Chochinov & Kristjanson, 1998) it is the ideal way to absorb, or more aptly, avoid the demand on resources as the population ages and dies. Yet this is often embedded in an approach to care that is client-centred and holistic; one that recognises that institutional care is not the only, or necessarily the best, option for care. Home is often idealised as the best place for care (Dunbrack, 2005; Stajduhar, 2002). This idealisation is particularly salient for care at end-of-life wherein the treatment goals of the patient are given priority and, where often the patient's preference is to die in the home (or at least in one's community). When in the home, a dedicated family member or close friend is *required* to realise this preference. Palliative and end-of-life family caregiving must be conceptualised within this context in order to fully appreciate the caring work that FCGs do and its impact thereof.

The results of this research project, as reviewed in Chapters 3 and 4, reflect the P/EOL family caregiving experience in rural Ontario. Four themes were identified: one macro theme, suspension of self and time along with three sub-themes, relating to support, motivation and health were identified. Each theme will now be discussed in greater detail.

5.1.1 Suspension of Self and Time

The experience for the FCGs in this study was characterised as operating through a "*suspension of self and time*". This is consistent with other research where FCGs describe the need to put their lives on hold provide care (i.e. Rhodes & Shaw, 1999; Stajduhar & Davies, 2005). This suspension reflects a liminal stage, marked by varying degrees of loss of personal identity to facilitate care. The sub-themes, relating to support, motivation and health, are highly influential in the degree to which this suspension was necessary *and* possible. Together the themes suggest that despite the recent efforts to improve palliative care, FCGs' ability to manage the experience and the likelihood of a successful home death are contingent upon a very high degree of self-sacrifice. Obviously this has important implications; one, it suggests that the support available to FCGs who care for their dying loved-ones at home is inadequate; and two, it puts ownership of the *caring* situation onto the FCG to succeed, for they alone experience incredible guilt if they are unable "manage". This organising principle then, is reflective of the different processes that created the context for palliative caregiving, thereby creating a "liminal self" (the caregiver) and liminal space (the home).

The concept of liminality has been used to examine spatial behaviour and experiences (Andrews, 2005). It is argued that there are different points along the life course [which may or may not be predictive and patterned (Pain, 1999)] that present "crisis" in which adaptation and renegotiation of identities and places are required (Andrews, 2005; Kenworthy-Teather, 1999; Winchester et al, 1999; Pain, 1999). This has typically included major points such as birth, adulthood and death, as well as events such as violence, maternity and breastfeeding. The concept of liminality is presented here as a framework through which to view the spatial and temporal dimensions of palliative family caregiving. It best explains how FCGs balanced this role, given the tensions that are created through health care system restructuring and the patient-focused approach to care at end-of-life.

Suspension of self and time was reflected in FCGs' need to make significant changes to their normal routines, activities and homes to provide care. Although the caregiving arrangements and family structures were unique, these FCGs experienced a large degree of restriction on their personal time. The FCGs in this study assumed this role suddenly, with little previous experience and no understanding of what was ahead. Changes to the home were made to accommodate care, including the addition of medical equipment/assistive devices and the reconfiguration of rooms. For the adult-children carers, households were significantly altered by moving their dying parent into the family home. Hallman (1999) refers to this as residential relocation wherein it is easier to move relatives closer to cope with the increased demands of caregiving (pp. 216). Moving parents into the home appears to be more common with female FCGs (Hallman, 1999). For the adult-child FCGs in this study, it was necessary to do so for two reasons: (1) it was easier to bring them into the home to allow FCGs to retain some semblance of their normal family routines; and (2) the patient required too high a degree of care to remain on their own. Thus without bringing them into the home, the patient would have been institutionalised because there was no one else willing or able to take on the responsibility. Most of the changes to the home were not permanent (with the exception of some major renovations in Tom's home), and restoring the physical environment of the home after the death was easy. The period of readjustment following the caregiving experience for the three cases in which was there was a home death was more difficult. Each decedent was a widow and therefore the tasks of arranging the funerals and settling estates was left to the FCG.

The idea of role reversal was noted in this study and is similar to the notion of caregiving transactions (Fast & Keating, 2000). In this way, the giving of care is reciprocal – at some time, one will give care and at another time, receive it. Reciprocity is but one influence on FCGs' decisions to provide care and to consider caring again in the future. It is important to note this connection, because it is suggested that the reliance on family members, particularly women, to engage in caregiving appears predicated at least in part by a sense of familial duty to care. Interestingly, while it was evident in this study that the FCGs experienced a sense of obligation, it was not possible to tease out *why* two of the adult-children FCGs felt more of a sense to care for their parents than the other siblings concerned; it was only noted that the uninvolved siblings would not do what the FCGs were doing.

The degree to which FCGs gave up pieces of their own lives, especially their jobs, was influenced in part by situational factors, such as having a working spouse, receiving some contribution to household expenses by the patient or having a retirement income. Not being active in the labour market appears to facilitate care in the home, especially if 24-hour care is required and it is suggested that the ability to leave employment is related to unskilled or low-skilled labour (Rhodes & Shaw, 1999). It may, however, be more difficult for rural caregivers to replace jobs after caregiving as rural areas are characterized as having unemployment rates that tend be higher on average. Despite the availability of the job security and employment insurance benefits through the Compassionate Care Benefit (CBB), as previously mentioned (see page 11), the CCB was not a determining factor in leaving employment. In fact, only one FCG in this study collected the benefit; two were ineligible because they were retired, one was ineligible because she was self-employed, and one simply did not bother to collect it.

While the restrictions on personal time were significant, the financial implications of caregiving were not perceived as substantial - although this was without considering the loss of income. The expenses FCGs incurred were not uniform, reflecting the patient's caregiving situations; however, they were, in all cases, greatly reduced for FCGs through their assignment to the PC case load. Most medications (including oxygen) were covered through the system as were various supplies (Depends diapers, incontinence pads). The provision of equipment was less consistent – some were provided free, some rented yet and yet others purchased. The most commonly purchased items included hospital beds and assistive devices for the bathroom; these items were often donated after caregiving had ceased. To the extent provided, public contributions to reduce the personal expenses of caregiving did buffer caregiver burden, especially in the cases of reduced income, and contributed to their ability to care at home. Other research has indicated that the costs involved can make caregiving prohibitive (Chochinov & Kristjanson, 1998) and medications can be especially so. Employing nurses privately enables more patients to die at home, but is also indicative of a two-tiered system of palliative care (Chochinov & Kristjanson, 1998). These costs are significant when FCGs leave employment to care (especially outside of the time covered by the Compassionate Care Benefit), as they are unlikely to be able to afford to hire private help to assist them through the gaps in formal services and informal support networks. Therefore, leaving employment can reduce the opportunity to procure assistance through the private sector. The tendency to give up aspects of one's self increased stress by reducing opportunities to get away from the caregiving situation; this was further complicated by a lack of formal and informal support.

5.1.2 Gaps, Cracks and Obstacles: Services and Support

Gaps, cracks and obstacles refers to the support FCGs had while caregiving. Access to support was essential to the process and though satisfied in general, the FCGs made due with limited support. They were grateful for what they did receive and spoke highly of the people with whom they came into contact. The fact that they were satisfied with the support may reflect low expectations they had of the medical community in terms of support through their homecare experience. Their ability to sacrifice so much of their personal time to provide care reduced their needs for support through the health care system.

FCGs had access to a wide range of services; albeit not specialised PC services that characterise most urban centres. Furthermore, contact was limited to primarily physicians, nurses, PSWs, and to a limited extent, respiratory therapists. While there was availability to access a wide array of other providers, such as social workers, occupational and physio-therapists, their use was very limited in this study. Access to assistive devices was normally organised through case managers, but this tended to be done on an as-needed (rather than anticipatory) basis and this need was often communicated via the nurses. This is problematic because: (1) it requires nurses to be knowledgeable concerning the equipment that is available. This knowledge is generally outside their realm of expertise unless they are a PC specialist (usually this type of service is provided through occupational therapists); and, (2) unless there is serious or on-going medical attention, nurses are generally only in the home one or two times a week for 20-30 minutes. This time is spent tending to the patient and monitoring their status and to a lesser degree, when required, explaining or training FCGs in procedures for care; this time is not generally spent *assessing* FCGs' on-going needs.

There was a lack of consistency between and across areas for similar services and little flexibility in the allocation of service time. Services were scheduled at certain days and times, according to the health care provider's schedules. This is similar to Twigg's (2000b) discussion around the conflict between time rhythms of home and the work schedules of service providers and the often little regard for the routines of home when services go in (Wiles, 2003). This was not so much the issue as was the lack of input and flexibility in terms of how the PSWs were utilised. There were limited hours and these hours did not necessarily conform to FCGs' needs or schedules. For example, service time was scheduled during the day and FCGs were encouraged to leave the home during this time. FCGs did not always feel comfortable leaving their loved-one; were too tired to leave; or did not feel there was enough time in which to meaningfully accomplish anything. More often than not, this time was spent running errands, not for personal or social activities. One option that did exist in one area was the provision of night care to allow FCGs to get some sleep. Night care was used only once by one of the FCGs in this study and was instituted very late in the process, when the FCG suffered from a cold when the patient's status had deteriorated significantly.

While the issue of trust did not materialise with any of the "professional" health care providers, there was some discussion of this as it pertained to the PSWs. Because PSWs spend so much time with their loved-one, a high level of trust was needed so that FCGs felt comfortable leaving their loved-one and the home. Initially, this involved issues of privacy, but once this relationship was developed, these issues dissipated. PSWs were not, however, relied upon as sources of information, but were valued immensely for the care and companionship they provided to their loved-ones. PSWs were not typically consulted or called on for an assessment of the situation by nurses or case managers, yet they spent the most time in the home. Their role appears critical yet undervalued by the system.

The reliance on nurses was tremendous and FCGs felt that the nurse involved provided optimal treatment and answered questions when needed; this was especially so in terms of information regarding medical treatment. The treatment by physicians is disturbing, not only in terms of the difficulty it imposed on the FCGs, which left them feeling devalued, but suggests a general lack of understanding and insensitivity to the needs of palliative patients and their families. This is not new to the caregiving literature but is part of larger concern due to the lack of experience and education physicians have around palliative care, especially in rural areas (Kelley, et al., 2004). Nuances by physicians that the patient should be institutionalised were also devaluing to FCGs and suggest that there is a lack of acceptance of homecare. The implications of such treatment are two-fold: (1) doctors may influence patients' and families' decisions to attempt a home death and patients may be unnecessarily institutionalised; and (2), it is indicative of the lack of integration across the system of providers. With a team approach all providers would have similar treatment and care goals and such nuances would be avoided.

