

# **Placing the intersection: A qualitative exploration of formal and informal palliative caregiving in the home**

**by**

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Thesis Submitted In Partial Fulfillment of the  
Requirements for the Degree of  
Doctor of Philosophy

in the  
Department of Geography  
Faculty of Environment

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**SIMON FRASER UNIVERSITY**

**Summer 2013**

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## **Abstract**

Currently over 259,000 Canadians die each year, yet only 15 percent access palliative care services prior to death. This reality raises significant concerns regarding the awareness, accessibility, and meaningfulness of these services for dying Canadians and their families. It also signals a need to examine lived experiences of palliative caregiving in order to gain a better understanding of what needs exist and what barriers may be influencing Canadians' access to this important care. As equity of access to health care is a main interest of health geographers, I address this need by seeking the experiential perspectives of those who work on the front-lines of providing palliative care in Canada, with a specific focus on the province of British Columbia. Using semi-structured interviews and ethnographic fieldnotes from three research studies, I undertake four diversity- or intersectional-based analyses that employ a relational concept of 'place' to explore experiences of palliative caregiving in the homecare context.

Findings from the analyses reveal that differences exist among palliative family caregivers and, importantly, that these differences intersect to impact caregivers' needs and patients' access to palliative care services and supports. By employing a relational concept of place, the findings show how Canadian palliative caregivers' opportunities, choices, decisions, and outcomes are shaped by where and how they are situated. As such, this dissertation disrupts the common notion in policy and practice that Canadian palliative caregivers are a homogeneous group with similar needs and thus require similar supports. Furthermore, the analytic findings offer specific implications for and research contributions to the geographies of care and caregiving, palliative caregiving policy, and homecare nursing practice. Considering Canada's rapidly aging population and impending increased need for palliative care in the coming years, this dissertation contributes knowledge that can help to inform decision-makers and health care administrators of ways to enhance services, improve access, and ultimately, better meet the needs of all dying Canadians and their family caregivers.

**Keywords:** family caregiving; palliative care; home care; diversity; intersectionality; Canada

## Dedication

*This dissertation is dedicated to all of Canada's unsung palliative caregivers, whose own dedication, devotion, and compassion ensure our dying transition from life to death with dignity and grace.*

## **Acknowledgements**

First and foremost, I would like to acknowledge my supervisor, Dr. Valorie Crooks, who has provided me with all of the support, encouragement, guidance and inspiration I could ever ask for throughout my entire six-year post-graduate education. It is because of her that I have made it to where I am today. I would also like to acknowledge Dr. Nadine Schuurman, who over the past six years has offered me invaluable advice, not only regarding my research, but on achieving professional success in this world of academia. I would also like to acknowledge Dr. Kelli Stajduhar, who gave to me the unforgettable opportunity to learn about and conduct ethnographic research in the unique palliative home care context and provided me with support and thoughtful guidance throughout my PhD program. I would also like to acknowledge Dr. Olena Hankivsky, who has inspired, encouraged, and assisted me throughout my ‘intersectional’ endeavors. Lastly, I would like to acknowledge all the front-line palliative care workers who took valuable time from their schedules to participate in this research as well as those families who so generously opened their doors to me. My doctoral work was supported by the Social Science and Humanities Research Council Canadian Graduate Scholarship award.

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# 1. Introduction

The recognition that 'place' matters to health is not new: acknowledgement of this place-health relationship dates as far back as 400BC and the holistic Hippocratic tradition of medicine (Cummins et al., 2007; Macintyre & Ellaway, 2003; Meade & Earickson, 2005). However, it was not until the late 1970s that the academic field of medical geography emerged (Andrews & Moon, 2005), and not until the early 1990s that 'place' became recognized by health researchers as a critical variable in the experience, production, and maintenance of health (Cummins et al., 2007; Kearns, 1993). Prior to the 1990s, place had been understood as a passive, fixed physical space: a bounded container of characteristics within which things transpired (Kearns & Collins, 2010; Kearns, 1993). Inspired by the humanistic approach and geography's cultural turn, in 1993 Robin Kearns proposed a new conception of the health-place interaction that emphasized the individuality of meanings, social constructions, and experiences of space and place (Andrews, 2003; Kearns, 1993). His influential publication, titled '*Place and Health: Towards a reformed medical geography*' (1993), is considered by many as the catalyst from which the current discipline of health geography developed. In this paper, *place* was cast as the central concept for studying health (Kearns & Collins, 2010).

In his 1993 publication, Kearns called for a reformation of the discipline of medical geography, which had a focused interest in positivist pathologies and sites and systems of care, to a more qualitative health geography, which would include a greater emphasis on place and the integration of social theory (Kearns & Collins, 2010; Kearns, 1993). This new *post-medical* geography, Kearns proposed, would be concerned primarily with understanding the dynamic relationship between health and place, in the broadest sense, and its impacts on both health services and the health of population

groups in particular places (Kearns, 1993). More specifically, Kearns (1993) aimed to reassess the link between place and health in medical geography by asserting that place should be understood more as a 'sense of place,' which relates to one's consciousness of place as well as the relationship between an individual's 'place-in-the-world' and experience of health. This call was made in response to developments in the philosophies of health that were influenced by the socio-ecological model, which understood health not just as the absence of disease, but as the relationship between a population and their social, cultural, and physical environments (Kearns, 1993). From this framing, Kearns suggested it would be possible for researchers to gain a nuanced understanding of diversity and differences in health and how they manifest in particular contexts. In response to Kearns' call, the discipline of medical geography was, for the most part, recast as *health* geography and has since flourished into an established field of researchers who aim to explore the diverse and complex intersections of place, people, and health (Luginaah, 2009).

The emergence of health geography and new framings of health and its relationship to place have led to the development of new research questions by health geographers and the subsequent employment of a broad range of research methods (Luginaah, 2009). Among these new questions are those that are informed by a 'social determinants of health' perspective. Social determinants of health are those broad and complex social conditions, within which people are born, grow, live, and work, shaping their health and health outcomes and ultimately determining, among other things, their individual social locations. These include conditions such as socio-economic status, access to health care, education, gender, and ethnicity (Commission on Social Determinants of Health, 2008). Health inequities are fundamentally linked to these social determinants of health. More specifically, unfair or unjust distributions of the resources that shape people's abilities to achieve or maintain health via these social determinants, such as power and wealth, can result in an inequitable distribution of negative health outcomes (Commission on Social Determinants of Health, 2008).

Building on contemporary understandings that health is experienced *in place* and acknowledgement of the social determinants of health, a key project for health geographers is to assess the place-based dimensions of these determinants, and ultimately, how complex social locations relate to, intersect with, and co-constitute place.

One way for health geographers to explore the social determinants of health and their intersection with place involves employing a *relational* understanding of space and place, a conception that has recently emerged in theoretical discussions in human geography (Cummins et al., 2007; Malpas, 2012). A relational conception rejects the idea that place is essentially aligned with a boundary. Instead it emphasizes the notion that places exist along relational networks that gather and flow, overlap, and stretch across time (Malpas, 2012; Massey, 2005). Relational perspectives of place also encourage a greater focus on the position of places relative to each other, which ultimately blurs the boundaries of scale (Cummins et al., 2007). As such, a relational perspective allows places to be defined as a result of various processes operating at multiple scales (Cummins et al., 2007). There is also a greater emphasis on the varying influences of context and time on place, which is similar to current theories about the influences of lifecourse factors on health and wellbeing (Cummins et al., 2007; Hopkins & Pain, 2007). Such an approach allows places to be dynamic, constantly evolving entities that ultimately will have positive and negative consequences, health-related and otherwise, for the people who experience them (Cummins et al., 2007; Macintyre, Ellaway, & Cummins, 2002).

Understanding place from a relational perspective is a promising approach for health geographers who wish to examine the social determinants of health inequities. This is because the social conditions referred to above are also unbounded dynamic processes that are constructed and shaped by various relational processes stretching across multiple scales, times, and spaces (Dolan & Thien, 2008; Hankivsky et al., 2011).

Taking a step further, and echoing Kearns' (1993) call for understanding place in light of one's 'place-in-the-world', there is a need for health geographers to expand their scope so as to consider how place is experienced *in relation to the social conditions that so greatly shape health and health inequities* (Dolan & Thien, 2008; Valentine, 2007). Thus, in order to gain a more nuanced understanding of how health and/or health care is experienced, place must be considered in relation to social conditions and the socio-economic, political, cultural, and historical axes that shape people's lived realities (Dolan & Thien, 2008; Moss, 1997).

In this dissertation I aim to contribute to the field of health geography by applying a relational and intersectional conception of place to the context of formal and informal palliative caregiving in Canada (Chapter 2) with a particular focus on the province of British Columbia (BC) (Chapters 3-5). I believe that such an approach contributes to the state of empirical evidence about how and why place matters for palliative care, while simultaneously acknowledging the wider socio-political, economic, and cultural conditions that shape everyday experiences of caregiving, death, and dying. In taking this approach, I work from the established perspective that place has no lasting boundaries, is something that fluctuates, and is not permanent (Cummins et al., 2007; Macintyre et al., 2002; Moss, 1997). Ultimately, my goal is to gain a better understanding of the ways that places relate to, shift, and change in accordance with people's needs, opportunities, choices, decisions, and outcomes (Kearns, 1993; Moss, 1997) within the context of formal and informal palliative caregiving practices.

In this chapter, I introduce the general focus as well as the specific objectives of my dissertation research. In the next section, I discuss some ways that place is currently conceptualized in the geographies of care and caregiving. I then present a brief discussion on the palliative care system in Canada and introduce formal front-line workers and informal family caregivers. I conclude this introductory chapter with an overview of my dissertation, including the four analytic chapters that follow.

## **1.1. Geographies of Care and Caregiving**

In recent years, health geography scholarship has become increasingly informed by a sub-field that focusses on issues surrounding the notion of care (Kearns & Collins, 2010; Milligan & Power, 2010). Generally speaking, the geographies of care and caregiving are concerned with the socio-spatial organization of health care and inequalities of access to this care (Milligan & Power, 2010). Within this sub-field, much debate exists surrounding how 'care' should be defined as it has different meanings depending upon the social, political, ethical, and cultural position of the user, whether policy-maker, researcher, provider, or patient. For this dissertation, I embrace Conradon's (2003) definition of care that considers it as the proactive interest of one person in the well-being of another, whereby care is understood as a physical, social, spiritual, and ethical encounter. In geography, care is generally interpreted within a relational framework that acknowledges the linkages between health and caregiving, the places in which care occurs, and those who deliver this care (Milligan & Power, 2010). The majority of research in the geographies of care and caregiving sub-field inquires into lived experiences of care and caregiving, particularly by whom and where, demonstrating an overarching focus on 'place-based' experiences (Kearns & Collins, 2010).

Understanding the socio-cultural role of place is a central theme in caregiving research in health geography. For example, health geographers pay particular attention to the spaces in which care takes place, with the aim to gain a better understanding of the meanings attributed to them and how they impact care practices. Expanding on the cultural and emotional dimensions of the home, Milligan's (2005) findings emphasize that care recipients who were relocated to a residential care home from their private homes were unable to ever 'feel at home' due to a perceived lack of privacy in this new space. This was the case not only for the care recipients, but also the family caregivers who felt a sense of displacement in the formal care home and a need to adjust their

caring roles and identities in this new environment (Milligan, 2003). Furthermore, health geographers exploring care in the home environment have found that the boundaries between public and private become increasingly blurred as the values and temporal structures that belong to the formal domain of health and social care provision intrude into the home space (Andrews, 2003; Milligan, 2003; Milligan & Power, 2010; Wiles, 2003). Building on Milligan's (2003) findings about privacy in the practice of care, this intrusion can be experienced as a transgression of privacy and integrity by families (Skott & Lundgren, 2009). Such transgressions may be especially concerning when a disjuncture between cultures of care occurs, such as between Western biomedicine and other traditional practices of health and healing (Crosato, Ward-Griffin, & Leipert, 2007; McGrath, 2006).

Some caregiving research conceives of place in a relational way, for example being *distal* and/or *proximate*; that is, the social experience of closeness or remoteness or physically being near or far from care services. For example, Bondi (2008) applies the notion of proximity through studying the use of spatial metaphors, like feelings of closeness during intimate practices of caregiving. Issues of proximity are also raised in Power's (2008) research on family members caring for adult children with disabilities, where his findings demonstrate that narrative proximity, which is facilitated by dialogue, is important as it builds trust between formal providers and care recipients. Proximity is also raised metaphorically with regard to characterizing the strength of caregiving relationships in different types of places. For example, while rural residents may live far apart from one another, they are often thought of as socially more proximate than urban dwellers, which ultimately plays a role defining caregiving relationships (Dolan & Thien, 2008; Skinner & Rosenberg, 2005).