FCGs' information needs were significant to their ability to provide care. FCGs relied on physicians to advise and guide them through the disease trajectory and the dying process; they expressed disappointment when this could not be achieved. Nurses and the PC case managers were consulted most often for information needs, as FCGs were unsure of to whom they should ask. There were, however, brochures provided in one area. FCGs who desired more information often had to approach this on their own. The internet was used as a resource, but with no guidance as to appropriate or reputable websites. The cataloguing and provision of such information may be one way to address FCGs information needs, although it cannot be assumed that all FCGs have both access to and the time to spend researching information. A number of reasons for failing to provide information to FCGs have been noted, including health care providers being too busy or uncomfortable with the subject of death, and finding it difficult to give information to FCGs/patients who are not ready to hear it (Dunbrack, 2005). While FCGs' needs for information are well documented in the literature (i.e. Dunbrack, 2005), given the extent to which this is known but still appears in this study is surprising. A recent publication critiques the current philosophy of palliative care and draws attention to several ethical issues that are rarely addressed, challenging how an all-encompassing definition of PC can adequately and fairly address the needs of both patient and family as a unit of care (Randall & Downie, 2005). They suggest that doctors are unable to do so because they have a duty first to the patient; issues such as a duty to care, conflict of interest, and confidentiality cause them to put patient needs ahead of those of the family (Randall & Downie, 2005). For example, physicians may be reluctant to disclose more information to the FCG than has been disclosed to the patient. Additionally, the CCAC regards the patient, not the FCG as their client; certainly attention is paid to the context of situation (i.e. the FCG is considered), but the first priority is to the patient. Furthermore, physicians are remunerated on the basis of treatment for the palliative patient, not the family, making it difficult to address the needs of the family as the unit of care. However, if FCGs are expected to provide medical care, they need to know how to do this, just as any health professional would. Thus it may be a matter of changing the mind-set of the medical community. While the results of this study suggest that physicians do not value the role of the FCGs, it is possible that failing to provide information to FCGs is related to an ethos of care to the patient; as such, doctors do not fully recognise that the information FCGs seek is related to their ability to provide care (or, *their* duty to care). The inclusion of the FCG as a member of the health care team could reduce this incongruence and empower FCGs in their role (Wilkes, et al, 2004).

It has been suggested that rural areas have strong networks of support, although that did not appear in this study. Families in this study were geographically dispersed; as such, the support they were able to provide to the FCG was limited in nature. Unsupportive families failed to provide help with both the physical tasks of caregiving and with emotional support. This created undue stress for the FCGs and increased the intensity of caregiving responsibilities. FCGs without access to family support may require extra support through the health care system. Additionally, those who are experiencing family tension may benefit from some type of counselling to deal with their feelings. This is something that should be monitored on an on-going basis, as clearly circumstances and feelings change over the course of the caregiving experience.

The *suspension of self* and the nature of the disease crippled the benefits that FCGs could receive through informal support, by limiting their opportunities to get away from the caregiving situation. Milligan (2005) argues that caregiving imposes a reduction in access to social networks. Friends may withdraw from these friendships and FCGs may not feel supported, especially in cases where the patient faces cognitive decline (Milligan, 2005). Such as was the case with Tom. While support groups (such as the Alzheimer's Society) can augment the lack of family support, they may not be available in all communities. Giving up employment, hobbies and other activities was necessary and the inflexibility of the respite hours may not be facilitative of maintaining these networks. For example, FCGs' friends may be working, or activities in which they want to participate (if they are not too tired) are held in the evening. Additionally, giving up paid employment may reduce FCGs' ability to hire extra help to seek outside activities. Thus, at a time when they could benefit most from the support of informal networks, they are least able to do so. Helping FCGs to reduce stress may be a matter of tailoring opportunities for respite to their needs.

Volunteer programmes, where available were beneficial but under-utilised. This is due to the restrictions that apply (i.e. limitations in terms of hours available and the advance notice that is required). It is also tied to the idea that FCGs found it difficult to leave their loved-ones with strangers. Clearly there is an increased role for volunteers as part of the health care team. Creating awareness as to their availability in the community is essential for uptake and may, in fact, attract more volunteers to the programme.

The degree of support available to FCGs in the study was strongly linked to their ability to provide and sustain care. There is a lack of support available to provide FCGs with respite and a failure to use a team approach to care. As a result, the burden placed on FCGs to provide care is tremendous; this needs to be better balanced so that they can retain aspects of their identities – work, hobbies, routines, friendships – to stay healthy while caregiving.

5.1.3 Drive within – Drive Behind: Motivations for Continuing the Role

FCGs in this study were motivated by various internal and external factors to provide care, all of which impacted the degree of suspension they experienced. The determination of the FCGs to re-arrange their lives to facilitate and accommodate care and to push on despite the often enormous burden they experienced was extraordinary. Feelings of duty (external motivators) were the strongest, and knowing how important it was to their loved-one to remain at home drove FCGs to remain caregiving despite the challenges they faced. This motivation to care among FCGs is consistent with other research (Stajduhar, & Davies, 2005; Wells & Kendig, 1996). Caring out of a sense of duty or obligation is referred to as the dark side of caring and carers who report this as a decision for providing care often feel more confined in the caregiver role (Guberman, Maheu & Maillé, 1992). The adult-children caregivers experienced this to greater degree than did the spousal caregivers, likely because of the other obligations they had. Unless they took opportunities to get away, the situation became very over-whelming, compromising their health in terms of increased stress and exhaustion. Tom recognised early in his caregiving experience that his health was critical to providing care. As such, he scheduled personal time into his caregiving routine (i.e. exercising, the support group, social outing, and respite) on a regular basis. This, however, may have been much easier for him to do than for the other FCGs because of the nature of his caregiving situation. Dealing with a degenerative disease, his situation was not as temporary. The others recognised the temporality of their situations and had less inclination to get away; they did not expect the caregiving arrangement to last as long as it did (although they were naturally pleased that they had this extended time).

FCGs were motivated as well to care at home because it was easier to do so; this increased the likelihood of them remaining in the caregiving arrangement. Providing care in the home allowed them to maintain some of their routines and they avoided having to travel to spend time with their loved-ones in other communities or in institutions. Experiences in hospitals and nursing homes reminded and helped them to empathise with their loved-ones' preferences, so even when faced with extreme stress, they pushed on. This is consistent with other research that suggests dissatisfaction with hospitals influences caregiver's decision for care (Stajduhar & Davies, 2005).

The reasons that FCGs in this study were motivated to care strongly impacted the degree of suspension they experienced during caregiving. While they wanted to care, out of love and respect for their loved-one, they also felt pressured to do so. This has significant consequences for FCG health, as they put aside their own needs to provide care.

5.1.4 Going the Distance – Prioritising Health Maintenance

The importance of health materialised in two ways: (1) for sustaining the caregiver in their role; and (2) as outcome of the caregiving experience. FCGs recognised how important it was to maintain their health in order to provide care, yet felt challenged to do so because of the demands of caregiving. That the FCGs in this study experienced exhaustion and stress as a result of their responsibilities is consistent with the research on palliative caregiving, and is related to the nature and intensity of changes over time. Exhaustion resulted from the demands of caregiving and inadequate sleep, while attempting to balance their other social roles. This obviously suggests that they could use greater support in the caregiver role. Exhaustion contributed to higher levels of stress and the FCGs had given up most of their social outlets to relieve stress. Maddie's cases illustrate why FCGs need outlets – in her case, to remain working salvaged her mental health. Others may just need opportunities to get away at their convenience. Caregivers should be encouraged from the outset to retain some of their activities so as to help balance their mental health with the demands of caregiving and isolation. Stress, exhaustion and neglect of health promoting behaviours can lead to other physical health problems, such as aggravation of previous conditions or susceptibility to illness; however, in these cases, the relatively young age of the FCGs likely mitigated against any long-term or serious consequences.

Health reinforces the need for extra support during the caregiving process. The impact on overall health following the caregiving experience was important for the three FCGs who experienced a home death, as exhaustion and stress carried over into the bereavement period. This may lead to a complicated grief pattern (Rando, 1998) with potentially serious consequences. Two of the FCGs suggested that they had not yet grieved, which may be indicative of complicated grief.

Problems with prognostication suggest that no one knows for certain how long the caregiver role will last. For those at death's door to rebound completely (Raymond) or live months, even a year beyond what was predicted (June, Rose), suggests that FCGs should be encouraged to approach the situation retaining aspects of themselves that promote strategies for self-care and loss of identity. In retrospect, the three adult-child FCGs (in the cases of home death) realised, too late, that they should have taken more opportunities to get away so that they could better cope. Tom recognised this through his extended involvement in caregiving. As Stajduhar (2003) suggests, caregivers should be advised that the caregiving situation could change and become too much to handle. FCGs' need to give up care, and feel that this possibility is at least palatable on some level, is something that should be discussed. Monitoring caregiver status throughout is one way to keep this dialogue open.

5.2 Limitations

The results of this research add to the evidence base for programme improvement; however, it is locally contingent and therefore may lack generalisability. The sample is small and atypical of the larger population (four Caucasian and one of Aboriginal descent). Furthermore, this sample may exclude the voices of those who were unable to overcome the challenges and could not therefore manage caregiving and/or the time to participate in the research process. This likely contributed to the inability to recruit participants from smaller "rural" communities as there are fewer opportunities from which to draw.

Another possible strategy to improve the pool from which to draw participants could be to use alternative sources for recruitment. For example, if there is a lack of awareness regarding the services that are available, this may indicate that not all those in need of or, in fact, in receipt of community services were using them. Furthermore, if doctors are reluctant for home care and death – a bias that is apparent in this study – it is possible that patients do not receive the option to receive homecare unless they have been hospitalised. Other strategies include the use of a snowballing technique (Patton, 1990), such as through newspapers advertisements, physicians and various support groups, which may capture more participants. A retrospective design may generate more participants because it is less onerous for FCGs to participate, given the tasks of caregiving; however, it may be subject to recall bias (McRae et al., 2000) and fails to capture the experience over time. The peaks and valleys of the disease trajectory certainly influenced the intensity of caregiving, revealing times of need and struggle for the FCGs, and this data may be lost as grieving FCGs attempt to find meaning and value in the experience to reconcile the loss during bereavement. In this study, FCGs tended to pay less attention to the peaks and valleys they experienced when interviewed during bereavement. Their ability to rationalise these challenges is a positive response, but it is still essential to recognise that there are weaknesses in the system and it is better to identify where and when they are occurring to direct improvement. This is best captured (longitudinally) over the caregiving experience.

5.3 Conclusions

Two important ideas flow from the research: first, a more caregiver-centric approach is suggested for the provision of home-based palliative care, and second, health should be treated as a resource to sustain FCGs in this role.

A caregiver-centric approach would include the FCG as part of both the health care team and the unit of care, which in turn would help the FCGs better balance their role. Engaging in more opportunities to assess their status, for example, by speaking with the FCG privately and routinely, would help service providers appreciate more fully how they are feeling and help them find solutions to deal with issues before they become too problematic. FCGs may have approached the situation with the knowledge that care would be limited in duration and rearranged their lives with this in mind. The impact of caregiving on relationships, finances and health were unknown, especially in long-term caregiving situations. As such, FCGs may require additional services based on their personal situational context of caregiving, rather than on patient diagnosis alone. It is possible that a FCG can do "everything possible"

(Maddie, Interview Two) and still not be able to keep their loved-ones at home. This must not be interpreted as failure; it could cause them to push on with little regard for their own health or complicate bereavement (Stajduhar & Davies, 2005). FCGs need to be advised that situations do change over time (the care required is more difficult than anticipated), and that the failure to provide and sustain care is no fault of their own but due to problems with the system, such as through inadequate support.

A caregiver-centric approach strongly supports the idea of FCG health as a resource that needs to be fed or nourished in order for FCGs to engage and manage the situation and avoid burnout. This is especially important to consider given the current context of the caregiving situation (patient focused care at end-of-life and health care restructuring in medically-underserviced geographies), and is most applicable to the *primary* FCG who has taken on the responsibilities of care and is attempting to optimise the quality of life of for their dying loved-one. The FCGs in this study revealed the great efforts they would go to meet the needs of their loved-ones, motivated through love and familial obligations as well as through the pressure they perceived from their loved-ones to do so. Personal context is important: adult-children FCGs, referred to as the sandwich generation, may have other responsibilities within which the caregiving situation takes place (i.e. dependents, work obligations) while the elderly may work at a diminished capacity due to health and ageing (Wells & Kendig, 2002; Fast & Keating, 2000).