People's sense of who and what they are is continually shaped and reshaped by how they *feel* about places and how they *feel* in places (Milligan, 2005). As such, the geography of emotions is highly relevant to caregiving research as care connects people,

whether they desire this connection or not, and this connection is imbued with a range of emotions that are shaped in place (Bondi, 2008; Dyck, 2005; Kearns & Collins, 2010). Milligan (2005), for example, proposes the use of an emotiospatial hermeneutic to examine how emotion and the affective practice of informal caregiving for frail older people is experienced as the site of care shifts from private to public space (Milligan, 2005). Emotional geographies are especially pertinent to palliative care, as places of death and dying are highly emotive (Morris & Thomas, 2007). For example, it has been found that emotional meanings of home strongly inform the preference for a home death among some who have been diagnosed with a terminal cancer, even though dying at home typically involves feelings of normality, loss, security, fear, control and embarrassment that must be constantly (re)negotiated in place (Morris & Thomas, 2007).

Andrews and Evans (2008) contend that although health care and access to care has been a major focus of the geographies of care research, health care *work* has been relatively neglected. Rather, they state that most health geographers exploring issues of health care are more concerned with health care consumption than production (Andrews & Evans, 2008). As such, the experiences and perspectives of those who are working on the front-lines in delivering care are often being missed in this field of research (Andrews & Evans, 2008). This is concerning given that formal and informal care providers hold significant experiential knowledge that can contribute valuable information for understanding a wide range of health care work issues. For example, their experiences can elucidate how place is interconnected with the workings of clinical practice, or why the spatial diffusion of formal caregiving into communities and the home matters for how they provide care. As such, my dissertation research attempts to address this gap by contributing knowledge that considers the valuable experiences and perspectives of informal and formal caregivers alike, specifically in the palliative care context. Moreover, I also aim to stretch beyond those spatial studies that are focussed solely on sites, settings, and systems of care to explore laterally how the socio-political,

cultural, environmental contexts of palliative care providers' locations influence their experiences of providing care.

## **1.2. Palliative Care in Canada**

Reflecting a demographic trend witnessed in many Global North nations, Canada is experiencing rapid population aging. As the generation commonly known as the 'baby boomers' approaches their retirement years, Canada's health care system is preparing for what has been referred to as a 'silver tsunami.' In 2011, an estimated 5 million Canadians were 65 years of age or older and this number is expected to double in the next 25 years, reaching over 10 million by 2036 (HRSDC, 2013). By 2051, about one in four Canadians will be over the age of 65 (HRSDC, 2013), a population group that accounts for over 75 percent of the total deaths in Canada each year (CHPCA, 2012). This rapid increase in the aged population raises many concerns for health care planners and administrators in Canada, particularly in regard to the growing need for palliative care in the coming years.

In this dissertation, I use the commonly referred to definition of palliative care developed by the World Health Organization (WHO, 2011), which describes it as:

*an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.*

In Canada, this typically involves services such as pain management, symptom management, social, psychological, emotional, and spiritual support, as well as caregiver support (Canadian Hospice Palliative Care Association, 2013).

Currently over 259,000 Canadians die each year; however, only 15 percent (less than 40,000) access palliative care services prior to death (QEOLCCC, 2010). This statistic raises many concerns regarding the awareness, accessibility, and meaningfulness of palliative services for dying Canadians and their families (QEOLCCC, 2010). Given that the country is experiencing a rapidly aging population, and a large percentage of dying Canadians and their caregivers are not accessing adequate palliative care, it is clear that a timely and significant need exists to enhance existing palliative care services and supports as well as their general awareness.

Despite concerns over the underutilization and delivery of this service, Canada is recognized as an international leader in the development of palliative care philosophy (Victoria Hospice, 2013; Williams et al., 2010a). The first hospice programs opened in 1975 at St. Boniface Hospital in Winnipeg and in Montreal at the Royal Victoria Hospital under Dr. Balfour Mount. It was Dr. Mount in Montreal who coined the now commonly used term 'palliative care' (*soins palliatif* in French) to distinguish it from the word 'hospice', which had become associated with a place of last resort for the poor and destitute (Victoria Hospice, 2013). Today, the term has evolved to encompass the philosophy of hospice care (Williams et al., 2010a), which has the ultimate goal to support and care for the most vulnerable in society – the dying and their family members. This philosophy is integrated into the World Health Organization's definition of palliative care shared above.

Within Canada, palliative care is offered across a range of sites, including nursing homes, acute care hospitals, respite facilities, and hospices by a variety of providers who can include family doctors, nurses, specialists, community volunteers, spiritual leaders, and family members (Carstairs, 2005). An increasing number of Canadians are now expressing their desires to die at home, surrounded by a familiar environment and loved ones (Burge, Lawson, & Johnston, 2003; Munday, Petrova, & Dale, 2009; QEOLCCC, 2010). This is resulting in a shift in the places where palliative care is given, moving away

from hospital settings and into the community, especially the home (Skinner & Rosenberg, 2005; Stajduhar, 2003). Considering this, there is not only a significant need to improve access to palliative care due to anticipated growth in demand, but also to develop palliative care services that support death and dying in a variety of settings (QEOLCCC, 2010; Stajduhar & Davies, 2005).

Over the past ten years, Canada has seen many advances in palliative care, largely due to national, provincial, territorial, and local governments recognizing the need for high quality care and investing in services for people who are dying (QEOLCCC, 2010). For example, in 1991, a national advocacy body was established, presently known as the Canadian Hospice and Palliative Care Association (CHPCA, 2013). However, in 2007, the federal government disbanded the Secretariat on Palliative and End-of-Life Care and stopped work on the national palliative and end-of-life care strategy (Health Canada, 2007; QEOLCCC, 2010). Although some aspects of palliative care have been included in other national strategies, such as cancer care, few specific steps have been taken in recent years to enhance services for dying Canadians and their caregivers (QEOLCCC, 2010). Thus, despite the numerous concerns and timely and significant need, palliative care in Canada remains at the margins as an undervalued component of the Canadian health care system, while much debate continues to exist regarding whether it should be categorized as specialized or generalized care (QEOLCCC, 2010; Williams et al., 2010a).

### **1.3. Palliative Care Delivery in British Columbia**

Within Canada, eligibility for, access to, and availability of health care services, including palliative care, is largely dependent upon where one lives (Williams & Kulig, 2012). This is because of the decentralized nature of the Canadian health care system and the associated roles and responsibilities of various levels of government in regard to providing such care (Carstairs, 2005). Specifically, it is the individual provincial and

territorial governments that have primary responsibility for the delivery of health care services, including palliative care, as legislated by the Canada Health Act, while smaller regional authorities hold responsibility for administering these services. The Canada Health Act sets out the primary objective of Canadian health care policy as it relates to the provision of public services, which is "to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers" (Health Canada, 2010 n.p. ). Through this Act, the federal government supports the publicly-funded health care system through: transfer payments to the provinces and territories, health policy creation that falls within its jurisdiction, and some other health care-related activities (Carstairs & MacDonald, 2011). The federal government also has a direct service delivery role for certain populations: First Nations on reserve and Inuit people, the military and veterans, refugee protection claimants, and inmates of federal penitentiaries (Carstairs & MacDonald, 2011). The federal government can provide leadership to the provinces through the creation of policy directives, such as the Canadian Strategy on Palliative and End-of-Life Care (Carstairs & MacDonald, 2011) and can also administer health-related programs, such as the Compassionate Care Benefit, through its various agencies. For example, the Compassionate Care Benefit is run through the contributory Employment Insurance scheme and administered via Service Canada with the aim to support eligible Canadians providing informal palliative care to a friend or family member during the last six weeks of life to take time away from work to provide this care (Service Canada, 2012). (I discuss this program in more detail in Chapter 2).

Although the federal government plays a major role in the funding of health care in Canada, it is the provincial and territorial governments that are responsible for providing local leadership and setting the overall direction for the health systems that fall under their jurisdiction (British Columbia Ministry of Health, 2006). In BC, this involves the provincial government undertaking actions such as policy creation and

enactment, legislative changes, and allocating funds to organizations and individuals who provide services. As such, the provincial government is responsible for legislative changes that are necessary to improve formal palliative care provision that falls within the scope of the public health care system (British Columbia Ministry of Health, 2006). Although the responsibility to deliver health care is further decentralized to the local health authorities, of which there are six in the province, the provincial government retains responsibility for funding some services essential for palliative care, such as physician and ambulance services and the BC Palliative Care Benefits Program (British Columbia Ministry of Health, 2006, 2013). The BC Palliative Care Benefits Program is aimed to support BC residents who have reached the end stages of a life-threatening disease or illness and who wish to receive palliative care at home (British Columbia Ministry of Health, 2013). More specifically, eligible care recipients can receive coverage of medication used in home palliative care through the PharmaCare BC Palliative Care Drug Plan as well as medical supplies and equipment through the local health authority (British Columbia Ministry of Health, 2013).

As mentioned previously, regional BC health authorities are responsible for the delivery of most health services, including palliative care, at the local and regional levels (British Columbia Ministry of Health, 2006). Generally, these publically-funded palliative care services are provided directly by persons working for the authorities, such as physicians, community nurses, community rehabilitation specialists, home support and hospital workers (British Columbia Ministry of Health, 2006). Additional services are also available and are funded in part by the health authorities, but delivered by private organizations and individuals. These include some community-based support services, residential care, home support, personal care services, adult daycare services, and hospices (CHPCA 2013). Although these services are regulated and subsidized by the health authorities, they are private (not-for-profit or for-profit) organizations and therefore Canadians are required to pay a user fee. Due to the limited availability and the restricted eligibility requirements of publically-funded palliative services, families

often find themselves in need of additional support and thus, paying out-of-pocket for these services. For example, it has been found that Canadians frequently shoulder 25 percent of the total cost of palliative care, especially for extra home-based services such as nursing and personal care (CHPCA 2012). Also, for those wishing to die in hospice in BC, beds cost users approximately \$30 per night (CHPCA 2012). Generally, many of these local organizations and types of support services are funded solely by charitable donations and rely entirely on the work of volunteers. For example, in Canada, over 50 percent of hospices and their support programs are funded from charitable donations, with the majority of the cost of hospices being provided by private donors (CHPCA 2013). Therefore, palliative care services are provided through the combined efforts of publically-funded and charitable organizations, as well as private-pay services.

#### **1.4. Providers of Formal and Informal Palliative Care in Canada**

Caregiving is a complex social relationship: not only is it highly dependent upon personal experiences and histories, but it is also reliant on socially and politically defined sets of expectations and practices regarding rights and responsibilities (Dyck, 2005; Milligan & Power, 2010). Within Canada, as well as other Global North nations, neoliberal restructuring has resulted in a growing expectation for the voluntary sector to play a prominent role in caregiving, including palliative care (Chouinard & Crooks, 2008; Skinner & Rosenberg, 2005). An outcome of such restructuring is, as I noted above, that many forms of care are more frequently taking place within the home and other community settings rather than in formal institutions (Burge et al., 2003; Lilly, Laporte, & Coyte, 2007; Skinner & Rosenberg, 2005). This has also brought about shifts in regard to who is viewed as being responsible for providing care. Specifically, the role of caregiving is now increasingly being ascribed to those who live and work in the home: family members or friends who are generally untrained and unpaid and who often do

not have the necessary support and/or resources to meet such demands (Milligan & Conradson, 2006; Skinner & Rosenberg, 2005; Stajduhar & Davies, 2005).

Although formal care providers (e.g., nurses, doctors, social workers) are invaluable in the delivery of palliative care, their efforts would not be successful without the hours of dedication and demanding work provided by family caregivers (CHPCA 2013; CIHI 2012). Within Canada, these informal caregivers and the supports they provide have become the backbone of the health and long-term care systems (CCC 2009). For example, estimates indicate that there are approximately 1.5-2 million family caregivers in Canada who contribute annually up to \$26 billion of unpaid care work (Hollander, Liu, & Chappel, 2009). Family, or informal, caregivers are those who provide care and assistance for family members and close others in need of support because of age, debilitating medical conditions, injury, long term illness, disability, or being at the end stages of life (CCC 2009). These caregivers often provide physical and emotional care and support as well as care coordination, among other tasks (CCC 2009).

There are a number of stresses associated with family caregiving (e.g., emotional, physical, financial) that, when experienced, are collectively referred to in the literature as 'caregiver burden' (Exley & Allen, 2007; Grunfeld et al., 2004). Supports are offered in order to minimize or eliminate this burden. One critical source of support that exists for family caregivers providing palliative care in Canada is having access to a formal palliative care team. As palliative care is inherently interdisciplinary, formal palliative care providers encompass a variety of specialist fields, including medicine, nursing, psychology, social work, spiritual care, rehabilitation services, nutrition, and pharmacology (NCPQPC 2009). As such, formal palliative care is often provided by an interdisciplinary team of physicians, nurses, social workers, chaplains, counsellors, nutritionists, pharmacists, and rehabilitation specialists (NCPQPC 2009). There may also be disease-specific specialists involved in providing palliative care who are effectively members of patients' teams, for example cardiologists, neurologists, and

endocrinologists (NCPQPC 2009). With palliative care increasingly being provided at home, community-based palliative care workers also play prominent roles as part of the palliative care team in supporting family caregivers, especially in regard to technical and medical care support (Giesbrecht et al., 2009; Stadnyk, 2002; Stajduhar et al., 2011b). For example, homecare nurses play significant roles in the delivery of palliative care in Canada, and as the name denotes, is the field of nursing practice that focuses on the provision of nursing care outside of institutional settings and most often in clients' homes (Stadnyk, 2002). Due to the increased desire for care to take place at home coupled with Canada's rapidly aging population, the Canadian Nurses Association anticipates that 67 percent of all nurses in Canada will be working in community settings by 2020, compared to just 30 percent in 2006 (Villeneuve & MacDonald, 2006).

## **1.5. Thesis Overview**

This dissertation is structured following the paper-based style, which involves uniting individual papers for publication with a common introductory and concluding chapter. Specifically, my dissertation is organized into six chapters consisting of four individual papers (Chapters 2-5) drawn together with one introductory and one concluding chapter. From the outset, Chapters 2 to 5 were written as independent papers to be published in scholarly journals and a policy analysis framework. Although my academic background and the research presented herein are rooted in the field health geography, I have purposely chosen to publish each of these analyses in venues falling outside the discipline. I believe that doing so exposes geographic thought and ideas to those who would not ordinarily 'think geographically' about palliative care. Chapter 2 has been published in the peer reviewed open access journal *International Journal for Equity in Health*, while Chapter 3 has been submitted for publication in the peer reviewed journal *Palliative & Supportive Care*. Chapter 4 has been published in *Nursing Inquiry*, which is also a peer reviewed journal. Lastly, Chapter 5 has been

published as a peer reviewed case study chapter in a framework report designed to facilitate Canadian policy and decision makers' use of intersectionality-based analyses (for more details, see Hankivsky et al., 2012).

The four analytic chapters in this dissertation contribute to *three different* studies that I have had the valuable opportunity to be involved in over the past four years. Each of these studies has operated with its own methodology, objectives, and aims. Despite these differences, the goals and objectives of this dissertation reflect a collective thematic direction. There are also two overarching research goals, which are to: disrupt the common notion in policy and practice that Canadian palliative caregivers are a homogeneous group who have similar needs and thus require similar supports, and; generate knowledge that can inform decision makers of ways to provide Canadian palliative caregivers with the most meaningful and equitable supports. In this section, I present my overarching thesis objectives. After this, I introduce the specific aims and objectives of my individual analytic chapters, while providing an overview of the larger studies to which these chapters contribute. First, however, I situate myself in the context of my dissertation research.

### **1.5.1. Positionality**

Reflecting on my academic background, I am a geographer at heart. As such, my research lens is framed around ideas about place and space and especially how these concepts are related to experiences of health and health care. I approach the world from a critical perspective, often influenced by theories of intersectionality. In this way I seek to gain a better understanding of issues of power, and more specifically, how power imbalances create and reinforce health inequities.

Recognizing the importance of positionality in the research process, I also acknowledge that I have had the privileged opportunity to attend university and obtain a PhD-level education; an opportunity I know is not available to everyone. I also

acknowledge that my gender, specifically identifying as a woman, shapes how I see the world and also how the world sees me. This is an important recognition, particularly as I conduct research on caregiving: an act that has highly feminized overtones in Canadian society.

One question I am often asked in relation to my research is why I chose to explore the topic of palliative care, as it often seen as a very heavy, emotional, and “depressing” topic. Although it was my Master’s supervisor, Dr. Valorie Crooks, who first introduced me to palliative care research, I did actively choose to continue this research focus into my PhD. I made this decision because of the incredible meaning and value I have come to see in palliative care work and how it too often remains invisible in our society, due in part to the death denying culture we are situated in (Williams et al., 2010a). Thus, my interest in undertaking palliative care research comes from a desire to give voice to formal and informal palliative caregivers through the research process. Their admirable work allows people to live out their final moments with dignity and feeling cared for. It is from the personal and conceptual positionings I have shared in this sub-section that I have approached my dissertation research on palliative caregiving.

### **1.5.2. Objective One**

*The first objective of this dissertation research is to contribute a novel geographic perspective to the existing body of Canadian palliative care research.*

Although death, dying, and palliative care research is inherently interdisciplinary, stretching across a number of disciplines and empirical fields (e.g., nursing, health sciences, sociology, philosophy, anthropology, among others), geography scholars have made some valuable contributions to this body of knowledge. For example, much research by health geographers explores questions surrounding where death occurs and the preferred places of death and dying (for examples, see Burge et al., 2003;

Liaschenko, Peden-McAlpine, & Andrews, 2011; Midson & Carter, 2010; Morris & Thomas, 2007). Connected to dying, much research also explores palliative care in a range of settings including homes, hospices, and hospitals (Andrews & Shaw, 2008; Castleden, Crooks, Schuurman, & Hanlon, 2010). Brown (2003), for example, explored the home as a site for death and found that a number of paradoxes arise, for example that dying is a private act, but palliative care is a philosophy and policy that involves the inclusion of others, including formal care providers, which inherently lessens privacy. As such, Brown contends that, through a relational perspective of public and private spaces, this public/private divide in the home becomes blurred during the dying process. The home as a site for dying is also explored by Morris and Thomas (2007), referring to the home as an 'emotional landscape', from which the meaning of 'home' will change throughout dying process from providing a sense of normality to a sense of complexity and loss of identity.

Health geographers have contributed unique, spatially-informed insights regarding access to palliative care services and associated supports in Canada. For example, some geographers have employed spatial analysis to determine access to palliative services in rural BC (Cinnamon, Schuurman, & Crooks, 2008; Crooks et al., 2011; Schuurman, Crooks, & Amram, 2010). The findings from their studies uncover pockets of spatial inequities, whereby populations are found to be living outside areas that would allow for meaningful palliative access, particularly in northern BC. Qualitative methods have also been used to explore access to palliative services and supports in Canada (Giesbrecht, Crooks, & Williams, 2010; Williams et al., 2010), and consider the barriers that may exist for particular groups like Aboriginal (Castleden et al., 2010) or rural populations (Crooks et al., 2009; Novik & Maclean, 2012).

Although the existing research summarized above contributes valuable knowledge regarding palliative care from a geographic perspective, what is missing is the employment of a relational concept of place that not only considers the physical site

of where palliative care is occurring but also those broader dimensions that simultaneously shape caregivers' experiences of providing palliative care. As such, I have set as an objective to address this gap by exploring experiences of the physical place (i.e., the home) in relation to the various other social and physical spaces that intersect to shape experiences of palliative caregiving. I believe that applying a relational conception of place to palliative caregiving research, one that also acknowledges the wider social conditions in which caregivers are situated, has the potential to assist with gaining a more nuanced understanding of family caregivers' complex lived realities. Such knowledge holds the potential to inform policy-makers of equitable ways to provide meaningful and useful palliative caregiver support.

### **1.5.3. Objective Two**

*The second objective of this dissertation research is to determine the diverse, yet interrelated, axes of difference that shape Canadian palliative caregivers' experiences in the context of the homecare environment.*

Providing palliative care is not a homogenous experience. Rather, it is informed by a number of unique multidimensional factors that shape experiences of providing care as well as gaining access to meaningful services and supports. For example, a recent study by Burns et al. (2010) explored age-related differences in experiences of family caregiving. They found that young caregivers (ages 15-29) providing hands-on palliative care assumed a different demographic profile than the average family caregiver and also had different experiences of caregiving relative to older carers. Their findings also revealed that younger caregivers more frequently reported negative experiences of caregiving compared to older carers and a need for greater support during the grief and bereavement process. There are a few studies that have also looked to explore cultural differences among caregivers. For example, research has been done with Aboriginal caregivers in order to gain a better understanding of their definitions of

health, illness, and death (Baydala et al., 2006; Crosato et al., 2007; Hotson, Macdonald, & Martin, 2004). Wiles (2003) found that relational, dynamic, and temporal social and environmental factors (e.g., material, physical, and emotional aspects of care) interact to shape caregiving experiences, particularly in regard to accessing services and resources in the community. Wiles (2003) and Burns et al.'s (2010) studies, along with the research conducted with Aboriginal caregivers, collectively demonstrate the importance of acknowledging the role that multiple axes of difference play, as they relate to both social and physical location, in shaping palliative caregiving.

Although some existing caregiving research contributes to our understanding of difference among caregivers, there is little that moves beyond considering singular axes, such as age or gender alone, to explore the multiple intersections of difference that simultaneously impact caregiving experiences and outcomes. This is true despite the growing calls in geography feminist scholarship in particular encouraging social scientists and others to examine these complex intersections and articulate the implications they hold for all aspects of social and spatial life (Valentine, 2007)). I respond to these calls in this dissertation by conducting analyses that aim to identify what differences exist and intersect to impact formal and informal caregivers' experiences in the context of providing palliative care in the home. By grounding this research in lived experiences and seeking the perspectives from those working on the front-lines in palliative care, I seek to garner valuable knowledge that can contribute to a better understanding of the complex diversity that exists among palliative caregivers in Canada and BC.

#### **1.5.4. Objective Three**

*The third objective of this dissertation research is to gain a better understanding of how Canadian palliative caregivers' opportunities, choices, decisions, and outcomes are shaped by where and how they are situated.*

As mentioned previously, experiences of palliative caregiving are not homogenous. While identifying the differences that exist is an important first step in acknowledging this (i.e., Objective Two), I believe it is critical to gain a better understanding of how these differences, in turn, shape the experience of palliative caregiving. In one study, Carlsson and Rollison (2003) investigated if and how socio-demographic factors played a role in determining whether care recipients died at home or in hospice. Findings indicate that the place of death differed significantly and varied according to gender and cohabitation status. More specifically, more men died at home while more women died in hospice. Another study by Weitzen et al. (2003) in the United States found that African Americans with low education were most likely to die in a hospital setting, while factors associated with dying at home involved being from a Western state, having at least 12 years of schooling, and receiving formal hospice services. Other studies have explored the inequities in access to palliative care. For example, a literature review by Maddison et al. (2011) synthesized inequities to accessing cancer care in Canada. Their synthesis demonstrates that income, education, age, sex, and geographic location of residence often contribute to an individual's level of access to cancer services in Canada even after adjusting for need factors. More specifically, they found that income has the most consistent influence on screening, while age and geography are most influential for accessing treatment services, including palliative care. Such studies point to how the social and physical locations of care recipients influence where death will occur and whether or not palliative care will have been accessed.

The existing research summarized above is valuable in contributing a greater understanding to how physical/social locations can shape the experiences of receiving palliative care; however, little research has attempted to explore how such factors shape the experience of providing care. As such, I address this gap in my dissertation by conducting analyses that identify and explore how axes of difference intersect to shape: (1) access to palliative care supports for diverse informal caregivers (Chapter 2); (2) the

capacity for informal caregiver resilience (Chapter 3); (3) the interactions between language and care delivery in the home among homecare nurses and informal caregivers (Chapter 4), and; (4) the need for palliative care services and support in BC that respond directly to diverse caregivers' needs (Chapter 5).

### **1.5.5. Thesis Structure**

As mentioned previously, this paper-based dissertation consists of four analytic chapters united by a common introductory and concluding chapter. Although my dissertation is guided by an overarching set of objectives and two crosscutting research goals, the four analytic chapters are derived from three different studies. In this section, I provide a brief overview of these studies and present the specific objectives and aims for the associated thesis chapters.

## **Chapter 2**

The first analysis (Chapter 2) originated from a national scale evaluative study I initially worked on during my Master's program. The aim of this study was to conduct an evaluation of a new (at that time) social benefit program for palliative caregivers, the Compassionate Care Benefit (CCB), in order to offer policy-relevant recommendations (for full study protocol see: Crooks & Williams, 2008). The CCB was implemented in 2004 to provide an eight-week secure employment leave and limited income assistance to eligible Canadians who are providing care for dying family members (Service Canada, 2012). This study was guided by Patton's (1997) utilization-focused evaluative approach, which aims to inform program improvements with a focus on "*intended use by intended user*" (1997, p 20, emphasis in original). Thus, this methodology places 'actual use' front and center in the evaluation process. As such, the perspectives of the CCB's primary users (i.e., palliative family caregivers) and those who were likely to assist them in their applications (i.e., front-line palliative care workers, human resources personnel) were sought. The evaluation study had three specific objectives, which were to: (1) examine

the usefulness of the CCB for family caregivers and determine those elements of the program that could be changed to better meet their needs; (2) explore front-line palliative care providers' perceptions of the CCB; and (3) investigate barriers and facilitators inherent in specific workplaces and the labour market that shaped CCB uptake from the perspective of employers. Multiple datasets were gathered in order to address these objectives.

Chapter 2 draws on interviews I conducted with 50 front-line palliative care providers (e.g., nurses, social workers) across 5 Canadian provinces for the CCB evaluation study. Using a diversity lens, this secondary thematic analysis draws on these participants' experiential knowledge to gain a better understanding of the aspects of diversity directly impacting Canadian palliative family caregivers' support opportunities, access to resources, and health outcomes. Findings from this analysis reveal that five axes of difference are commonly raised by front-line palliative care providers when discussing differences in family caregivers' experiences: culture; gender; geography; lifecycle stage; and material resources. The results of this analysis are used to identify the implications of caregiver diversity for the successful administration of the CCB program, while emphasizing the larger need for policy to re-frame how palliative caregivers and caregiver needs are viewed and understood more generally.