Further, there is a need for greater emphasis on the information needs of caregivers and for increased access to respite services, and/or the development of services that will allow FCGs to access resources that are available. Essential services seem to be focused around patient status rather than caregiver distress, and there are few mechanisms that lead to regular and consistent assessment of FCG functioning. It is assumed that FCGs will have access to informal networks of support. That the FCGs in this study experienced great satisfaction with their ability to provide care is a testament to the potential of home-based P/EOL care; however, focusing only on the positive aspects of caregiving may lead them to lose sight or downplay the challenges along the way, including the loss of personal identity and guilt for wanting and needing to take time for themselves. FCGs in this study initially did not leave the caregiving situation but found over time, especially as the situation extended unexpectedly, that it was necessary to take breaks to preserve their mental health. With few supports available, there were few opportunities to get away. While things may have appeared to 'look okay' on the surface (i.e. to the service providers) it does not mean that it is so, as revealed in this research.

The fact that the lack of services did not materialise as a greatly perceived problem in this study is likely due to FCGs' ability to accommodate to the situation. Even though the FCGs in this study were not, with the exception of Lisa, living in "rural" communities per se (i.e. based on the OECD definition), the context of health care in northern Ontario can be classified as rural (Williams & Cutchin, 2002). This study has contributed to the health geography literature by stressing the importance of *place* – in this case both the home space and a rural geography – to the palliative family caregiving experience. It is suggested here that access to resources can mitigate against caregiver burden, but the availability of such resources is unevenly distributed.

As a result, those FCGs with access to resources may have more of an advantage over other FCGs in providing a home death, and with less of an impact on their health and well-being.

5.4 Future Research

Several issues emanate from this study that are worthy of exploring further. First, there is a need to understand the reasons that FCGs continue to experience such high unmet information needs; the idea of the "duty to care" is one plausible avenue for investigation. Secondly, there is more work to be done on looking at useful strategies the CCAC can use to assess caregiver burden and distress over the caregiving process. Any strategy must be quick and easy to use, given the time constraints that health care providers face, but must capture the depth of the experience in order to isolate and act on the problem(s). Finally, while there is a growing body of literature that illustrates the impact of caregiving, there is more work to be done on theorising the experience. The concept of liminality provides a useful framework to link the experience of caregiving into wider social, political and economic processes that impact identity at different stages throughout the life course.

5.5 Final Thoughts

The themes here suggest that there is high degree of reliance on FCGs to provide care for their dying loved-ones and that they do so under extraordinary circumstances, as illustrated through the themes of suspension of self and time, support, motivation and health. Recognising the importance of FCGs, to both the palliative process in particular, and the wider context of health care planning, is important and timely. As a P/EOL care strategy moves forward, it is important to have evidence on which to base the decisions that guide the development of policy. More attention needs to given to the context of care and to the importance of health as a resource for FCGs. Looking at the experience within different spatial contexts and scales, and over time, reiterates that a "one size fits all" approach to care is ineffective. Levine (1999) has articulated it best:

> "It is unjust and unrealistic to expect caregivers to forgo other obligations, to their children, for example, and give up so much of life's satisfactions and challenges that they lose not only their health, financial security, and their relationships with others but also their identity as persons. Total self-sacrifice may be ennobled in legend; it is a decidedly unsatisfactory way to live one's life and a poor basis for public policy." (pp 348).

Few studies target the perspectives of FCGs within the local context of health care delivery in Ontario. This study has brought to light several challenges that FCGs face as they manage home-based palliative caregiving. In doing so, it has highlighted areas to target to specifically reduce these challenges and preserve the health of FCGs. Most areas of improvement are administrative and organisational in nature, and would not require a great deal of financial resources to implement. The voice of FCGs has been recognised in this study; those that participated felt valued and appreciated for their work.

References

Abelson, J., Tedford-Gold. S., Woodward, C., O'Connor, D. & Hutchison, B. (2004). Managing under managed community care: The experiences of clients, providers and managers in Ontario's competitive home care sector. *Health Policy, 68*, 359-372.

Anderson, T. (2002). The history and evolution of long-term care in Canada. In M. Stephenson and E. Sawyer (Eds.), *Continuing the care: The issues and challenges for long-term care* (2nd ed) (pp. 1-56). Ottawa: CHA Press.

Andrews, G.J. (2002). Towards a more place-sensitive nursing research: An invitation to medical and health geography. *Nursing Inquiry, 9*(4), 221-238.

Aoun, S.M., Kristjanson, L.J., Currow, D.C., & Hudson, P.L. (2005). Caregiving for the terminally ill: At what cost? *Palliative Medicine, 19,* 551-555.

Baines, C.T., Evans, P.M., & Neysmith, S. M. (1991). Caring: Its impact on the lives of women. In Bains, C.T., Evans, R.M. and S.M. Neysmith (Eds.), *Women's caring: Feminist perspectives on social welfare* (pp.11-35). Toronto, ON: McClelland & Stewart Inc.

Bains, N., Dall, K. Hay, C., Pacey, M., Sarkella, J. & Ward, M. (n.d). Population health profile: North east LHIN. Retrieved August, 13, 2007 from: http://www.health.gov.on.ca/transformation/providers/information/resources/profiles/profile_northeast.pdf

Barenek, P.M., Deber, R., Williams, A.P. (1998). Policy trade-offs in "home care": the Ontario example. *Canadian Public Administration, 42*(1), 69-92.

Baxter, J., & Eyles, J. (1997). Evaluating qualitative research in social geography: establishing "rigour" in interview analysis. *Transactions of Institute of British Geographers, 22,* 505-525.

Brown, M. (2004). Between neoliberalism and cultural conservatism: Spatial divisions and multiplications of hospice labor in the United States. *Gender, Place and Culture, 11*(1), 67-82.

Brown, M. (2003). Hospice and the spatial paradoxes of terminal care. *Environment and Planning A, 35,* 833-851.

Brown, P., Davies, B., & Martens, N. (1990). Families in supportive care, part II: Palliative care at home: A viable care setting. *Journal of Palliative Care, 6* (3), 21-27.

Bryant, C., & Joseph, A.E. (2001). Canada's rural population: trends in space and implications in place. *Canadian Geographer, 45*(1), 132-137.

Bull, C.N., & Bane, S. (1993). The rural elderly: Providers' perceptions of barriers to service delivery. Sociological Practice.

Burge, F., Lawson, B., & Johnston, G. (2003). Trends in the place of death of cancer patients, 1992-1997. *Canadian Medical Association Journal, 168* (3), 265-270. Retrieved November 8, 2005, from http://www.cmaj.ca/cgi/reprint/168/3/265.

Cameron, J.I., Franche, R.L., Cheung, & Stewart, D.D. (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer, 94*(2), 521-527.

Canadian Home Care Association. (2004a). Home care: A national health priority. Retrieved December, 28, 2006 from http://www.cdnhomecare.on.ca.

Canadian Home Care Association. (2004b). New health agreement a positive step for home care. Retrieved December 28, 2006 from http://www.cdnhomecare.on.ca.

Canadian Hospice Palliative Care Association (2006). *Strategic plan and progress report*. Retrieved: December 28, 2006, from http://www.chpca.net/about_us/CHPCA_Strategic_Plan_2006_2009.pdf

Canadian Institute for Health Information. (2007). *Public-sector expenditures and utilization of home care in Canada: Exploring the data*. Ottawa: Canadian Institute of Health Research.

Canadian Institute for Health Information. (2006). *How healthy are rural Canadians? A component of the initiative "Canada's rural communities: understanding rural health and its determinants*. Ottawa: Canadian Institute for Health Information. Retrieved August 11, 2007, from http://secure.cihi.ca/cihiweb/products/rural_canadians_2006_report_e.pdf

Carstairs, S. (2005). *Still not there, quality end-of-life care: A progress report*. Retrieved October 18, 2005, from http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare_e.asp

Carstairs, S., &, Beaudoin, G.A. (2000). *Quality end-of-life care: The right of every Canadian*. Ottawa: Subcommittee to update "Of Life and Death" of the Standing Committee of Social Affairs, Science and Technology, Parliament of Canada. Retrieved on October 18, 2005 from: http://sen.parl.gc.ca/scarstairs/PalliativeCare/Still%20Not%20There%20June%202005.pdf

Carter, P.A., & Chang, B.L. (2000). Sleep and depression in cancer caregivers. *Cancer Nursing, 23* (6), 410-415.

Chappell, N.L., & Reid, R.C. (2002). Burden and well-being among caregivers: Examining the distinction. *The Gerontologist, 42*(2).

Chochinov, H.M., & Kristjanson, L. (1998). Dying to pay: The cost of end-of-life care. *Journal of Palliative Care, 14* (4), 5-15.

Clipp, E.C., Adinolfi, A.J., Forrest, L., & Bennett, C.L. (1995). Informal caregivers of persons with AIDS. *Journal of Palliative Care, 11*(2), 10-18.

Cloutier-Fisher, D., & Joseph, A.E. (2000). Long-term care restructuring in rural Ontario: Retrieving community service user and provider narratives. *Social Science & Medicine, 50*, 1037-1045.

Cloutier-Fisher, D., & Skinner, M.W. (2006). Levelling the playing field? Exploring the implications of managed competition for voluntary sector providers of long-term care in small town Ontario. *Health & Place, 12*, 97-109.

Cohen, C.A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17,* 184-188.

Community Care Access Centre for the District of Thunder Bay and Kenora/Rainy River. (2005). End-of-life care service delivery model for Northwestern Ontario.

Coyte, P.C., & Young, W. (1997). Applied home care research. *International Journal of Health Care Quality Assurance incorporating Leadership in Health Services, 10*(1), 1-4.

Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among the five traditions.* Thousand Oaks, CA: Sage Publications.

Decima Research Inc. (2002). National profile of family caregivers in Canada – 2002. Ottawa: Health Canada.

Denzin, N.K., & Lincoln, Y.S. (2000). The discipline and practice of qualitative research. In N.K. Denzin and Y.S. Lincoln (Eds.), *Handbook of qualitative research* (2nd Ed.) (pp. 1-28). Thousand Oaks: Sage Publications.

Devery, K., Lennie, I., & Cooney, N. (1999). Health outcomes for people who use palliative care services. *Journal of Palliative Care. 15*(2), 5-12.

Donovan, R.M. & Williams, A.M. (Forthcoming). Making Home Space Therapeutic for Palliative Patients and Their Caregivers. In: A.M. Williams (Ed.) *Therapeutic Landscapes: Advances and Applications.* Burlington, VT: Ashgate Publishing.

Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vezina, L. (2006). Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine, 9*(4), 912-921.

Dunbrack, J. (2005). *The information needs of informal caregivers involved in providing support to a critically ill loved one.* Ottawa: Health Canada.

du Plessis, V., Beshiri, R., & Bollman, R.D, (2002). Definitions of rural. Agriculture and rural working paper series. Working paper no. 61. Ottawa: Statistics Canada.

Dyck, I. (2001). Centring the home in research. *Canadian Journal of Nursing Research, 33*(2), 83-86.

Dyck, I. (1999). Using qualitative methods in medical geography: Deconstructive moments in a subdiscipline? *Professional Geographer, 51*(2), 243-253.

Dyck, I., Kontos, P., Angus, J., & McKeever, P. (2005). The home as a site for long-term care: meanings and management of bodies and spaces. *Health & Place, 11* 173-185.

Elliott, S.J. (1999). And the question shall determine the method. *Professional Geographer, 51*(2), 240-243.

Emanuel, E.J., Fairclough, D.L., Slutsman, J., & Emanuel, L.L. (2000). Understanding the economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine, 132*(6), 451-459.

Evans, R. & Stoddart, G. (1990). Producing health, consuming health care. In (R.G. Evans, M.L. Barer, T.R. Marmor, (Eds.) *Why are some people healthy and others not?* New York: Aldine De Gruyther.

Evans, R., Stone, D., & Elwyn, G. (2003). Organizing palliative care for rural populations: A systematic review of the evidence. *Family Practice, 20,* 304-310.

Exley, C., Field, D., Jones, L., & Stokes, T. (2005). Palliative care in the community for cancer and end-stage cardiorespiratory disease: The views of patients, lay-carers and health care professionals. *Palliative Medicine. 19,* 76-83.

Fast, J.E., & Keating, N.C. (2000). Family caregiving and consequences for carers: Toward a policy research agenda. (CRRN Discussion paper No. F/10). Ottawa: Canadian Policy Research Networks, Inc.

Faull, C., Carter, Y.H., Daniels, L. (2005). *Handbook of palliative care* (2nd Ed.). India: Blackwell Publishing (Replika Press Pvt. Ltd.).

Finkel, A. (2006). *Social policy and practice in Canada: A history.* Waterloo, ON: Wilfrid Laurier University Press.

Gaugler, J.E., Hanna, N., Linder, J., Given, C.W., Tolbert, V., Kataria, R. et al. (2005). Cancer caregiving and subjective stress: A multi-site, multi-dimensional analysis. *Psycho-Oncology. 14,* 771-785.

Gesler, W.M. (1992). Therapeutic landscapes: medical issues in light of the new cultural geography. *Social Science & Medicine, 24*(7), 735-746.

Given, C.W., Given, B., Stommel, M, Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health, 15,* 271-283.

Glajchen, M., Kornblith, A., Homel, P., Fraidin, L., Mauskop, A., & Portenoy, R.K. (2005). Development of a brief assessment scale of the medically ill. *Journal of Pain and Symptom Management, 29* (3), 245-254.

Goldstein, N.E., Concato, J., Fried, T.R., Kasl, S.V., Johnson-Hurzeler, R., & Bradley, E.H. (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care, 20*(1), 38-43.

Graham, H. (1991). The informal sector of welfare: A crisis in caring? *Social Science and Medicine, 32*(4), 507-515.

Grande, G.E., Addington-Hall, J.M., & Todd, C.J. (1998). Place of death and access to home care services: Are certain patient groups at a disadvantage? *Social Science and Medicine, 47*(5), 565-579.

Grbich, C., Parker, D., & Maddocks, I. (2001). The emotions and coping strategies of caregivers of family members with terminal cancer. *Journal of Palliative Care, 17*(1), 30-36.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, D.D., et al. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal, 170* (12), 1795-1801.

Guberman, N., Maheu, P., & Maillé, C. (1992). Women as family caregivers: Why do they care? *The Gerontologist, 32*(5), 607-617.

Haley, W.E. (2003). The costs of family caregiving: implications for geriatric oncology. *Critical Reviews in Oncology/Hematology, 48,* 151-158.

Halfacree, K.H. (1993). Locality and social representation: Space discourse and alternative definitions of the rural. *Journal of Rural Studies, 9*(1), 23-37.

Hallman, B.C. (1999). The transition into eldercare: An uncelebrated passage. In E. Kenworthy-Teather (Ed.), Embodied geographies: Spaces, bodies and rites of passage (pp. 208-223). London: Routledge.

Harding, R., & Higginson, I. (2001). Working with ambivalence: informal caregivers of patients at the end of life. *Support Care Cancer, 9,* 642-645.

Hauser, J.M., & Kramer, B.J. (2004). Family caregivers in palliative care. *Clinics in Geriatric Medicine, 20,* 671-688.

Hayward, L., Davies, S., Robb, R., Denton, M., & Auton, G, (2004). Publicly funded and family-friend care in the case of long-term illness: The role of the spouse. *Canadian Journal on Aging, Supplement*, S39-S48.

Health Canada. (2002). *Canada's aging population.* Ottawa: Division of Aging and Seniors; Minister of Public Works and Government Services Canada.

Hotson, K.E., Macdonald, S.M., & Martin, B.D. (2004). Understanding death and dying in select First Nation communities in northern Manitoba: Issues of culture and remote service delivery in palliative care. *International Journal of Circumpolar Health, 63*(1)25-38.

Hsieh, H., & Shannon S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288.

Hughes, P.M., Ingleton, M.C., Noble, B., & Clark, D. (2004). Providing cancer and palliative care in rural areas: A review of patient and carer needs. *Journal of Palliative Care, 20*(1), 44-49.

Huttlinger, K., Schaller-Ayers, J., Lawson, T., & Ayers, J. (2003). Suffering it out: Meeting the needs of health care delivery in a rural area. Online Journal of Rural Nursing and health Care. 3(2): [Online]. Retrieved December, 12, 2005 from http://www/rno.org.libaccess.lib.mcmaster.ca/journal/issues/Vol-3/issue-2/Huttlinger_article.htm.

Johnson, B., & Clarke, J. (2003). Collecting sensitive data: The impact of researchers. *Qualitative Health Research, 13*(3), 421-434.

Johnston, R.J. (1986). *Philosophy and human geography: An introduction to contemporary approaches.* (2nd ed.) Baltimore: Edward Arnold.

Kearns, R.A. (1993). Place and health: Towards a reformed medical geography. *Professional Geographer, 45*(2), 139-147.

Kearns, R., & Moon, G. (2002). From medical to health geography: Novelty, place and theory after a decade of change. *Progress in Human Geography, 26*(5), 605-625.

Keating, N., Fast, J., Frederick, J., Cranswick, K., & Perrier, C. (1999). Eldercare in Canada: context, content and consequences. (Catalogue no. 89-570-XPE). Housing, Family and Social Statistics Division. Ottawa: Statistics Canada.

Kelley, M.L., Habjan, S., & Aegard, J. (2004). Building capacity to provide palliative care in rural and remote communities: Does education make a difference? *Journal of Palliative Care, 20*(4), 308-315.

Kelley, M.L., Sellick, S., & Linkewich, B. (2003). Rural nonphysician providers' perspectives on palliative care services in northwestern Ontario, Canada. *The Journal of Rural Health, 19*(1), 55-62.

Kenworthy-Teather, E. (1999). Introduction: geographies of personal discovery. In E. Kenworthy-Teather (Ed.), Embodied geographies: Spaces, bodies and rites of passage (pp. 1-26). London: Routledge.

Kinsella, G., Cooper, B., Picton, C., & Murtagh, D. (2000). Factors influencing outcomes for family caregivers of persons receiving palliative care: Toward an integrated model. *Journal of Palliative Care, 16*(3), 46-54.

Kirby, M.J., & LeBreton, M. (2002a). *The health of Canadians – The federal role.* Ottawa: The Standing Senate Committee on Social Affairs, Science and Technology, Parliament of Canada.

Kirk, P., Kirk, I., & Kristjanson, L.J. (2004). What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *British Medical Journal, 328,* 1343-1349.

Koop, P.M., & Strang, V.R. (2003). The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clinical Nursing Research, 12*(2), 127-144.

Kristjanson, L., Dudgeon, D., Nelson, F., Henteleff, P., & Balneaves, L. (1997). Evaluation of an interdisciplinary training program in palliative care: Addressing the needs of rural and northern communities. *Journal of Palliative Care, 13*(3), 5-12.

Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing.* Thousand Oaks, California: Sage Publications.

Ladner, C., & Cuellar, N.G. (2003). Depression in rural hospice family caregivers. *Online Journal of Rural Nursing and Health Care, 3*(1). Retrieved December 12, 2005, from http://www.rno.org.libaccess.lib.mcmaster.ca/journal/issues/Vol-3/issues-1/Ladner.htm

Lattanzi-Licht, M., & Connor, S. (1995). Care of the dying: The hospice approach. In H. Wass and R.R. Neimeyer (Eds.) *Dying: Facing the Facts* (3rd ed.) (pp.143-162). Washington: Taylor & Francis.

Levine, C. (1999). Home sweet hospital: The nature and limits of private responsibilities for home health care. *Journal of Aging and Health, 11*(3), 341-359.

Ley, D.C.H. (1989). The first international conference on the palliative care of the elderly. *Journal of Palliative Care, 5*(4), 43-58.

MacLean, M.J. & Kelley, M.L. (2001). Palliative care in rural Canada. *Rural Social Work, Special Australian/Canadian Issue, December,* 63-73.

Maida, V. (2002). Factors that promote success in home palliative care: A study of a large suburban palliative care practice. *Journal of Palliative Care, 18*(4), 282-286.

Martin, S. (2003). Burden of home care borne by women. *Canadian Medical Association Journal, 168*(11), 1459.

McCorkle, R., & Pasacreta, J.V. (2001). Enhancing caregiver outcomes in palliative care. *Cancer Control, 8*(1), 36-45.

McDaniel, S.A. (2005). The family lives of the middle-aged and elderly in Canada. In M. Baker (Ed.), *Families: Changing trends in Canada* (5th ed.) (pp.181-199). Toronto, ON: McGraw-Hill Ryerson.

McKeever, P. (1999). Between women: nurses and family caregivers. *Canadian Journal of Nursing Research, 30*(4), 185-191.

McRae, A., Caty, A., Nelder, M., & Picard, L. (2000). Palliative care on Manitoulin Island: Views of family caregivers in remote communities. *Canadian Family Physician, 46,* 1301-1307.

Merriam, S.B. (1998). *Qualitative research and case study applications in education.* San Francisco, CA: John Wiley & Sons, Inc.

Miles, M. B., & Huberman, A.M. (1994). *Qualitative data analysis, an expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage Publications

Miller, K.L., McKeever, P., & Coyte, P.C. (2003). Recruitment issues in healthcare research: The situation in home care. *Health and Social Care in the Community, 11*(2), 111-123.

Milligan, C. (2005). From home to 'home': Situating emotions within the caregiving experience. *Environment and Planning A, 37,* 2105-2120.

Milligan, C. (2000). "Bearing the burden": Towards a restructured geography of caring. *Area, 32*(1), 49-58.

Ministerial Advisory Council on Rural Health. (2002). *Rural health in rural hands: Strategic directions for rural, remote, northern and Aboriginal communities.* Ottawa: Office of Rural Health, Health Canada.

Ministry of Health and Long-term Care [MOHLTC]. 2007. Local Health System Integration Act, 2006. Retrieved on August 13, 2007 from: http://health.gov.on.ca/english/public/legislation/lhins/lhins_faq.html

Ministry of Health and Long-term Care [MOHLTC]. (2005). News Release. Retrieved on October 2, 2006, from http://www.health.gov.on.ca

Mitura, V., & Bollman, R. (2003). The health of rural Canadians: A rural-urban comparison of health indicators. [Catalogue no. 21-006-XIE, V. 4(6)]. *Rural and Small Town Analysis Bulletin.* Ottawa: Statistics Canada.

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R. van den Bos, G.A.M. (1999). Measuring both negative and positive reactions to giving care to cancer patients: Psychometric qualities of the Caregiver Reaction Assessment (CRA). *Social Science and Medicine, 48,* 1259-1269.

Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R.J., & van den Bos, G.A.M. (1998). Cancer and caregiving: The impact on the caregiver's health. *Psycho-Oncology, 7,* 3-13.

Noonan, A., Tennstedt, A. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist, 36*(7), 785-794.