### **Chapters 3 and 4**

The second and third analyses (Chapters 3 and 4) stem from data collected for an ethnographic study I was involved in as a research assistant during the first two years of my PhD program. This study aimed to gain a better understanding of how 'empowerment' is enacted, interpreted and experienced within the palliative and chronic illness homecare context in BC. As the aim of this study was to gain a deep understanding of behaviours and experiences within their own environmental context, an ethnographic methodology was selected (Fetterman, 2003; Schensul, Schensul, & LeCompte, 1999). This study was informed by Smith's (2004) critical standpoint

perspective, which advocates for a linking of the micro- and macro-processes that shape everyday experiences. Generally, ethnographers working from critical perspectives are concerned not only with how power, social structures, and ideologies constrain individual experiences, but also with how to generate practical knowledge that can influence change (Thomas, 1992, 2003). Data collection for this study included ethnographic participant observations of homecare nursing visits and semi-structured interviews with family caregivers, care recipients, and homecare nurses.

Using data collected for the ethnographic study, Chapter 3 aims to identify the socio-environmental factors that influence palliative family caregivers' capacities for resilience against caregiver burden/burnout in the homecare context. In this secondary analysis I used a case study approach. Case studies seek to capture the uniqueness and complexity of a single case within its context to gain a better understanding of lived experience (Hammersley, 2007; Stake, 1995; Winslow, 1998). Two cases are included in the analysis; both are palliative family caregivers whose interviews and homecare nursing visits revealed aspects of resilience. An intersectional approach is used to direct the thematic coding process. An intersectionality lens considers the simultaneous interactions and combined impacts of social locations and structural processes on the creation and perpetuation of inequities (Hankivsky, Cormier, & de Merich, 2009; Hankivsky et al., 2011). Findings from this analysis reveal that palliative family caregiver resilience is influenced not only by individual variables, but also by broader socio-environmental factors. This demonstrates that resilience in the palliative context is multi-dimensional.

In Chapter 4, a sub-set of the data collected for the ethnographic study (i.e., the first-hand fieldnote data I collected from 5 complete observational cases, 4 palliative and 1 chronic illness) is used to explore the intersection of language, place, and health-care in the BC homecare context. It was found during my observations that language and its spatiality play an important role in the home during health care interactions. As

such, an 'ethnography of communication' approach is taken to pursue this secondary analysis, which is a technique used to examine interactions among members of a specific community (Carbaugh, 2007). The results of this analysis demonstrate how the home environment informs decisions regarding language use, and exemplifies how language and place mutually influence experiences and delivery of home health-care by formal and informal caregivers alike. More specifically, the findings reveal four place-care-language interrelationships: homecare nurses view themselves as 'guests'; home environments facilitate the development of nurse-client relationships; nurses adapt health care language to each home environment, and; storytelling and illness narratives largely prevail during medical interactions in the home. The findings of this analysis advance understandings of medical exchanges in diverse places, raising associated implications for best nursing practice.

## **Chapter 5**

My fourth analysis (Chapter 5) comes from a study I independently led that serves as a case study for a larger collaborative project. More specifically, this analysis is published in '*An Intersectionality-based policy analysis (IBPA) framework*' (for full framework, see: Hankivsky et al., 2012). The IBPA framework was developed by a team of intersectionality scholars with the aim of creating a resource for a wide range of Canadians working in health and social determinants of health-related policy sectors. The IBPA resource is intended to enhance decision-making capacity and enable meaningful equity-focussed policy development and evaluation. Intersectional approaches aim to move beyond single or favoured categories of analysis (e.g., gender, sex, culture, geography) "to consider simultaneous interactions between different aspects of social identity as well as the impact of systems and process of oppression and domination" (Hankivsky et al., 2009 p. 3). In other words, intersectionality aims to consider the ways that race, class, gender, ethnicity, sexual orientation, ability, status and other markers of social difference intersect to simultaneously inform individual realities and experiences (Hancock, 2007). Development of the IBPA tool followed an

iterative process that included input from target knowledge user groups. Furthermore, the drafted IBPA tool went through a formal external peer review process prior to its release.

Guided by the IBPA framework, the analysis presented in Chapter 5 aims to examine the perspectives that front-line palliative care providers in BC have about local palliative care policy and how family caregivers' social and physical locations impact their access to care supports and services. Data collection involved interviewing front-line palliative care providers across BC, with interviews inquiring into participants': (1) experiences of working with families experiencing death and dying; (2) perspectives on the diversity of families in need of palliative care supports and access to these supports; (3) perspectives on current palliative care policy in BC; and (4) suggestions for policy improvement. Findings from this study reveal underlying policy assumptions about who is thought to be experiencing death and dying in BC and what are believed to be their associated palliative care needs. The study also uncovers the kinds of population groups that are affected by such policy assumptions, what inequities exist, and how issues of privilege and power are currently being reinforced. These findings offer knowledge that can inform BC policy makers of more equitable ways to deliver palliative care, including in the home, and support palliative caregivers as well.

## **Chapters 6**

Chapter 6 concludes the dissertation, wherein I discuss key contributions of the four analyses. In this chapter I synthesize my research findings and revisit my overarching objectives, discussing each separately and describing how they have been met. I also examine the contributions and implications these analyses offer to the field of geographies of care and caregiving, palliative care policy in Canada, and best palliative care nursing practice, while speaking to my dissertation goals. I conclude this chapter by acknowledging some limitations of this research and providing suggestions for potential future research directions.

## 2. Critically examining diversity in end-of-life family caregiving: Implications for equitable caregiver support and Canada's Compassionate Care Benefit<sup>1</sup>

### 2.1. Abstract

**Introduction:** Family (i.e., unpaid) caregiving has long been thought of as a 'woman's issue', which ultimately results not only in gendered, but also financial and health inequities. Because of this, gender-based analyses have been prioritized in caregiving research. However, trends in current feminist scholarship demonstrate that gender intersects with other axes of difference, such as culture, socio-economic status, and geography to create diverse experiences. In this analysis we examine how formal front-line palliative care providers understand the role of such diversities in shaping Canadian family caregivers' experiences of end-of-life care. In doing so we consider the implications of these findings for a social benefit program aimed at supporting family caregivers, namely the Compassionate Care Benefit (CCB).

**Methods:** This analysis contributes to a utilization-focused evaluation of Canada's CCB, a social program that provides job security and limited income assistance to Canadian family caregivers who take a temporary leave from employment to provide care for a dying family member at end-of-life. Fifty semi-structured phone interviews

<sup>1</sup> This chapter has been published as: Giesbrecht, M., Crooks, V.A., Williams, A., Hankivsky, O. (2012). Critically examining diversity in end-of-life caregiving: implications for equitable caregiver support and Canada's Compassionate Care Benefit. *International Journal for Equity in Health*, 11:65. Copyright © 2012 Giesbrecht, Crooks, Williams, & Hankivsky.

with front-line palliative care providers from across Canada were conducted and thematic diversity analysis of the transcripts ensued.

**Results:** Findings reveal that experiences of caregiving are not homogenous and access to services and supports are not universal across Canada. Five axes of difference were commonly raised by front-line palliative care providers when discussing important differences in family caregivers' experiences: culture, gender, geography, lifecourse stage, and material resources. Our findings reveal inequities with regard to accessing needed caregiver services and resources, including the CCB, based on these axes of difference.

**Conclusion:** We contend that without considering diversity, patterns in vulnerability and inequity are overlooked, and thus continually reinforced in health policy. Based on our findings, we demonstrate that re-framing categorizations of caregivers can expose specific vulnerabilities and inequities while identifying implications for the CCB program as it is currently administered. From a policy perspective, this analysis demonstrates why diversity needs to be acknowledged in policy circles, including in relation to the CCB, and seeks to counteract single dimensional approaches for understanding caregiver needs at end-of-life. Such findings illustrate how diversity analysis can dramatically enhance evaluative health policy research.

## **2.2. Background**

Determining who provides care, whether paid or unpaid, is a complex and dynamic process embedded within socially- and politically- defined sets of expectations and practices regarding rights and responsibilities (Dyck, 2005; Milligan & Power, 2010). Among Western nations, neoliberal policies and resulting health care reforms are increasingly shifting this responsibility of care from the state to the voluntary and

informal sectors (Skinner & Rosenberg, 2005). This shift has resulted in an increased deinstitutionalization of care, moving caregiving out of formal settings like hospitals and into the community, especially the home. As a result, greater expectations are now being placed on those within the home, largely family members and/or friends who are unpaid and untrained, to take on the role of providing care in this informal environment (Milligan & Conradson, 2006; Skinner & Rosenberg, 2005; Stajduhar & Davies, 2005). Generally, these family caregivers<sup>2</sup> provide physical and emotional care as well as care coordination, among other tasks, for those who are in need of support (Canadian Caregiver Coalition, 2009). In Canada, family caregivers and the supports they provide have become the backbone of the health and long-term care systems (Canadian Caregiver Coalition, 2009), with estimates indicating that there are approximately 1.5-2 million family caregivers in Canada contributing up to \$26 billion of unpaid care work annually (Hollander et al., 2009; Lilly, 2010). Due to a rapidly aging population and unprecedented numbers of citizens requiring end-of-life care, a growing number of these caregivers are being called upon to provide care for dying family members (Canadian Policy Research Networks, 2009). Considering the valuable role that these family caregivers play in the Canadian health care system, it is imperative we seek ways to ensure they have access to the supports that they need to provide care in a way that does not negatively impact their own health and wellbeing.

Although family caregiving at end-of-life can bring positive, empowering, and memorable experiences (Balducci et al., 2008), it is also commonly associated with personal costs. Importantly, such costs are not distributed equally across society. For example, the shift of care from institutions to the home means that those who work within the home, largely women, are filling the gaps in labour and services that have been left by neo-liberal policies (Dyck, 2005; Williams, 2002). Feminist scholars have

<sup>2</sup> In this paper, we use the term family caregiver to refer to those family members, friends, and/or close others who informally provide care to a recipient, often without out pay.

long acknowledged that the role of family caregiving is largely taken up by women because they are often associated with the traditional gendered division of unpaid work within the home (Armstrong, Armstrong, & Scott-Dixon, 2008; Dyck, 2005; Mackinnon, 2009; Yantzi & Rosenberg, 2008). Emphasizing the gendered aspect of care provision, Bondi (2008) describes how caring work is 'given' to women and that this often becomes a defining characteristic of their self-identity and lifework. Taking a closer look, however, it becomes apparent that women are not one homogenous group, but are complex and diverse individuals who simultaneously inhabit other distinct socioeconomic, cultural, political, and historical locations, and as such, their experiences of caregiving are likely to vary dramatically (Bondi, 2008; Dolan & Thien, 2008). Therefore, caregiving results not only in gendered inequities, but also complexly overlaps with other factors of social location that may result in particular economic and health inequities being experienced in light of giving care (Armstrong, Armstrong, & Scott-Dixon, 2008).

Taken together, the emotional, psychological, physical, and financial demands that occur as a result of family caregiving are commonly referred to as 'caregiver burden' (Bialon & Coke, 2012). For example, the mental drain associated with mastering vast amounts of new information on a range of complex issues (e.g., medication management, symptom observation) can be more than some caregivers are able to cope with, thereby creating stress and ultimately burnout (Ashpole, 2004; Crooks et al., 2007). The negative health impacts associated with such burdens are significant and have been reported in older spousal caregivers to increase mortality rates by 63% when compared to non-caregivers (Schulz & Beach, 1999). Inequities in income are also commonly experienced by family caregivers. For example, the Canadian Caregiver Coalition (2009) reports that these caregivers frequently incur more than \$100 per month in direct costs (e.g., supplies, prescriptions, travel costs), which totals approximately \$80 million in out-of-pocket costs paid by Canadian caregivers each year. For some, the dual responsibility of maintaining paid employment while providing care

is challenging and such stress can further diminish the health of family caregivers and heighten caregiver burden (Canadian Policy Research Networks, 2009; Crooks et al., 2007).

Importantly, the above-mentioned examples of negative health and economic impacts associated with caregiver burden are not experienced uniformly: inequities exist, which are shaped by vulnerability to stressors and exposure to risk (Pinquart & Sorensen, 2006). Furthermore, family caregivers' abilities to cope with stress and burden and to access needed supports is largely shaped by the situated social/physical locations in which they live (Cloutier-Fisher & Kobayashi, 2009; Dyck, 2005; Mackinnon, 2009), which in turn, influences whether or not they experience negative health outcomes.