Ontario Association of Community Care Access Centres. (2003). *Issues facing CCACs in the delivery of effective palliative home care services.* Discussion paper. Retrieved December 21, 2005, from http://www.oaccac.on.ca.

Pain, R. (1999). Women's experience of violence over the life-course. In E. Kenworthy-Teather (Ed.), Embodied geographies: Spaces, bodies and rites of passage (pp. 126-141). London: Routledge.

Pattison, E.M. (1978). The living-dying process. In C.A. Garfield (Ed), *Psychosocial Care of the Dying Patient* (pp. 133-168). New York: McGraw Hill.

Patton, M.Q. (1990). *Qualitative evaluation and research methods* (2nd ed). Newbury Park, CA: Sage Publications.

Payne, S., Smith, P., & Dean, S. (1999). Identifying the concerns of informal carers in palliative care. *Palliative Medicine, 13,* 37-44.

Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Pope, C., & Mays, N. (1995). Reaching the parts other methods cannot reach. *British Medical Journal, 311,* 42-45.

Prigerson, H.G., Cherlin, E., Chen, J.H., Kasl, S.V., Hurseler, R., & Bradley, E.H. (2003). The stressful caregiving adult reactions to experiences of dying (SCARED) Scale: A measure for assessing caregiver exposure to distress in terminal care. *American Journal of Geriatric Psychiatry, 11, (3),* 309-319.

Public Health Agency of Canada. (2006). *Determinants of health.* Retrieved January 3, 2006, from http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html

Quality End-of-Life Care Coalition of Canada. (2005). Still not there – with the number of deaths expected to increase, Canadian health care crisis looms. Retrieved on October 18,2005 from http://www.chpca.net.

Ramirez, A., Addington-Hall, J., & Richards, M. (1998). ABC of palliative care: The carers. *British Medical Journal, 316,* 208-211.

Randall, F., & Downie, R.S. (2006). *The philosophy of palliative care: Critique and reconstruction.* New York: Oxford University Press.

Rando, T.A. (1995). Grief and mourning: Accommodating to loss. In H. Wass and R.R. Neimeyer (Eds.), *Dying: Facing the Facts* (3rd ed.) (pp. 211-242). Washington: Taylor & Francis.

Rhodes, P., & Shaw, S. (1999). Informal care and terminal illness. *Health and Social Care in the Community, 7*(1), 39-50.

Romanow, R. J. (2003). Sustaining medicare: The commission on the future of health care in Canada. In F. Baylis, J. Downie, B. Hoffmaster and S. Sherwin (Eds), *Health care ethics in Canada* (pp. 79-100). Toronto: Nelson.

Romanow, R.J. (2002). *Building on values: The future of health care in Canada.* Ottawa: Commission on the Future of Health Care in Canada.

Roush, C.W., & Cox, J.E. (2000). The meaning of home: How it shapes the practice of home and hospice care. *Home Healthcare Nurse, 18*(6), 388-394.

Saunders, C. (2000). The evolution of palliative care. *Patient Education and Counseling, 41,*7-13.

Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of American Medical Association, 282*(23), 2215-2219.

Schulz, R., O'Brien, A., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *The Gerontologist. 35*(6), 771-777.

Sellick, S.M., Charles, K., Dagsvik, J., & Kelley, M.L. (1996). Palliative care providers' perspectives on service and education needs. *Journal of Palliative Care, 12*(2), 34-38.

Service Canada. (2007). Employment insurance (EI) compassionate care benefit. Retrieved on September 12, 2007, from http://www.hrsdc.gc.ca/en/ei/types/compassionate_care.shtml#family.

Shamian, J. (2006). New strategies for health care in the home. Waterloo Smarter Health Seminar Series. Retrieved on May 23, 2006 from www.infranet.uwaterloo.ca.

Shapiro, E. (2002). *Home care.* The Health transition fund synthesis series. (Catalogue #H13-6/2002-2). Ottawa: Minister of Public Works and Government Services Canada.

Stajduhar, K.I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care, 19*(1), 27-35.

Stajduhar, K.I. (2002). The idealization of dying at home: the social context of home-based palliative caregiving. *Journal of Palliative Care, 18*(3), 208-208.

Stajduhar, K.I. & Davies, B. (2005). Variations in and factors influencing family members' decisions for palliative home care. *Palliative Medicine, 19,* 21-32.

Stajduhar, K.I., & Davies, B. (1998). Death at home: Challenges for families and directions for the future. *Journal of Palliative Care, 14*(3), 8-15.

Stake, R.E. (2000). Case Studies. In N. K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 435-454). Thousand Oaks: Sage Publications.

Statistics Canada. (2007). Local health integration networks. Retrieved April 10, 2007, from http:// www.statcan.ca

Statistics Canada. (2005). Northern Ontario health regions. Retrieved October 18, 2005, from http://www.statcan.ca.

Strang, V.R., Koop, P.M., & Peden, J. (2002). The experience of respite during home-based family caregiving for persons with advanced cancer. *Journal of Palliative Care, 18*(2), 97-104.

Strasser, R. (2003). Rural health around the world: Challenges and solutions. *Family Practice, 20*(4), 457-463.

Thomas, C., Morris, S.M., & Harman, J.C. (2002). Companions through cancer: The care given by informal carers in cancer contexts. *Social Science and Medicine, 54,* 529-544.

Troughton, M.J. (1999). Redefining "rural" for the twenty-first century. In: W. Ramp, J. Kulig, I. Townshend, & V. McGowan (Eds.), *Health in rural settings: Contexts for action* (pp.21-38). Lethbridge, AB: University of Lethbridge.

van Exel, N.J.A., Scholte op Reimer, W.J.M., Brouwer, W.B.F., van den Berg, B., Koopmanschap, M.A., & van den Bos, G.A.M. (2004). Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. *Clinical Rehabilitation, 18,* 203-214.

Wells, Y.C., & Kendig, H.L. (1996). Changes in carers' capacity and motivation to provide care. *Journal of Family Studies, 2*(4), 15-28.

Wikipedia.org. (2007). Peripherally inserted central catheter. Retrieved August 6, 2007, from: http://en.wikipedia.org/wiki/Peripherally_inserted_central_catheter.

Wiles, J. (2003). Daily geographies of caregivers: mobility, routine, scale. *Social Science and Medicine, 57,* 1307-1325.

Wilkes, L., White, K., & O'Riordan, L. (2000). Empowerment through information: Supporting rural families of oncology patients in palliative care. *Australian Journal of Rural Health, 8,* 41-46.

Williams, A.M. (2006). Restructuring home care in the 1990's: Geographical differentiation in Ontario, Canada. *Health & Place, 12,* 222-238.

Williams, A.M. (2004). Shaping the practice of home care: critical case studies of the significance of the meaning of home. *International Journal of Palliative Nursing, 10* (7), 333-342.

Williams, A.M. (2002). Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine, 55,* 141-154.

Williams, A.M. (1998). An assessment of community palliative care needs: the case of Niagara. *Palliative Care, 15*(2), 45-52.

Williams, A.M. (1996). The development of Ontario's home care program: a critical geographical analysis. *Social Science & Medicine, 42*(6), 937-948.

Williams, A.M. & Cutchin, M. P. (2002). The rural context of health care provision. *Journal of Interprofessional Care, 16*(2), 107-115.

Williams, A.M., Forbes, D.A., Mitchell, J., Essar, M., & Corbett, B. (2003). The influence of income on the experience of informal caregiving: Policy implications. *Health Care for Women International, 24,* 280-291.

Williams, A.P., Barnsley, J., Leggat, S., Deber, R., Baranek, P. (1999) Long-term care goes to market: Managed competition and Ontario's reform of community-based services. *Canadian Journal on Aging, 18*(2), 125-153.

Wilson, D.M., Justice, C., Sheps, S., Thomas, R., Reid, P., & Leibovici, K. (2006). Planning and providing end-of-life care in rural areas. *The Journal of Rural Health, 22*(2), 174-181.

Wilson, D.M., Northcott, H.C., Truman, C.D., Smith, S.L., Anderson, M.C., Fainsinger, R.L. et al. (2001). Location of death in Canada: A comparison of 20th-century hospital and nonhospital locations of death and corresponding population trends. *Evaluation & the Health Professions, 24*(4), 385-403.

Winchester, H.P.M., McGuirk, P.M., & Everett, K. (1999). Schoolies week as a rite of passage: A study of celebration and control. In E. Kenworthy-Teather (Ed.), Embodied geographies: Spaces, bodies and rites of passage (pp. 59-77). London: Routledge.

World Health Organization. (2007). WHO definition of palliative care. Retrieved April 10, 2007 from http://who.int/cancer/palliative/definition/en/print/html.

World Health Organization. (2004). *A glossary of terms for community health care and services for older person.* WHO Centre for Health Development. Ageing and Health Technical Report. Volume 5.

Wyatt, G.K., Friedman, L., Given, C.W., & Given, B.A. (1999). A profile of bereaved caregivers following provision of terminal care. *Journal of Palliative Care, 1* (1), 13-25.

Yin, R.K. (2003). *Case study research: Design and methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Appendix One

Sources of Data

Table 2.1

Sources of Evidence	Types	Source
1. Interviews	Semi-structured, longitudinal (Caregiving)	Family Caregiver
	Semi-structured (Bereavement)	Family Caregiver
	Caregiver Reaction Assessment (survey)	Family Caregiver
	Self-Rated Burden Scale (survey)	Family Caregiver
	Informal /Conversations	CCAC
2. Direct Observations	Non-verbal Behaviours	Family Caregiver
	Medicalisation of Home	Family Caregiver
	Family/Relationships	Family Caregiver
3. Documents	Journal Narratives	Family Caregiver
	Organisational Records	Websites
	Maps	Websites
	Community Supports	Websites/ Brochures
	Field Book	Researcher

Adapted from Yin (2003)

Appendix Two

Letter of Information and Consent

Caregiver Participant

The Effect of Home-Based Care on Family Caregivers in Rural Areas

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Canada Graduate Scholarship – Master's Level
Funding Period: Sept/05 - Aug/06

Ministry of Training, Colleges and Universities

Ontario Graduate Scholarship – Master's Level

Funding Period: Sept/06 – Aug/07

Purpose of this Letter

The purpose of this letter is to explain the study and what I am asking of you as a participant in this study. It will explain your rights as a participant and how I will protect them. It will also explain any risks you might experience and the ways I will try to protect you. After we have read over this form together, I will ask you to sign it. This will indicate that you are freely consenting to participate in the study.

Purpose of the Study

The purpose of this study is to understand how family members manage the experience of living and caring for loved-ones who are facing a life threatening illness. Very little research has been done with caregivers living in rural areas and I want to understand what is involved in your experience and learn if this affects your health. I want to understand if caregivers in rural areas experience caregiver burden and what factors may be contributing to or reducing it. I hope to understand if your experience is affected in any way by the services that are available to you because you live in a rural area.

Procedures involved in the Research

You will be asked to participate in up to four private interviews while you are caregiving. I would like to schedule these interviews about every six weeks. The reason for asking you to participate in four interviews is to understand your experience as it happens over time.

You will be asked to answer some questions and complete two brief surveys. I will ask you personal questions about your experience. For example, I will ask you to discuss the history of your caregiving and provide details of the tasks you perform. I will ask questions to see if caregiving affects any routines or other responsibilities you have and discuss any expenses you are responsible for. There will be questions concerning your needs and how you are prepared for and supported in your role as caregiver. You will also be asked questions about your health and overall satisfaction as a caregiver. The first survey contains questions about your reactions to caregiving and the second survey measures caregiver burden. If you uncomfortable with this, we can eliminate the survey component

I will provide you with a journal that you can use to record your thoughts and important things that you want to remember for our interviews. You do not have to record anything if you are not comfortable doing so or if you do not have time. If you do use the journal, I would like to use it to help me write the report. I will return the journal to you when I am finished. You can let me know if there are any private thoughts that you do not want me to use in the report and I will respect your privacy.