Canada's federal government responded to the need to lessen caregiver burden and better support the needs of family caregivers at end-of-life by implementing the Compassionate Care Benefit (CCB) program in January of 2004. The primary goal of the CCB is to alleviate financial burdens by providing income assistance and job security to workers who take temporary leave from employment to care for a terminally ill family member at risk of dying within 26 weeks (Service Canada, 2012). Program recipients can receive up to 55% of their average insurable earnings, to a maximum of \$485 per week, over a six-week period to provide care. Because Human Resources and Skills Development Canada (HRSDC) administers this program as an Employment Insurance special benefit, eligible applicants must demonstrate that their regular weekly earnings have decreased by more than 40% and that they have accumulated 600 insurable hours over the preceding 52-week period. Although estimates demonstrate that more than 1.5 million Canadians provide care for dying individuals annually (Hollander et al., 2009), HRSDC reports that only 5,978 successful claims were made during the 2009/10 fiscal year (HRSDC, 2010). One reason for the limited uptake is that those who are working part-time, are employed seasonally, or are unemployed are eliminated due to the

eligibility criteria, thereby excluding many family caregivers. The design of the program itself is also thought to reinforce low uptake through lack of appeal to caregivers for a number of reasons, including that: support lasts for only six weeks, recipients must go through a two-week waiting period before benefits are initiated, and it is difficult to accurately prognosticate death within a 26-week window (Armstrong & O'Grady, 2004; Osborne & Margo, 2005; Williams et al., 2010). Aside from program-specific features, there exists a more critical obstacle to the CCB's successful uptake: the general lack of public awareness regarding the existence of the program (Canadian Cancer Society, 2008; Giesbrecht et al., 2009; HRSDC, 2007). Specifically, family caregivers are routinely not gaining access to information about the CCB program.

Considering that family caregivers, and particularly end-of-life family caregivers, play such a significant role in Canadian society, it is imperative to seek strategies that minimize or alleviate inequitable caregiver burden and the potential negative physical/mental/emotional health, employment, and financial outcomes it bestows, especially upon those who are most vulnerable (Canadian Caregiver Coalition, 2009; Canadian Policy Research Networks, 2009). However, the diversity and differing vulnerabilities that exist within the caregiver population are rarely recognized in existing research and associated health and health-related policy. This signals the need for a re-framing of how we view caregivers and caregiving needs more generally, in order to develop effective policies and programs that recognize difference and account for inequities within this group. In relation to the CCB, what remains unexplored is how family caregivers' differing social/physical locations may be informing the underutilization of the program, or may be exposing specific groups to harsher uptake barriers than others. In this article, we pose the question: for whom is this program *not* working? We address this question through undertaking a diversity analysis that highlights how particular axes of difference may ultimately inform family caregivers' use of the CCB. More specifically, our objective is to examine family caregiving at the end-of-life in Canada from the perspective of formal front-line palliative care providers (e.g.,

community nurses, social workers) in order to gain a better understanding of the axes of difference directly impacting family caregivers' support opportunities, access, and outcomes. Front-line palliative care providers' employment allows them on-going access into the lived realities of numerous families experiencing death and dying. As such, they hold a broad and valuable experiential perspective from which to comment upon the general differences they observe between the family caregivers they interact with in their work. The results of our analysis are used to understand the implications of caregiver diversity for the CCB and also the need to re-frame how caregivers and caregiver needs are understood and acted upon in health and social policy more generally.

### **2.3. Methods**

This analysis contributes to a larger evaluation study that aimed to gather the perspectives of the CCB program's key stakeholder groups, namely family caregivers, front-line palliative care providers, and human resources personnel, in order to offer policy-relevant recommendations for program improvement. The overarching methodology of the evaluative study is Patton's (1997) utilization-focused evaluative approach, which aims to inform program improvements through the use of research findings with a specific emphasis upon "*intended use by intended users*" (Patton, 1997, 20, emphasis in original). Examining diversity within the caregiver experience was not an original objective of the CCB evaluation study, but rather emerged as an important issue from the evaluation study findings. Although family caregivers were interviewed for the larger evaluation, in this analysis we draw on interviews with front-line palliative care providers because they were able to 'step-back' from offering an experiential account of caregiving and comment more broadly on trends observed among those family caregivers they have worked with. These observations were informed by their

employment, which offers them intimate access to lived realities of families experiencing death and dying.

### **2.3.1. Data collection**

Fifty front-line palliative care providers were sought to participate in phone interviews from across Canada, ten from each of five provinces chosen to reflect Canada's linguistic and regional diversity: British Columbia, Manitoba, Ontario, Quebec, and Newfoundland and Labrador. We purposely aimed to include participants from an array of workplace settings (e.g., administrative, clinical, home care) and occupational groups (e.g., nurses, physicians, social workers) in order to garner as much diversity in employment sectors as possible. Participants were required to be formal palliative care providers working in one of the target provinces whose employment placed them in *direct* contact with end-of-life family caregivers and/or care recipients. Prior to data collection, ethics approval was granted by the research ethics offices at Simon Fraser and McMaster Universities.

The recruitment strategy involved widely disseminating an information letter written in English and French that summarized the study purpose and participant inclusion criteria. The letter was sent to a number of palliative and hospice organizations in the target provinces asking them to share it with their own employees and other organizations in their networks. Interested potential participants were asked to reply by e-mail or call a toll-free number to schedule an interview in either English or French at a time convenient for them.

Semi-structured interviews were conducted via telephone by the first author. Generally, the interviews lasted 30 minutes and inquired into: the CCB's usefulness; its barriers and facilitators to access; experiences of recommending the CCB to potential applicants; and suggestions for program improvement. Prior to the interview, interviewees were informed of their rights as participants in a research study and

provided their verbal consent. In total, 48 English- and two French-language interviews were conducted ( $n = 50$ ), which resulted in 10 participants for each of the five provinces. Participants came from a variety of occupational groupings and work settings, as shown in Table 1. Thirty-seven held full-time employment, 12 worked part-time, and one had retired one month prior to the interview. Participants' years of experience working in palliative care are shown in Table 2.

**Table 2.1 - Front-line palliative care provider participants by occupational grouping**

<b>Occupation</b>	<b>Number of Participants</b>
Social Worker	11
Palliative Care Director / Coordinator	9
Clinical/Oncology/Palliative Nurse	7
Community Health/Home Care Nurse	7
Oncologist/Physician	6
Chaplain/ Pastoral Care	2
Counselor	2
Volunteer Coordinator	2
Facility Patient Care Manager	1
National Nursing Officer	1
Nurse Coordinator	1
Occupational Therapist (Home Care)	1
<b>TOTAL</b>	<b>50</b>

**Table 2.2 - Employment experience of the front-line palliative care provider participants**

<b>Years of Employment Experience in Palliative Care</b>	<b>Number of Participants</b>
Less than 1 year	5

1 to 5 years	16
6 to 10 years	12
11 to 15 years	5
16 to 20 years	5
Over 20 years	6
Total	50

### **2.3.2. Analysis**

Forty-nine interviews were digitally recorded and transcribed verbatim, and one was recorded through note taking due to this participant’s preference to not be recorded. Transcripts and notes were entered into NVivo7™ data management software and thematic analysis was conducted. Thematic analysis involves identifying dominant emergent themes in the data that are then used as categories for analysis (Fereday & Muir-Cochrane, 2006). Emerging from the larger evaluative study findings was the main theme of ‘diversity’ among caregivers and caregiving experiences. Thus, a secondary analysis was performed upon the front-line palliative care provider data set using a critical diversity method.

To enact a critical diversity analysis we first developed a coding scheme that integrated both inductive and deductive perspectives informed by Hankivsky, et al.’s (2009) definitions of social categories. Our six-step process of coding involved: (1) reviewing three randomly selected transcripts to identify initial themes regarding diversity; (2) drafting a full coding scheme; (3) revising the full coding scheme following further transcript review for confirmation; (4) coding five transcripts; (5) reviewing coded transcripts in order to refine the scheme (e.g., collapsing redundant themes); and (6) coding the entire dataset with the refined scheme. In order to enhance consistency of interpretation, multiple investigators were involved in implementing the six-step coding process, as well as in reviewing the associated coding extracts that were used to inform the present analysis.

Our critical diversity analysis draws upon the emergent inductive codes of ‘culture’, ‘gender’, and ‘geography’, among others, as well as a number of deductive sub-codes such as ‘family caregivers – differences in – culture’ and ‘family caregivers – differences in – gender’. Reviewing these particular coding extracts, we determined as a group the scope, limitations, and interrelationships within and between each axis of diversity, creating an interpretive framework for understanding how each was understood by the interviewees. Our approach to doing this was informed by Young’s notion of seriality (Young, 1994), which disrupts the notion that ‘groups’ are to be organized by single-dimensional characteristics (e.g., women), and emphasizes that people are individuals in a ‘series’ with their positioning based on various sets of material and immaterial social constructs. In addition to this, our analysis was also informed by the intersectionality work of Hankivsky et al. (2009), which requires consideration of simultaneous interactions between different aspects of social identity as well as the impact of systems and processes of oppression and domination. Our approach of intersectionality used in this analysis is grounded in lived experiences, while providing a theoretical foundation for the pursuit of social justice. Importantly, we did not begin with predetermined categories of difference that were of interest to us, but instead relied on these axes to emerge from the data through undertaking the coding and analyses processes. Following our consensus regarding the interpretation of various axes of difference that emerged, we moved to identify ways in which these particular diversities matter for the CCB specifically and other caregiver support programs more broadly.

## **2.4. Results**

Thematic critical diversity analysis revealed five axes of difference that were commonly raised by front-line palliative care providers when discussing end-of-life family caregivers: (1) culture; (2) gender; (3) geography; (4) lifecourse stage; and (5)

material resources. While there is no doubt that other significant differences exist among family caregivers that directly influence their experiences of providing care, such as sexual orientation, (dis)ability, and health status, they were not explicitly discussed by the participants and so are not examined here. It is important to emphasize our recognition that such axes of difference are not static containers, but are fluid and dynamic, varying across time, place, and especially context (Hulko, 2009b; Siltanen, 2006). Furthermore, we also recognize that lived realities are highly complex and ‘differences’ are inherently constructed, relational, and interconnected (Dolan & Thien, 2008; Hankivsky, 2005). However, we believe that a critical starting point to addressing inequities lies in determining *what* differences exist and *how* they impact experiences of family caregiving at end-of-life. As such, in the following subsections we discuss our findings of each of the five axes of difference, which are defined in Table 3 in detail. In the discussion section we then move to consider these axes in relation to one another, and how their intersection may heighten the barriers family caregivers face in utilizing the CCB program.

**Table 2.3 - Operating definitions employed in the diversity analysis**

Axis of Difference	Operating Definition
Culture	the totality of the ideas, beliefs, values, knowledge, and way of life of a group of people who share certain historical, religious, racial, linguistic, ethnic and/or social backgrounds
Gender	the manner in which a society defines and constrains the array of socially constructed roles and relationships, personality traits, attitudes, behaviours, values, relative power and influences based on a differential basis of being a ‘woman’ or ‘man’
Geography	the physical and social places in which various activities happen that are shaped by actions, processes, and other powerful happenings occurring both within and beyond them
Lifecourse Stage	the sequence of socially defined events and roles that individuals enact over the progression of their life from birth to death

Material Resources	the tangible goods and consumables and the means by which they are purchased, wherein an absence of these resources can result in material deprivation
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### **2.4.1. Culture**

Our findings indicate that front-line palliative care providers perceive cultural differences to play a major role in influencing experiences of family caregiving at end-of-life, especially when personal beliefs contrast with the clinical culture of the Canadian health care system. For example, an occupational therapist noted that in her region *“a lot of our doctors are not from the area or even from Canada, so I guess the biggest cultural barrier is between the doctors and the patients themselves.”* Participants discussed how families from various cultural groups can have differing understandings, priorities, and/or needs, thus requiring additional support in order to achieve quality end-of-life care. As an example, a palliative care coordinator explained that she had worked with a family of Chinese heritage who did not want a death to occur in their home as this was believed to negatively affect the value of the home, both spiritually and financially. In this case, cultural preferences had informed decisions regarding the place of care and ultimately death.

Generally, participants believed that caregiver supports (e.g., psychosocial, religious, spiritual, bereavement) needed to accommodate families from differing cultural backgrounds as much as possible. Emphasizing the complexity of this task, however, a palliative care nurse remarked *“[t]here’s lots to recognizing the different cultures and how different people approach dying, how they want their family members to approach it. [But] do they [care recipients and family caregivers] ever want to talk about it?”* Lack of discussion about cultural needs may result in some family caregivers not having access to needed supports. For example, several participants explained that First Nations or Métis family caregivers and care recipients should always be asked if

they have any spiritual and cultural needs related to end-of-life or family caregiving, such as performing a sweet grass or smudging ceremony<sup>3</sup>. The challenge here, however, is that front-line providers must first be able to discern which families are First Nation or Métis in order to ask them if they would like such supports. One's cultural heritage, however, may not always be easily recognizable; therefore, such an approach relies heavily on self-identification (i.e., explicitly presenting oneself as First Nations or Métis to others). As self-identification may not always be appropriate or desirable, First Nation or Métis may face barriers in accessing supports that meet their cultural needs. As per the definition of culture used for this analysis, language is one of the many various cultural components discussed by participants. Participants raised language as an important issue in the experience of caregiving, specifically with regard to language barriers and caregivers' abilities to access necessary information and supports. These comments were often raised with regard to newcomers to Canada, where participants stressed that not being able to communicate is a major barrier to determining caregiver needs. A social worker explained that: *"the challenge sometimes is getting someone who speaks English [in the home]. And sometimes the ones who do speak English are working, while it's the sister-in-law or the daughter-in-law, the one that's providing all the care, that doesn't speak English, so we use translators a lot."* However, communication through a translator was seen as problematic, especially if information was being *"filtered"* through another family member because details may become exaggerated upon or simply left out. It was also noted that language barriers can create major informational needs and thus increase the risk of caregiver burnout and stress as these caregivers can be hesitant to seek out the help they need.

<sup>3</sup> Smudging ceremonies involve the burning of clipped herbs, such as sweet grass, sage, or cedar to create a smoke that can be lightly brushed over one's body. This is done to cleanse one, both spiritually and physically, of any bad spirits or negative energy.

#### **2.4.2. Gender**

Traditionally, and still today, the role of family caregiver is largely ascribed to women. Unsurprisingly, participants confirmed this as a clear observation from their work experience<sup>4</sup>. Some participants, however, stated that they have noticed a recent increase in men taking on caregiving responsibilities, though not necessarily as the primary caregiver. As a social worker explained, “[t]he reality is that there is a gender bias still in our society, so women are still primarily the family caregivers, they’re primarily the child-rearers. There are many, many men who are doing those things, but women are still primarily in that role.” Participants widely agreed with this view, explaining that they perceived societal expectations to still fall more heavily upon women to provide care within the home, thus resulting in the majority of the family caregivers they interacted with being women. In some situations, participants also observed women who were not immediate family, for example a daughter-in-law or sister-in-law, providing care, which further demonstrates the extent of gendered implications associated with caregiving expectations.

Although it was clear that participants were cautious to convey gendered generalizations, some did believe that differences existed between men and women with regard to caregiving styles. For example, this community health care nurse explained that:

*Female caregivers are more in tune to the person’s physical needs, whereas male caregivers tend to get very organized and business-like about it. You know, they’ll pull together little flow-charts and books and sort of stand back and let me deal with the things like bowel care and hygiene... I find that men have a really hard time with that personal care aspect.*

<sup>4</sup> An analysis that offers further discussion on some of the geographic and gender differences highlighted in this article can be found in Giesbrecht et al. 2010.

Given such observations, it is not surprising that some participants raised gender-specific caregiving needs. These participants felt that it was men, rather than women, who required extra support in order to successfully fulfil their role as a family caregiver. For example, a palliative care coordinator stated that in some cases, challenges arise when a woman who has always taken care of everything in the home is dying and in need of care *“and the husband doesn’t have a clue how to, you know, do anything...”* This sentiment was echoed by a home care nurse who stated that sometimes *“[m]en...looking after women, where the woman has been the manager of the house, need a lot more information on managing home situations than a woman might.”* Considering these findings, it becomes apparent that gender and gendered expectations regarding behaviour play a role in determining caregiver support needs.

### **2.4.3. Geography**

Several front-line palliative care providers discussed the impact that geographic differences have on the experience of family caregiving at end-of-life. Specifically, they felt that where one lives determines access to services. The most prominent differences were raised by participants working in Newfoundland and Labrador<sup>5</sup> who believed that the relatively isolated location of this lightly populated province created unique challenges for families in terms of accessing end-of-life care supports compared to the rest of Canada. Several participants from this province explained that a rapidly aging population, in conjunction with the increased outmigration of the youth, has left few able bodied family caregivers to draw from for support. As an oncology nurse remarked:

*[t]he situations in our province, they [caregivers] thin out quite a bit because of migrations, and smaller family size and that kind of stuff. We have a lot of people living in smaller areas who really have nobody around them now. Or the people around them are very elderly and no better off themselves, or able to care for the person who's dying.*

<sup>5</sup> Newfoundland and Labrador is a province of Canada located on the Atlantic Coast.

Those participants working in rural communities throughout Canada also identified unique challenges for caregivers associated with low populations residing across vast distances, which results in fewer resources being made available and long commutes to access needed supports. Participants from rural communities also commented on the extra costs family caregivers from these areas must endure in order to travel to-and-from urban centers to access supplies and services.

Another geographic difference that emerged from the interviews involves the place where care and ultimately death occurs, such as the hospital, hospice, or home. According to participants, the preferred place of care and death was said to differ according to each family's wishes, though generally family caregivers preferred to have the care recipient stay at home for as long as possible. Regardless of these preferences, it was noted that decisions regarding the location of care were almost always made based on the level of access to supports and the resources caregivers had to draw from. However, because of a lack of access to needed supports and resources within the home, participants felt that some family caregivers are left with no option but to move care recipients to formal settings such as a hospital palliative unit. Especially approaching the very end-of-life, participants expressed that continuous support is required and thus family caregivers who do not have resources or access to supports will need to cease providing care in the home. A palliative care coordinator explained that *'...as a healthcare professional...I think there would be a lot more caregiving going on in the homes if we could support more people to caregive for their family.'* As such, one's geographic location in relation to supports and services plays a critical role in enabling care provision in certain environments, such as the home.

#### **2.4.4. Lifecourse Stage**

Participants made a number of comments indicating that where a caregiver was situated in his/her lifecourse, versus her/his specific age, significantly impacted the

types of supports required by family caregivers at end-of-life<sup>6</sup>. Participants stated that care recipients are generally elderly, over the age of 80, and that it was common to find spouses providing end-of-life care, resulting in what one nurse explained as “*seniors taking care of seniors.*” Explicitly commenting on the differences in stages of the lifecourse among family caregivers, one social worker stated that:

*...if they [caregivers] are seniors...you're going to be dealing with perhaps a caregiver who has health problems too and so may not have the physical stamina or ability to give intensive care...if the person [care recipient] has a high care need, it may be overwhelming to the spouse.*

On the other hand, it was sometimes mentioned that because elderly spousal caregivers are typically retired or career homemakers, they are viewed as ideally situated to provide care because there will be no disruption to employment or income levels.

Although many end-of-life family caregivers were thought to be elderly, several participants explained that it is not uncommon for children to take on the role of caregiving for dying parents. This was thought to be concerning if the daughter/son caregiver also had a family with young children of their own to care for. It was explained that family caregivers who find themselves in this ‘sandwich generation’ are likely to experience conflicting familial roles, which results in particular challenges, stresses, and support needs, such as child care. Concerns were also raised regarding family caregivers from younger families where one spouse is at the end-of-life and the other is providing their care. Again, participants explained that this scenario is incredibly challenging for families where young children are involved. A broad concern regarding these lifecourse-related scenarios is that younger families were thought to be more vulnerable financially than older ones: “*...with a younger family, if one of the spouses is the one*

<sup>6</sup> Although age is often related to one’s experiences at various stages of the lifecourse, social experiences are not biologically determined by age, hence our decision to use lifecourse for this axis of difference.

*who's dying and is unable to work, and it has been a two income family, that's a huge impact on the family if they're losing one income."* As a result, younger families are said to require more support in terms of financial and job security: *"Especially our young families, they need to know that they are going to have job security, and resources, financial resources for the time period that they're going to be off [from paid employment to provide care]."* The provision of such security is muddled by the fact that caregiving at end-of-life rarely follows a predictable trajectory.

#### **2.4.5. Material Resources**

Although 'socio-economic status' is an axis of difference often highlighted in diversity analyses, in this study participants' comments pertained mostly to the specific circumstance of access to material resources rather than the broader category of socio-economic status. Many front-line palliative care providers emphasized how variations in families' access to material resources, such as income, equipment, medication, and formal respite and home care support, resulted in dramatic differences in the caregiving experience. As one social worker said, *"we say that homecare is universal [in Canada], but it's not really universal. It's based on your finances and what you're able to provide in terms of concrete help..."* There are many extra financial costs associated with providing care for a dying family member in the home, such as making home renovations and purchasing, renting, and/or installing medical equipment. A palliative home care nurse commented on these costs:

*I think that caring for someone in their own home is expensive. And I don't think we look into that enough, because...they've [caregiver] taken time off from work, they don't have an income, and then they've got all these extra things that they have to get. They have to buy a walker; they have to get a wheelchair – none of that is something that we provide.*

Participants were particularly concerned about families who do not have private medical insurance and therefore are required to pay in full for needed supplies and

other items, which in some cases places families in great financial stress. An oncology nurse shared one of her experiences of working with a family that experienced financial hardship as a result of caregiving responsibilities:

*...I saw that disease destroy, financially ruin, people. Because before they were diagnosed with the disease, they had a bit of money. They were...middle class people with a little bit of money in the bank. And by the time the person affected with the disease ended up dying, the family had nothing left... When the person died, they couldn't afford to take the body home...and that was the only time they received a bit of help, was when they had to go to social services to get the body home. It's devastating.*

Participants pointed out that financial pressure may place increased stress on family caregivers, thereby negatively affecting their health.

Some family caregivers' inability to access material resources, particularly medications, respite care, and transportation, results in inequitable care outcomes. For example, a palliative care coordinator said that *"quite often patients are suffering because they [caregivers] don't have the money to buy medications."* Such a situation may not only be disheartening for the care recipient, but also the caregiver who is unable to manage pain and relieve distress. Access to in-home respite support was also believed by many participants to be a resource that greatly affected caregivers' abilities to manage their role through mitigating the risk of caregiver burnout. With regard to family caregivers' need for respite support, a social worker stated that *"if we're sending people [care recipients] home with the expectation that they're having 24 hour care, it's only realistic if that person [family caregiver] gets some time to breathe as well."* Many participants commented on how unavailable this support generally is for Canadians, not only due to costs, but also to geographic issues whereby in many rural and remote areas respite support is simply not an option. Furthermore, access to transportation was discussed as being a material necessity for family caregivers in order to take care-recipients to appointments. However, not all caregivers have reasonable access to

transportation, let alone a vehicle that can accommodate the space and comfort requirements of a care recipient.

## **2.5. Discussion**

Our analysis of 50 interviews with front-line palliative care providers reveals that acknowledging diversity among Canadian family caregivers is an important aspect of understanding the caregiving experience. Apparent is that front-line palliative care providers observed cultural, gendered, geographic, lifecourse stage, and material differences between family caregivers, shaping the types of experiences caregivers have as well as the supports they have access to. These axes of difference also reveal segments of the caregiver population that may be particularly vulnerable to experiencing inequities with regard to accessing needed services and resources. These groups include non-English or non-French-speakers, cultural minorities, rural residents, employed caregivers who are women, caregivers who are men, caregivers with young children, and those who do not have or are unable to purchase meaningful material supports. Given that having adequate access to services and resources serves to lessen exposure to caregiver burden (Grinfeld et al., 2004; Sharpe et al., 2004), it is quite likely that these groups also have increased risk of negative health outcomes as a result of taking on a caregiving role. Furthermore, vulnerability to caregiver stress, burden, and negative health outcomes may be amplified for those whose lived reality overlaps *multiple* segments of these particular population groups. Without considering diversity, such patterns in vulnerabilities and inequities would simply be overlooked, and ultimately, continually reinforced (Hankivsky et al., 2009).

### **2.5.1. *Implications for the CCB***

From a policy perspective, this analysis demonstrates why diversity needs to be acknowledged in policy circles, including in relation to the CCB, and seeks to counteract

single dimensional approaches for understanding family caregiver needs at end-of-life that simply cannot account for inequities. As noted above, the objective of the CCB program is to provide employment security with basic financial assistance for eligible family caregivers during the last eight weeks of a care recipient’s life. A number of implications emerge from the findings of this critical diversity analysis for the structure of the program and the way in which it is administered. Importantly, in reviewing these implications, summarized in Table 4, it becomes clear that the solutions for improving supports for end-of-life family caregivers in Canada do not rest solely on adjusting the CCB program. Due to the complexity of death and dying, there is a need for multiple governmental sectors (e.g., Medicare, employment insurance, family allowance) to become involved in better supporting end-of-life family caregivers at multiple levels (e.g., local, provincial and national) in order to address the complex needs of families experiencing death and dying. This multi-sectoral approach, however, requires coordination, a shared vision, and political commitment from leaders and champions in order to be successful (Williams et al., 2010b).

**Table 2.4 - Implications for the CCB program**

Axis of Difference	CCB Implications
Culture	<p><i>Language:</i> Limited access to information on CCB outside of English and French</p> <p><i>(New) Immigrants:</i> Linguistic and cultural barriers may limit caregivers’ abilities to complete applications forms or front-line providers’ abilities to convey program information</p>
Gender	<p><i>Eligibility:</i> Women are more likely to be ineligible for the CCB due to employment circumstances while more likely to serve as family caregivers</p>

	<i>Utilization:</i> Men are proportionally underrepresented among successful CCB applicants, which suggests that the program may not meet their needs
Geography	<i>Travel:</i> Costs for travel, local or otherwise, to provide care are not covered by the CCB program  <i>Place of Care and Death:</i> Lack of formal support may discourage potential or on-going family caregivers from providing care in the home when receiving the CCB
Lifecourse Stage	<i>Elderly:</i> Retired caregivers are not eligible for the CCB program  <i>Young Families:</i> Costs for child care support are not covered by the CCB program
Material Resources	<i>Homecare:</i> High costs to provide care in the home are not covered by the CCB program  <i>Supply Costs:</i> High costs of services and supplies for caregivers without medical insurance are not covered by the CCB

The CCB is commonly thought of as a positive step towards broadly meeting the needs of Canada’s end-of-life family caregivers (Williams et al., 2010). However, this analysis has shown that individuals who fall within this broad demographic are likely to experience barriers to accessing this support. For example, though Canada is renowned for its multicultural landscape (Citizenship and Immigration Canada, 2010), formal (i.e., government-sponsored) information about the CCB and its application forms are only available in English and French (Service Canada, 2012). This leaves front-line palliative care providers and community groups to play a significant role in informing groups such

as new immigrants and linguistic minorities about the program through websites and fact-sheets. However, interviewees clearly pointed out that informational access to the CCB can be hindered if front-line providers are unable to communicate well enough with family caregivers to assess their needs, which may result in them not informing families of the CCB's existence or assisting them with completing the application form. Here, cultural brokers and translators may be able to play a valuable role.