It is mainly meant to help you keep track of important events or feelings that you experience while you are caregiving.

The interviews will take about an hour to complete. The surveys can be completed very quickly, in about 10 minutes. The first interview will take a little longer than the other ones because I will ask you some questions (such as your age, education, work status and other household information) that I will not need to ask again. I will take notes and would like to tape-record our conversations. These tape recordings will be transcribed word-for-word to ensure the accuracy of our conversations. Please indicate your choice by checking one of the following:

☐ **I consent to the interviews being tape-recorded.**

☐ **I do not consent to the interviews being tape-recorded.**

I will give you the opportunity to review the entire transcript of our interview and a summary of my reflections in order to verify that it accurately reflects your views and check if there is anything you wish to delete or clarify.

I will ask you to sign this consent form at the beginning of each interview to ensure that you understand your rights as a participant and be sure that you want to continue participating in the study.

Potential Harms, Risks or Discomforts

It is not likely that there will be any physical harm to you for participating in the study, but you may feel uncomfortable or sad as you talk about your experience. The time you take to participate in the interviews may disrupt your schedule. You will be asked to reveal some personal information about yourself and your loved one.

You do not need to answer questions that make you feel uncomfortable or that you do not want to answer. We can stop recording the interview if you need to take a break or we can stop the interview altogether and reschedule it for another time if you request. We can schedule the interviews at places and times that are convenient for you and I will travel to you for the interviews. You will not have to miss work or appointments to participate.

If you decide that you would like to do the interviews in your home, I would like to offer the assistance of a personal support worker (PSW) to spend time with your loved-one while you participate in the interviews. There is no obligation, but is available to you at no cost. She is trained to work with the elderly and the ill, and will sign a confidentiality form to protect you and your loved-one's identity. I will provide you with proof of her employment (in a letter from her employer) and references so that you can be sure of her abilities, if you desire.

Potential Benefits

The research will not benefit you directly, although you may feel valued for being able to share your experiences.

This research will benefit health care providers and the broader research community by providing insight into how caregivers in rural areas experience caring for their loved-one in the home. This will help us to better understand any challenges that rural caregivers may face and to understand if the experience can be improved for others in this position.

Payment or Reimbursement

You will not be compensated for your participation in the study.

Confidentiality

Your privacy will be respected. Your name and the names of your loved-one and any family members will be altered to protect your identity, unless you state otherwise. I will refer to the overall study area as "one of seven health districts that comprise the Northern Ontario Health Region". The specific name of your community will not be revealed, unless you state otherwise. When I write the report, I will only refer to your community by its approximate population and its distance in time (i.e. minutes/hours) from available services.

I will not reveal to anyone that you are participating in my study. Only I will have access to any information collected and it will be kept in a locked cabinet in my office. My supervisor and I are the only people who will view your data.

Any tape recordings will be erased at the end of the study but the written information will be kept for future analysis. I will use it to write my Master's thesis, to prepare a report for the participating Community Care Access Centres and for future publications and presentations. The data specific to the surveys may be used in a larger national study specific to palliative family caregivers. Your name or identity will not be revealed. If you agree to this, please check the following:

☐ **I consent to the information collected from the surveys to be used in a larger national study specific to palliative family caregivers. My name or identity will not be revealed.**

Legally Required Disclosure

Information obtained will be kept confidential to the full extent of the law.

Participation

Your participation in this study is voluntary. If you decide to participate, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to stop participating, there will be no consequences to you. If you do not want to answer some of the questions you do not have to, but you can still be in the study. With your permission, I will keep and use any data that you provide up to the point of withdrawal for my report and any future reports. If you choose not to provide permission, then the data collected to date will be destroyed.

Study Debriefing

In addition to having you verify information contained in the transcripts, I will provide you with a written copy of the report at the end of the study.

Rights of Research Participants:

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster Research Ethics Board Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Office of Research Services

E-mail: ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Rhonda Donovan of McMaster University. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I have been given a copy of this form.

____

Name of Participant

In my opinion, the person who has signed above is agreeing to participate in this study voluntarily, and understands the nature of the study and the consequences of participation in it.

____

Signature of Researcher or Witness

Appendix Three

Interview One: Primary Family Caregiver

*Note: Insert name of *patient* or *caregiver* as appropriate.

Part One: Managing the Caregiving Experience

1. Can you tell me how the decision to provide care in the home was arrived at?

Probes:

-uninformed, indifferent, negotiated with patient

2. Are you comfortable with this decision?

Probes:

-Why or why not?

3. Do you feel you have other options for care?

Probes:

-What are they?

-Why not?

4. Can you tell me about the history of your caregiving experience with *patient*?

Probes:

-How long have you been caring for patient?

-Has the nature and intensity changed over time?

Nature – time line	Intensity

5. Can you describe your experience as the primary caregiver thus far?

Probes:

-How much time do you spend per week in this capacity?

-What types of tasks/activities do you do?

Activities	Time Spent

6. How were you helped in preparing for this role?

Probes:

-From whom?

-In what ways?

7. Have you had to learn any new skills in your role as caregiver?

Probes:

-What are they? How are you managing them?

-Do you feel confident in your abilities?

8. Do you feel you get the information you need when you need it?

Probes:

-What type of information do you feel you need?

-How do you obtain this information?

-How well do health care professionals respond to your requests for assistance?

9. Can you describe the support you currently have in your caregiver role?

Probes:

-Formal support services (i.e. paid health care professionals involved in patient's care)

-Describe your relationships with them.

-Informal support services (unpaid family, friends, organized community volunteers)

-Do they provide help with responsibilities over and above what they would normally do for you?

-Describe your relationships with them.

Formal Support	Frequency of Visits	Duration of Stay

Informal Support		

10. a) Do you feel the formal support is adequate?

Probes:

-Is there anything you would change anything about this?

-What do you value most/least?

b) Do you feel the informal support is adequate?

Probes:

-Is there anything you would change anything about this?

-What do you value most/least?

11. Does where you live affect your ability to access support and services?

Probes:

-Can you describe how?

-Are there any services that are not available in your community?

-i.e. respite care, home support, home making services, etc.

12. Has caregiving affected you in any way financially?

Probes:

-Can you tell me about any costs you have had to assume?

-Have you been affected in any other ways?

Part Two: Roles

Now I would like to ask you some questions about your role as a caregiver.

1. Have other responsibilities *in and around the home* been affected since the caregiving began?

Probes:

-i.e. caring for other dependents, household chores, yard work etc.

-How do you manage this situation?

2. Has caregiving affected any responsibilities or activities *outside* of the home?

Probes:

-Describe any responsibilities/activities that have been affected.

-How do you manage this situation?

3. **Describe things you do to cope with your role as caregiver.**

Probes:

-Do you take time for yourself?

-How do you spend this time?

-Are there opportunities to get away?

-How often?

-What kinds of things do you do when you are away?

-How do you feel when you are away?

-How does this impact the caregiver role?

-How do you feel when you have returned?

4. How do you feel about your caregiving role?

Probes:

-Please describe.

5. Do you find any aspect of this experience rewarding?

Probes:

-Please describe.

Part Three: Health Status

Next I would like to ask you some questions about your health status.

1. **Would you describe the health status of *patient* as:**

   Good, Satisfactory or Poor?

Probes:

-i.e. concerning their dependency and functioning

2. **In general, would you describe your health as:**

   Excellent, Very Good, Good, Fair or Poor?

3. **Describe your physical health.**
4. **Describe your mental health.**

Probes:

Emotionally, psychologically

5. Has your health status changed since you started caregiving?

Probes:

-Can you describe these changes?

-Have you sought treatment?

-Has caregiving affected your recovery?

-Do you engage in any activities to promote/maintain health?

-Do you get enough sleep?

-If not, how does this affect you?

Part Four: Other

Is there anything else about this experience that you would like to share with me that we have not already talked about?

Part Five: Residential/Family Formation History (Appendix One)

Part Six: Demographic Information (Appendix Two)

Part Seven: Administer CRA/SRB Assessments

Appendix Four

Final Interview: Primary Family Caregiver

*Note: Insert name of *patient* or *caregiver* as appropriate.

1. Can you tell me about patient's passing?

Probes:

-Where did patient pass on?

-How would you describe the death?

-Was he/she in the company of loved ones?

-Was it quick/prolonged?

2. How are you coping with your loss?

Probes:

-Are you getting any assistance in dealing with your bereavement?

-Have any caregiving personnel who were providing care visited since the death?

3. Who has helped you through this time?

Probes:

-Are you utilising any community networks/services?

-Are family and friends involved?

Formal Services	**Type of Support**
Informal Services	

4. What are some of the things you have had to look after?

Probes:

-i.e. returning medical equipment, furniture moved around, arranging funeral

-Have you had help with this?

5. How would you describe your satisfaction with the overall experience?

Probes:

-Were there positive aspects? Please describe.

-Were there negative/challenging aspects? Please describe.

Positive	**Negative/Challenging**

6. How would you describe your satisfaction with the support you have received throughout the caregiving process?

Support	**Positive**	**Negative**
Formal		
Informal		
Informal (organized) volunteers		

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

Excellent, Very Good, Good, Fair or Poor?

8. Can you describe how you are feeling physically?

9. Can you describe your mental health?

Probes:

-emotionally, psychologically

10. Has caregiving affected who you are as person?

Probes:

-Can you describe how?

11. Of the things you did to cope with your role as caregiver, which did you find most worthwhile?

Probes:

-Taking time for yourself?

-How?

-Getting away?

-How?

-Any other

12. Looking back, how do you feel about your caregiving role?

Probes:

-Please describe.

13. Looking back, do you find any aspect of this experience rewarding?

-Please describe.

14. Is there anything else about this experience that you would like to share with me that we have not already talked about?

15. What do you feel is most important for people to understand about the caregiving experience?

Appendix Five

Caregiver Reaction Assessment

Study Identification # _____________ Date:_________________

I am trying to understand how providing care for your family member has affected you, your family and your daily routine. In the questions that follow, please circle the response that represents *how you feel* about each statement.

The blank line in the sentence refers to the person you are caring for. Please do not fill in their name so that we can keep this confidential.