As we have noted above, research has repeatedly demonstrated that women are most likely to become family caregivers at end-of-life in Canada; however, it is also women who are least likely to be eligible for the CCB. In Canada, women generally make up the majority of stay-at-home parents and part-time workers and thus are less likely than men to contribute to Employment Insurance and be able to draw upon its programs (Armstrong & O'Grady, 2004). Although we might expect women to have lower uptake of the CCB, program utilization data show that they do indeed make up the majority of CCB claimants (HRSDC, 2007). These same data also show that women receive on average lower weekly benefit payments than men (HRSDC, 2011), which is a direct result of women applicants having more limited salaries. These utilization data point to an interesting set of paradoxes: while women are generally less likely than men to be eligible for the CCB due to having more limited labour market participation, they are actually more likely than men to receive the Benefit; and, while men are likely to receive greater financial support while on the CCB- due to higher salaries, they are less likely than women to actually use the program and thus may be underutilizing the Benefit relative to their labour market participation. Such circumstances create clear implications for the CCB, the solutions for which extend well beyond the scope of the program.

The interviews revealed that geography, particularly differences in access to services and the presence of family caregivers between places, is a significant axis of difference in the caregiving experience. For example, interviewees reported that

Newfoundland and Labrador's rapidly aging population and concurrent high rates of youth out-migration has generally resulted in the elderly caregiving for the elderly. This demographic trend have been well established in statistical reports (Statistics Newfoundland and Labrador, 2010). Although this region is in great need of caregiver support, the CCB as it is currently administered does not cover nor supplement the cost of travel for family members to relocate for care provision. Furthermore, at a more localized level, travel within or between communities to gather supplies and access medical appointments is also not covered by the program. Such realities may require family caregivers in these locations to use CCB program monies to offset travel costs.

Participants viewed one's lifecourse stage to greatly impact the caregiving experience, including a caregiver's need for particular types of support such as the CCB. Importantly, participants commented that younger "*sandwich generation*" caregivers are more likely to be participating in the workforce while providing care, thus heightening their financial vulnerability. As such, the CCB may be best suited for meeting some of these caregivers' needs by ensuring their jobs are secured while providing some financial assistance. Participants also explained that it was common for younger caregivers to need access to child care while providing end-of-life family caregiving. However, the CCB does not provide a child care allowance, which may result in some relying on the financial assistance of the CCB to cover child care costs rather than truly supplementing income. Because the CCB does not consider circumstances regarding the loss of dual incomes, or the shifting of child care responsibilities due to caregiving demands, working-aged family caregivers may not find the CCB to be a viable option to meet their financial needs.

Finally, many participants emphasized how variations in access to material resources, such as medication, equipment, and respite care, result in noticeable differences in the caregiving experience. Access to such resources was thought to impact caregivers' quality of life as well as decisions regarding where care should take

place. As it is currently administered, the CCB provides relatively limited financial assistance (up to a maximum of \$485 per week). This minimal level of income support has been viewed by many as major deterrent for caregivers to utilize the CCB (Armstrong & O'Grady, 2004; Crooks & Williams, 2008; Osborne & Margo, 2005). The financial costs associated with purchasing equipment, supplies, and medications can be relatively high for some caregivers, and the financial assistance provided by the CCB may not be meeting their financial support needs. Moreover, it has been found that caregiving can potentially enhance the risk of poverty as it contributes to high levels of stress and associated negative health outcomes, which in turn affects caregivers' abilities to return to paid employment (Wakabayashi & Donato, 2006).

### **2.5.2. *Intersecting Differences – A Future Research Direction***

It is important to explicitly recognize that every caregiving situation is different and that every caregiver has unique concerns and difficulties (Hankivsky, 2004). However, dominant approaches to caregiving research and policy to date have failed to adequately acknowledge issues of diversity or what diversity in the experiences of caregivers might mean for existing programs and/or services, or for advancement in policy. In this research, we have moved beyond many other studies by explicitly teasing apart the axes of difference reported on by participants and organizing them into separate categories for the purpose of conducting a critical diversity analysis. Advancing feminist thought, and keeping in line with intersectionality scholarship, however, we do recognize that these axes of difference are inherently linked, which in turn structurally shape one's social/physical location and thus influence one's caregiving experience. Reflecting this complexity, intersectional scholars (for example, see Crenshaw, 1994a; Hancock, 2007; Hulko, 2009a) observe that no single dimension of diversity or difference should be given favour but that, instead, researchers should consider simultaneous interactions between these dimensions (Crenshaw, 1994b; Hancock, 2007; Weber & Parra-Medina, 2003). In other words, it may not be a caregiver's experience as

a woman that exposes her to the most significant inequities, even though this axis tends to receive the most attention in the caregiving literature (Armstrong et al., 2008; Bondi, 2008; Dolan & Thien, 2008; Mackinnon, 2009). Rather, it may be her collective inability to speak English or French, residence in a rural community, and lack of access to appropriate medical equipment *intersecting with* gender that determine support needs and in particular, whether or not programs like the CCB are effective in meeting them. Following from the current analysis, there is a need for caregiving research to examine and articulate such intersections among axes of difference in order to adequately consider and address existing inequities as well as the underlying structures of power that reinforce them.

Our findings shed light upon some major differences that exist among family caregivers that can dramatically shape caregiving experiences and access to meaningful supports. However, this is simply the first step and this analysis serves to signal the need to further pursue this line of inquiry, including the application of social justice approaches, in future caregiving research and policy creation. Attention to diversity and inequity is slowly beginning to emerge in the caregiving literature (see Evans-Campbell et al., 2007; Ferree, 2010; Hankivsky & Cormier, 2010; Hsuing & Nichol, 2010; Minkler & Fuller-Thomson, 2005; Welsh et al., 2006). For example, in their examination of foreign domestic care workers, Hsuing and Nichol (2010) argue that the complexity of the experiences of these workers “cannot be fully captured simply by examining any single axis of their identity; it requires an examination of the intersections of race, class, and gender” (p.773). To the best of our knowledge, intersectionality has yet to be applied to the context of end-of-life caregiving. Based on our findings and the traction they hold for more general examinations of care work, an intersectional analysis shows great promise in advancing knowledge in relation to end-of-life caregiving, and in the longer term may provide evidence that will be the basis of much needed critical challenges to Canadian policy in this area, as well as policies in other countries that rely heavily on the labour of unpaid family caregivers.

### **2.5.3. Limitations**

This study has three main limitations. First, we use the perspectives of front-line palliative care providers to draw conclusions about family caregivers. Although this was done purposely because front-line palliative care providers have exposure to a range of family caregivers and can comment on this, the analysis misses out on the experiential comments that can be offered by family caregivers themselves. This serves as an important direction for future research. Second, our reliance on phone interviewing means that we were unable to observe nuances of facial expression and other subtleties that in-person interviewing allows. However, we used phone interviews because they are cost effective, particularly given our cross-country sample, and are known to yield reliable data (Chapple, 1999; Sturges & Hanrahan, 2004) and so we are not concerned that this limitation has had a negative impact on the analysis. Third, as there is no population- or national-level data that characterizes the full spectrum of front-line palliative care providers, we cannot know how representative our participants are of this health worker group. As our study is qualitative in nature, we do not actually seek representativeness to achieve overall generalizability, but rather the transferability of the findings. Given this, the lack of population- or national-level data did not serve as a true limitation in our research.

## **2.6. Conclusion**

Through conducting a critical diversity analysis, a nuanced portrait of the complex realities experienced by Canadian family caregivers within the context of end-of-life care has been revealed in this article. It is important to note, however, that this analysis considers front-line palliative care providers' perspectives, and not those of the family caregivers themselves, and so should be taken as such. Yet, front-line palliative care providers have valuable perspectives regarding the diversity of families experiencing death and dying and therefore should be considered in policy-related

caregiving research. While most research in this field does not explicitly consider diversity, that which does tends to focus on one or two pre-defined axes, such as gender and/or economic status and/or culture (for examples, Carlsson & Rollison, 2003; Kelly & Minty, 2007; Pinquart & Sorensen, 2006). While the findings of this study point to the importance of these axes, they also demonstrate that others are also of great significance in shaping the caregiving experience, such as geography and lifecourse stage. We see these findings as a critical first step in exploring what meaningful differences exist among family caregivers and how these differences impact caregiving experiences at end-of-life. We believe that understanding of these meaningful differences can inform the development of more effective and more equitable policies and supports.

In this analysis we have helped to disrupt the common policy discourse that implies family caregiving is simply a 'gendered' experience. In doing so we have provided input that not only can inform CCB improvement, but can also provide valuable insights on how policy-makers can most equitably meet the needs of family caregivers in Canada. Importantly, our findings also signal the need for a *re-framing* on how we view and categorize family caregivers and understand their needs. This involves recognizing that some groups of caregivers may be particularly vulnerable to caregiver burden or other negative health outcomes in addition to barriers to accessing needed supports. Finally, this analysis has helped to cast light upon the often invisible work of and hidden burdens experienced by family caregivers. Their effort, understanding, and compassion enables so many dying individuals to live out their final days with dignity (Canadian Caregiver Coalition, 2009). It is thus imperative for us to recognize the extraordinary effort that is made every day by family caregivers who care for dying individuals with dedication, and ensure that they are provided with all the means necessary to carry out this valuable work.

### **3. Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: A qualitative case study<sup>7</sup>**

#### **3.1. Abstract**

**Objective:** In Canada, friends and family members are becoming increasingly responsible for providing palliative care in the home. This is resulting in some caregivers experiencing high levels of stress and burden, which, ultimately, may surpass their abilities to cope. Recent palliative care research has demonstrated the potential for caregiver resilience within such contexts. This research, however, is primarily focused on exploring individual-level factors that contribute to resilience, minimizing the inherent complexity of this concept and how it is simultaneously influenced by one's social context. Therefore, this study aims to identify socio-environmental factors that play a role in facilitating palliative family caregivers' capacity for resilience against caregiver burden/burnout in the Canadian homecare context.

**Method:** Drawing on ethnographic fieldnotes and semi-structured interviews with family caregivers, care recipients, and homecare nurses, this secondary analysis uses an intersectionality lens and qualitative case study approach to identify socio-environmental factors that facilitate family caregivers' capacity for resilience. Following a case study methodology, two cases are purposely selected for analysis.

<sup>7</sup> This chapter has been submitted for publication in the journal *Palliative & Supportive Care*

**Results:** Findings demonstrate that family caregiver resilience is influenced not only by individual-level factors, but also the social environment, which sets the lived context from which caregiving roles are experienced. Thematic findings of the two case studies reveal six socio-environmental factors that played a role in shaping these palliative caregivers' capacities for resilience: access to social networks, education/knowledge/awareness, employment status, housing status, geographic location, and life course stage.

**Significance of Results:** Findings contribute to existing research on caregiver resilience by empirically demonstrating the role of socio-environmental factors in caregiving experiences. Furthermore, using an intersectional approach, these findings build on existing notions that resilience is a multi-dimensional, complex, process influenced by numerous related variables that intersect to create either positive or negative experiences. Implications of the results for optimizing best homecare nursing practice are discussed.

### **3.2. Introduction**

Family caregivers and the support they provide have become the backbone of health systems across much of the 'global north', including in Canada (Canadian Caregiver Coalition, 2009; Lilly, Robinson, Holtzman, & Bottorff, 2012). Due to policy shifts and health care restructuring, friends and family members are increasingly being called upon to provide informal palliative care in Canadian homes (Canadian Caregiver Coalition, 2011; Lilly, Laporte, & Coyte, 2007; Skinner & Rosenberg, 2005). These family caregivers typically provide physical, medical, and psychosocial care, which may result in responsibilities, demands, and stresses that are greater than some caregivers' abilities to cope (Crooks et al., 2007; Exley & Allen, 2007; Grunfeld, 2004). 'Caregiver burdens', which are the commonly experienced stresses associated with providing such care, can directly impact caregivers' physical and mental health, leading to injury, depression,

anxiety, fatigue, as well as bringing about financial problems and employment losses (Carstairs, 2005; Lilly et al., 2012; Pinguart & Sorensen, 2006). In some cases, caregiver burden leads to complete caregiver 'burnout', which occurs when caregivers become so physically, mentally, and emotionally depleted that they are no longer able to provide care, leaving the caregiver in great distress and the care recipient at risk of institutionalization (Bialon & Coke, 2012; Canadian Institute for Health Information, 2012; Lilly et al., 2012; Melin-Johansson, Axelsson, & Danielson, 2007). It is also important to recognize that stress, burden, and burnout are not experienced in the same way by all family caregivers. Instead, their onset is shaped not only by variables such as the care recipient's health status and resulting care needs, but also by complex factors such as caregivers' access to social, material, and financial resources, or, in other words, their socio-environmental contexts (Burns et al., 2010; Canadian Policy Research Networks, 2009; Carlsson & Rollison, 2003; Currow et al., 2012; Giesbrecht, 2012; Giesbrecht et al., 2012; Pinguart & Sorensen, 2006; Sharpe et al., 2004). It is thus likely that family caregivers' abilities to be resilient or act resiliently in the face of stress, burden, and burnout is also shaped by such contexts, which is what we examine in this article.