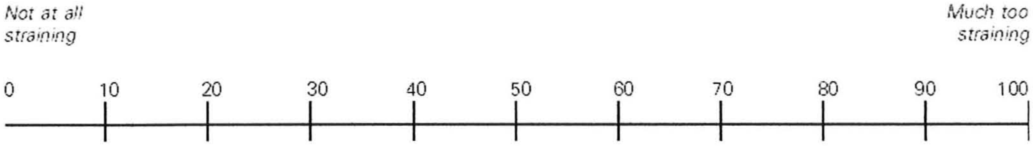
Statement	**Strongly Disagree**	**Disagree**	**Neither Agree or Disagree**	**Agree**	**Strongly Agree**
1. I feel privileged to care for _______.	1	2	3	4	5
2. Others have dumped caring for _______ onto me.	1	2	3	4	5
3. My financial resources are adequate to pay for things that are required for caregiving.	1	2	3	4	5
4. My activities are centred around care for _______.	1	2	3	4	5
5. Since caring for _______, it seems like I am tired all of the time.	1	2	3	4	5
6. It is very difficult to get help from my family in taking care of _______.	1	2	3	4	5
7. I resent having to take care of _______.	1	2	3	4	5
8. I have to stop in the middle of work to care for _______.	1	2	3	4	5
9. I really want to care for _______.	1	2	3	4	5
10. My health has gotten worse since I've been caring for _______.	1	2	3	4	5
11. I visit family and friends less since I have been caring for _________.	1	2	3	4	5

12. I will never be able to do enough caregiving to repay					
______.	1	2	3	4	5
13. My family works together at caring for ________.	1	2	3	4	5
14. I have eliminated things from my schedule since caring					
for ________.	1	2	3	4	5
15. I have enough physical strength to care for ________.	1	2	3	4	5
16. Since caring for _______, I feel my family has abandoned					
me.	1	2	3	4	5
17. Caring for _______ make me feel good.	1	2	3	4	5
18. The constant interruptions make it difficult to find time for					
relaxation.	1	2	3	4	5
19. I am healthy enough to care for _______.	1	2	3	4	5
20. Caring for ______ is important to me.	1	2	3	4	5
21. Caring for ______ has put financial strain on the family.	1	2	3	4	5
22. My family (brothers, sisters, children) left me alone to					
care for ______.	1	2	3	4	5
23. I enjoy caring for _______.	1	2	3	4	5
24. It is difficult to pay for ______'s health needs and services.	1	2	3	4	5

Appendix Six

Self-rated burden (SRB)

On the scale below '0' means that you feel that caring for or accompanying . . . at the moment is not hard at all; '100' means that you feel that caring for or accompanying . . . at the moment is much too hard. Please indicate with an 'X' on the scale *how burdensome you feel caring for or accompanying your partner is at the moment.*



Source:

van Exel, Reimer, Brouwer, van den Berg, Koopmanschap & van den Bos (2004). Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. *Clinical Rehabilitation, 18*, 203-214.

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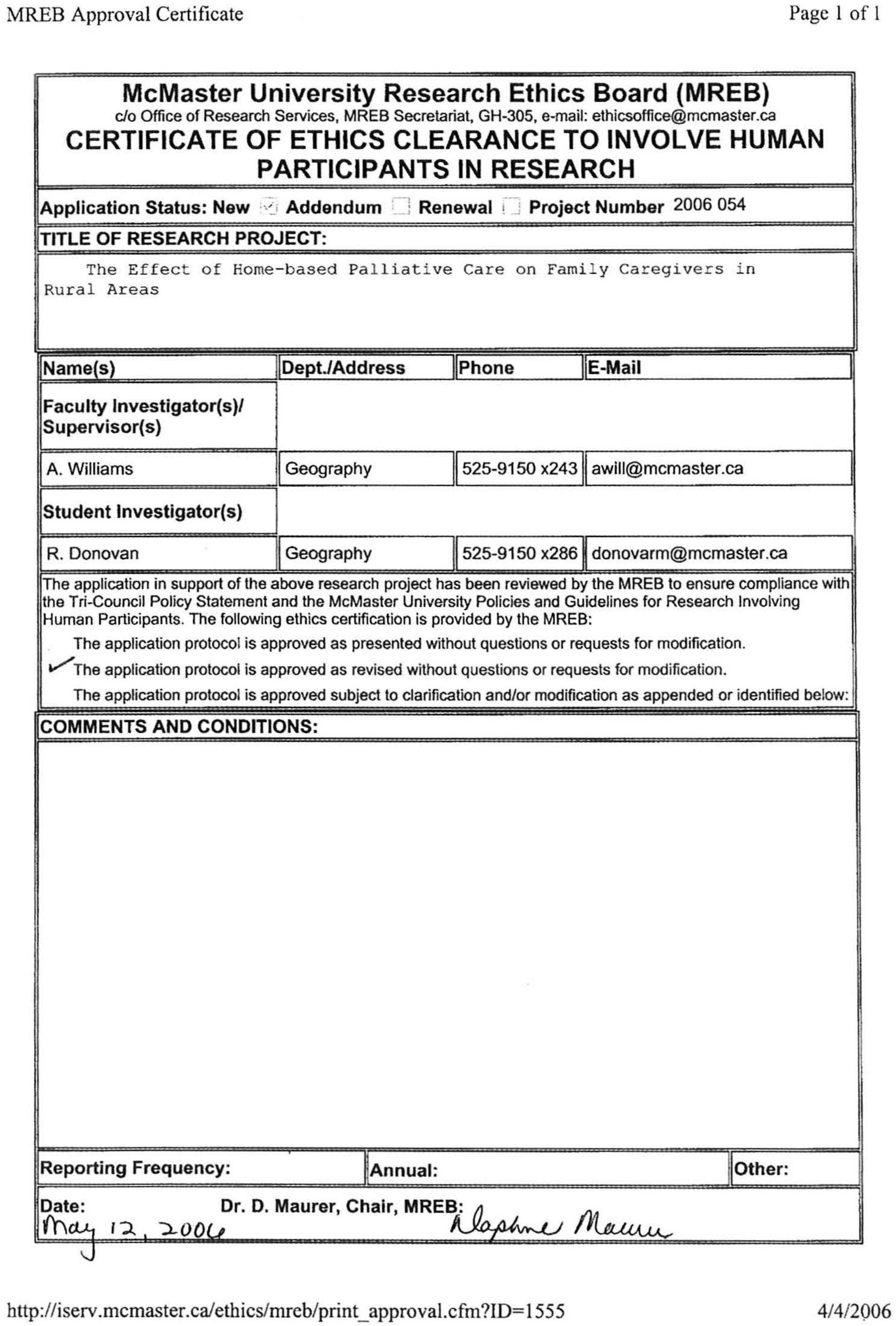
Appendix Seven

Ethics Certificates



MREB Approval Certificate Page 1 of 1

McMaster University Research Ethics Board (MREB)

c/o Office of Research Services, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Application Status: New ☑ **Addendum** ☐ **Renewal** ☐ **Project Number** 2006 054

TITLE OF RESEARCH PROJECT:

`The Effect of Home-based Palliative Care on Family Caregivers in Rural Areas`

Name(s)	**Dept./Address**	**Phone**	**E-Mail**
Faculty Investigator(s)/ Supervisor(s)			
A. Williams	Geography	525-9150 x243	awill@mcmaster.ca
Student Investigator(s)			
R. Donovan	Geography	525-9150 x286	donovarm@mcmaster.ca

The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:

The application protocol is approved as presented without questions or requests for modification.

✓ The application protocol is approved as revised without questions or requests for modification.

The application protocol is approved subject to clarification and/or modification as appended or identified below:

COMMENTS AND CONDITIONS:

Reporting Frequency:	**Annual:**	**Other:**

Date: May 12, 2006 **Dr. D. Maurer, Chair, MREB:** Daphne Maurer

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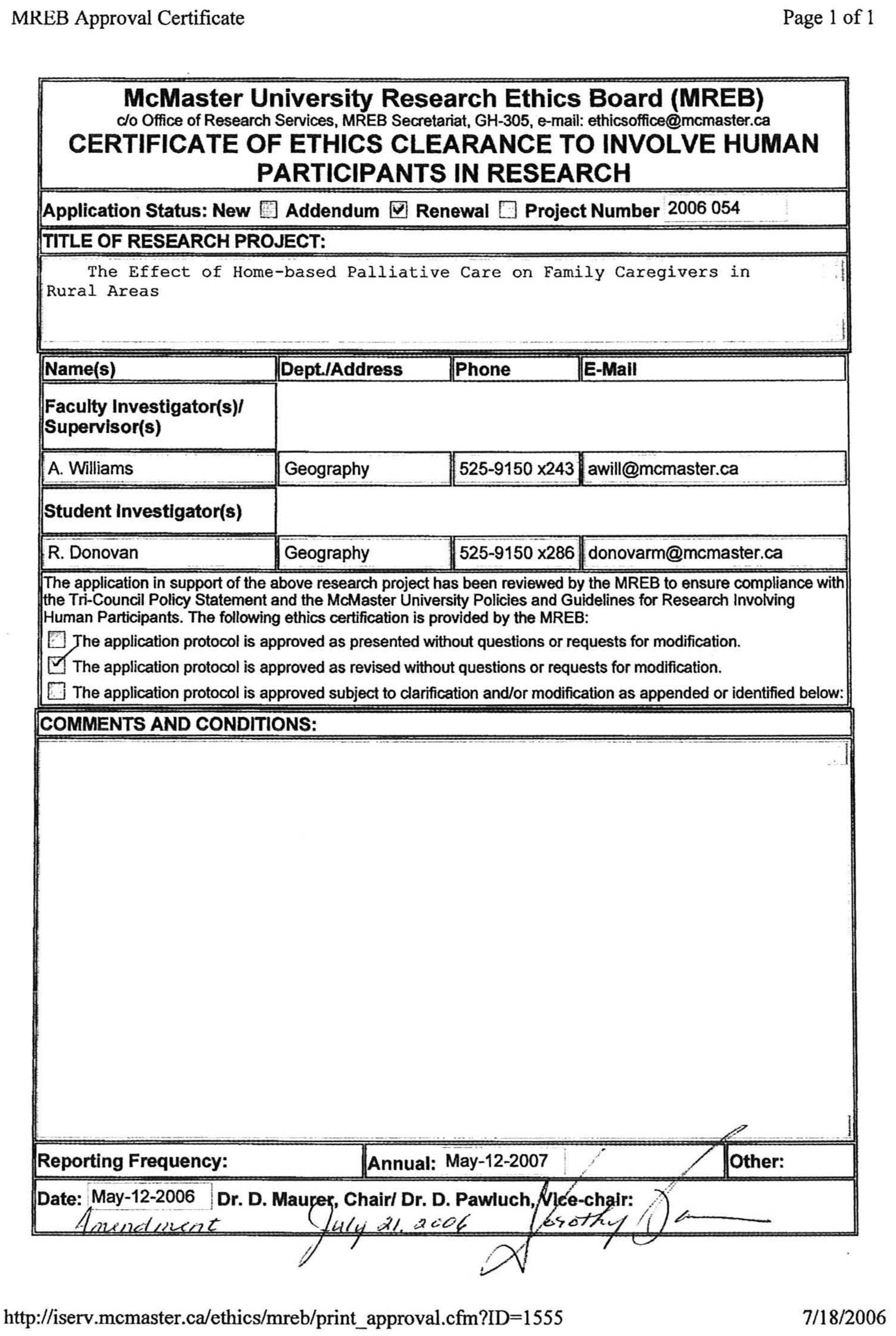

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Student Investigator(s)			
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COMMENTS AND CONDITIONS:

Reporting Frequency: **Annual:** May-12-2007 **Other:**

Date: May-12-2006 **Dr. D. Maurer, Chair/ Dr. D. Pawluch, Vice-chair:**

Amendment July 21, 2006 Dorothy

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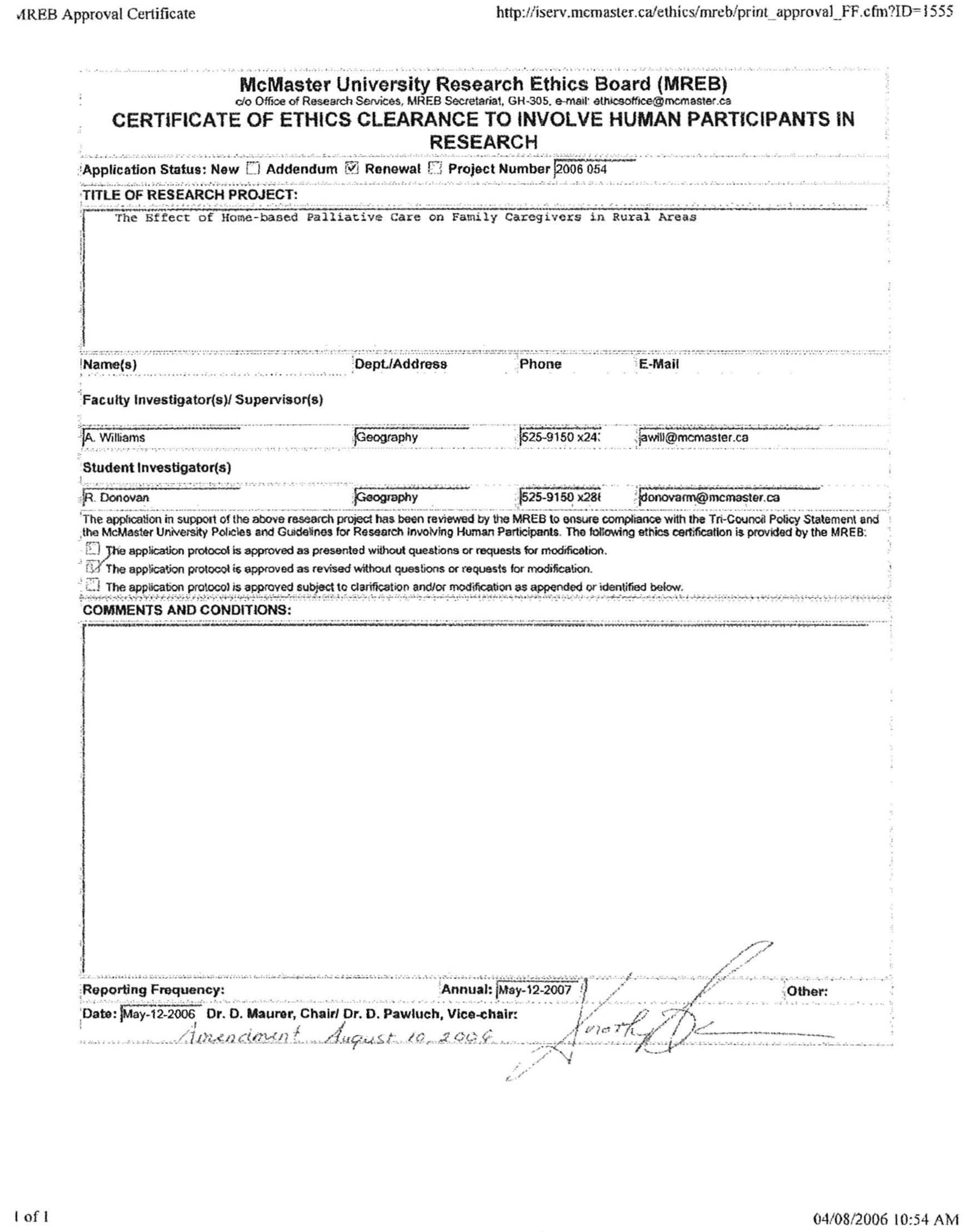

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McMaster University Research Ethics Board (MREB)

c/o Office of Research Services, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca

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Application Status: New ☐ Addendum ☑ Renewal ☐ **Project Number** 2006 054

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The Effect of Home-based Palliative Care on Family Caregivers in Rural Areas

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Faculty Investigator(s)/ Supervisor(s)			
A. Williams	Geography	525-9150 x24	awill@mcmaster.ca
Student Investigator(s)			
R. Donovan	Geography	525-9150 x28	donovarm@mcmaster.ca

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☑ The application protocol is approved as revised without questions or requests for modification.

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COMMENTS AND CONDITIONS:

Reporting Frequency: **Annual:** May-12-2007 **Other:**

Date: May-12-2006 **Dr. D. Maurer, Chair/ Dr. D. Pawluch, Vice-chair:**

Amendment August 10, 2006

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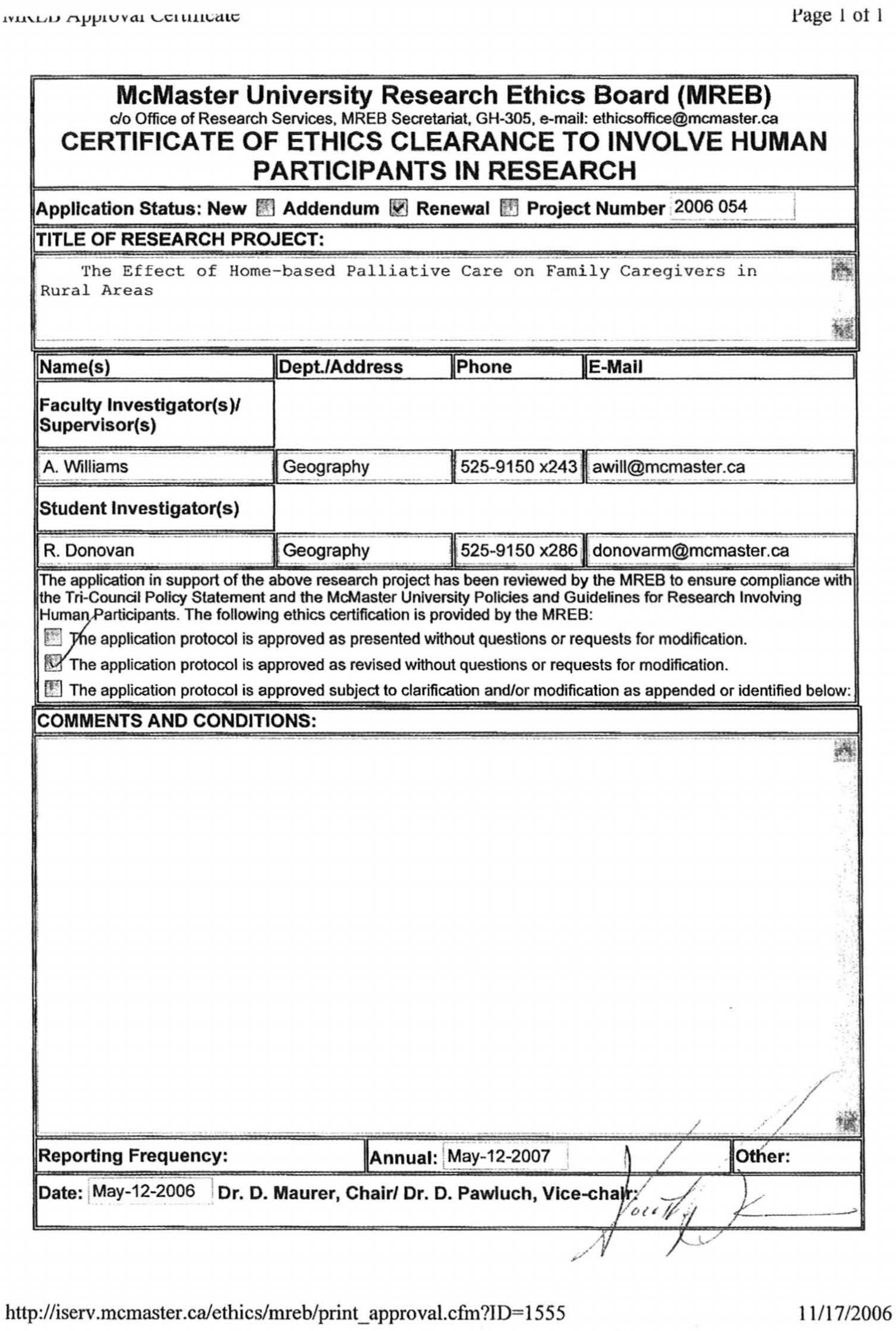

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Date: May-12-2006 **Dr. D. Maurer, Chair/ Dr. D. Pawluch, Vice-chair:**

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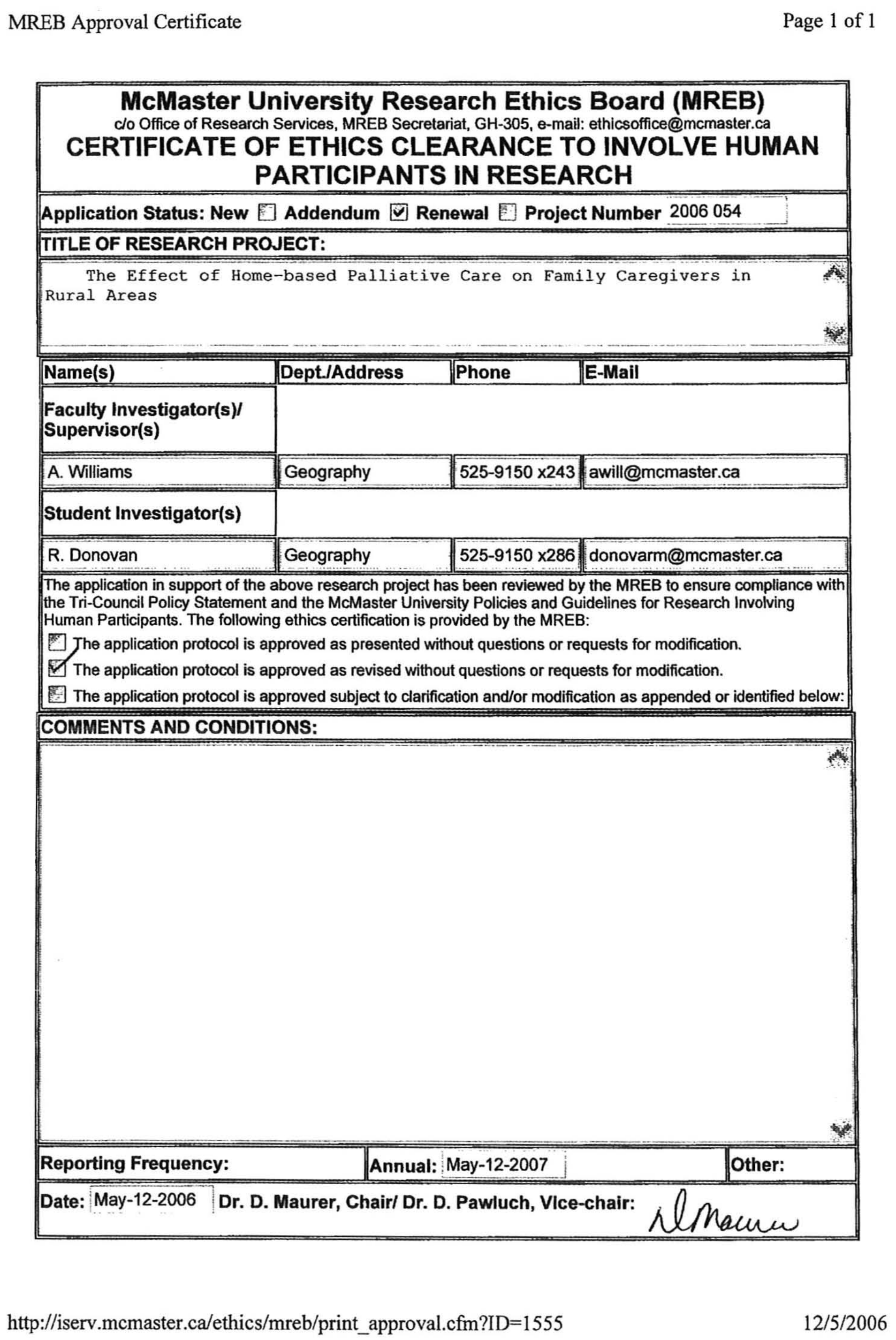

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Date: May-12-2006 **Dr. D. Maurer, Chair/ Dr. D. Pawluch, Vice-chair:** DMaurer

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