Resilience is a complex concept. Much debate exists regarding how it should be understood, operationalized, and measured (Allen et al., 2011; Bluglass, 2007; Luthar, Cicchetti, & Becker, 2000; Monroe & Oliviere, 2007). Although resilience can be thought of as a personality trait and/or outcome, it is commonly understood by scholars to be a dynamic process that encompasses positive adaptation in the face of significant adversity (Allen et al., 2011; Bluglass, 2007; Luthar et al., 2000; Masten et al., 1999). This process is often associated with a person, group, or community's capacity to prevent or overcome damaging effects (Newman, Yates, & Masten, 2004), such as coping with the physical, emotional, and financial stress associated with providing palliative care at home. A variety of factors that lead to an individual's capacity for resilience have been suggested in previous health research, for example: having mastery of one's immediate

surroundings when facing life transitions (Kinsel, 2005; Masten et al., 1999) or demonstrating self-efficacy and other similar psychosocial attributes (Allen et al., 2011; Kinsel, 2005; Masten et al., 1999).

Although personal attributes play an important role in experiences of resilience, it is not solely determined by an individual's state of mind. Achieving resilience is highly complex as this process is simultaneously being influenced by the individual *and* by the broader socio-environmental context they are situated in (Luthar et al., 2000). Although such multi-dimensional conceptions of resilience are being increasingly advocated for (Allen et al., 2011; Bluglass, 2007; Luthar et al., 2000; Monroe & Oliviere, 2007), even within the family caregiving literature in palliative care (Coon, 2012; Monroe & Oliviere, 2007), little empirical research has attempted to operationalize resilience in this way. Instead, much research focuses on the psychological characteristics of the individual, while examining only one aspect of resilience at a time (Coon, 2012; Diehl, Hay, & Chui, 2012). Therefore, knowledge remains limited regarding how resilience is achieved in real lived contexts, including by palliative family caregivers in the homecare setting. Given the desirability of facilitating positive adaptation and mitigating burden/burnout among this group (Parliamentary Committee on Palliative and Compassionate Care, 2011), obtaining such knowledge is certainly desirable.

Much palliative caregiving literature is focused on caregiver stress, burden, and burnout. At the same time, however, there is a growing awareness of the fulfilling and positive aspects of caregiving (Armstrong & Kits, 2001; Hankivsky, 2004; Lilly et al., 2012). Building on this awareness, we explore in this article the multi-dimensional aspects of palliative family caregiver resilience using a qualitative case study approach. More specifically, we ask: what socio-environmental factors facilitate Canadian palliative family caregivers' capacities for resilience against caregiver burden or burnout in the home setting? Recognizing that resilience is complex and multi-dimensional, we divert attention from the more commonly researched individual-level factors to focus here on

exploring the ways that family caregivers' socio-environmental positioning may shape their care choices, opportunities, and outcomes, and thereby capacities for resilience. Gaining an understanding of resilience from this perspective is useful to health care providers and administrators because of the increasing reliance on family caregivers and the subsequent need to understand how to support them, for example by facilitating resilience, so that they are able to fulfill this valuable role with minimal personal cost.

### **3.3. Methods**

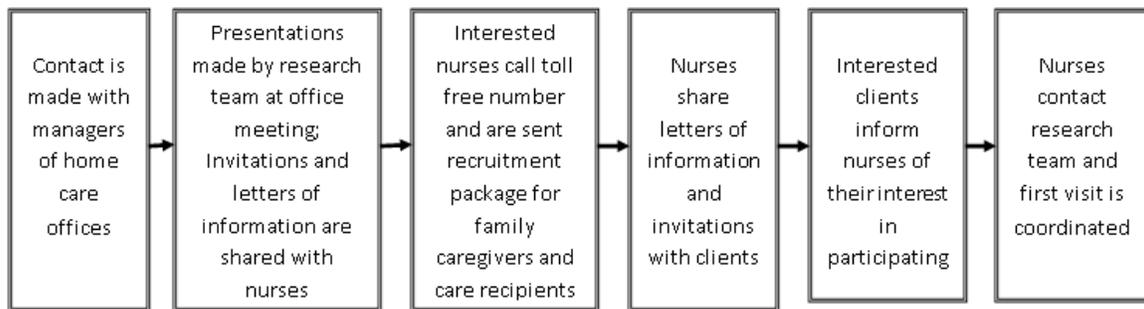
#### **3.3.1. Study overview**

This secondary analysis is drawn from a larger ethnographic study that aimed to explore how 'family empowerment' is enacted within Canadian homecare nursing in the palliative and chronic care contexts using a critical standpoint perspective (Funk, *in press*; Stajduhar et al., 2011a). Ethnographers working from critical perspectives are concerned not only with how power, social structures and ideologies constrain individual experiences, but also with how to generate practical knowledge that can influence change (Thomas, 2003). Our interdisciplinary research team was comprised of academics as well as Master's trained clinical nurse specialists who work in homecare. The team worked collaboratively throughout the design, implementation of recruitment strategies, and data collection processes.

Data collection took place from March 2010 to June 2011, during which time triads of homecare nurses and their clients (informal caregivers and care recipients) were sought to participate in the study. The recruitment strategy we followed is summarized in Figure 1. Seventeen homecare nurses from six homecare offices in the Canadian province of British Columbia agreed to participate. Participation of homecare nurses involved the recruitment of their clients for participation and having a researcher

observe their interactions in the home environment. Participating nurses were informed to recruit family caregivers and care recipients whose health, they believed, was stable enough to allow for multiple consecutive visits.

**Figure 3.1- Strategy for recruitment**



In total, 16 families agreed to participate in the study, of which 11 care recipients were palliative and six were chronic. This analysis is based upon the extensive fieldnote data collected by observing participating homecare nurses during their visits into participating palliative clients' homes. Researchers were directed in the collection of their fieldnotes through use of an observational guide. Where possible, families were observed during multiple home care visits. Additionally, semi-structured interviews were conducted with all three participant groups (homecare nurses, family caregivers, care recipients) and transcribed verbatim.

Overall, there were over 75 hours of observational fieldnotes and 11 interviews with home care nurses, 13 interviews with family caregivers, and 3 with care recipients. Due to extremely busy nursing schedules, the unpredictability of palliative care, and the delicate and emotional nature of death and dying, we were unable to conduct interviews with all participants who were observed. For example, some care recipients were either not well enough or died before interviews were conducted, while some family caregivers declined interviews due to their emotional state after a death occurred and their desires to withdraw from the study at those times. Consent was obtained from

all those who agreed to participate in the study. Prior to data collection, ethics approval was obtained from university and health authority ethics boards.

During observations, and primary analysis of the larger study, it became apparent that resilience among caregivers was a major theme. As such, we set out to perform a secondary analysis that diverts from the larger study's original objectives in order to focus more in-depth on this particular theme (Heaton, 2008). The secondary analytic process began by reviewing all fieldnotes and transcripts for the palliative care triads who participated in the study ( $n=11$ ). There was agreement among the authors that various levels of resilience were evident in the data, and also that this resilience seemed to be shaped by participants' observed socio-environmental contexts. Following this, the palliative family caregiving literature about resilience and broader resilience literature was reviewed.

A qualitative case study methodology, which is well suited to investigate complex multi-dimensional issues, such as resilience, at greater depth was employed (Hammersley, 2007; Stake, 1995). Case studies aim to capture the uniqueness and complexity of a single case *within its context* to gain a better understanding of lived experience (Hammersley, 2007; Stake, 1995; Winslow, 1998). A selection process is necessary in order to determine those cases that are most representative of the research issue at hand (Stake, 1995). Thus, through review of the eleven palliative cases, the authors collectively confirmed that two particular cases were best suited to provide evidence for resilience. Existing resilience literature was used to guide us in selecting these two palliative care case studies. Two case studies were selected not only because together they captured most of the indicators of resilience found across the sample, but also because using two cases would allow for comparability and the opportunity to explore thematic findings among both lived socio-environmental contexts.

### **3.3.2. Analytic process**

The fieldnotes and interview transcripts associated with the two selected case studies were reviewed in-depth using an ‘intersectionality lens’ to identify aspects of the socio-environmental context that were observed to facilitate resilience. An intersectionality lens acknowledges that human lives cannot be reduced to a singular category or social location (e.g., being a woman), instead recognizing that real lived experiences are more complex. Thus, intersectionality aims to explore the simultaneous interactions and combined impacts of *multiple* social locations and structural processes (e.g., gender, race/ethnicity, class, etc.) on the creation and perpetuation of health inequities (Hankivsky et al., 2009; Hankivsky et al., 2011). An intersectionality approach does not use predetermined variables for analysis, but rather encourages critical reflection to move beyond the common gender/race/class triad used in much health research today (Hankivsky et al., 2012). Thus, intersectionality not only aims to identify what multiple variables are important, but how they relate and interact within specific contexts (Hankivsky et al, 2012). As such, this approach is well suited to explore complex lived experiences of resilience among palliative family caregivers using a case study approach. Coding was informed by an intersectionality lens and undertaken using NVivo™, with data pertinent to emerging socio-environmental factors being extracted from the transcripts and stored in code files. The coded data was then reviewed extensively and themes regarding socio-environmental categories were identified. These findings were then compared to the existing resilience literature to assist with interpreting their significance.

### **3.4. Findings**

Observations of both palliative care triads focused on here spanned multiple homecare visits (case study 1=4 visits; case study 2=5 visits). Most visits occurred with the care recipient, family caregiver, and home care nurse being present. Separate one-

on-one interviews were conducted with the family caregivers and home care nurses in each case. Interviews with the care recipients, however, were not conducted as death had occurred prior to their participation in this aspect of the study. In the next section, the two case studies are presented, drawing together the interview and observational data collected, while focusing on the caregiver. Following this, the findings from our thematic analysis are presented. In order to protect anonymity, pseudonyms are used throughout and some identifying details have been altered. Verbatim quotes are italicized.

#### **3.4.1. Case Study #1 – Julia’s context**

Julia was a 64 year-old English-speaking Canadian citizen, and was the primary informal caregiver for two very close friends of hers, Alex (96 years old) and his wife Grace (85 years old). Alex was dying of prostate cancer and had deep vein thrombosis in both of his legs. His wife Grace had carotid stenosis, a pacemaker, and was beginning to experience symptoms of dementia. Julia was not related to Alex or Grace, but had developed a deep relationship with them through her husband William. At a young age, William had lived with Alex and Grace. Growing up in their household, they developed a strong relationship whereby he thought of them as his parents and they thought of him as their child. Alex and Grace owned a moderately sized, three-bedroom detached home in a community situated at the edge of an urban area. Their neighbourhood was relatively quiet, with roads densely lined with large trees and other moderately sized family homes. Their house was located close to services and amenities, enabling convenient access to their material needs. The house was also built with a basement suite, which allowed Julia and William to eventually move in to provide Alex and Grace’s care.

The development of Julia’s caregiving role evolved rather slowly, over a period of five years. It began in 2006, when cognizant of her mother’s dementia, Alex and Grace’s

daughter asked Julia to begin accompanying Grace to her doctor's appointments in order to keep her better informed on what the doctor had said and her mother's condition. Julia was well positioned to take on this role as she held a high level of informal medical knowledge due to her mother, aunts, and uncles all being public health nurses or medical doctors. She also owned a vehicle and her part-time employment provided a great deal of flexibility, allowing her to work mostly from home. Although Alex and Grace had four adult children of their own, three were unwilling to take an active role in their parents' caregiving due to living out of province, other existing personal commitments, and/or personal preferences. Only their one daughter, Maria, who lived out of province, provided some long-distance care and support.

Recognizing Grace's need for direct personal care, Julia became the primary caregiver with her husband William's assistance. Although Julia provided personal care for Grace and assisted with tasks such as medical management, William assisted Julia with cooking and cleaning for Grace and Alex and helped to drive Grace to-and-from her medical appointments. However, this support was relatively sporadic as William's employment frequently took him out of town for long periods of time, leaving Julia to cope on her own. Two years later, in 2008, Alex fell ill so Julia and William began accompanying him to his doctor's appointments as well. When Alex was diagnosed with prostate cancer and developed kidney failure, Julia also became his primary caregiver, administering his medication and providing physical care. At this time, Julia began receiving formal nursing and community support to provide care in the home. It was observed that Julia had a heightened ability to handle the complexities surrounding frequently fluctuating medications and schedules, especially considering she had to administer medications for both Grace and Alex. During homecare nursing visits, Julia further demonstrated her capability by frequently reporting to the nurse how she was independently identifying and responding to particular medical issues as they emerged. Rather than feeling overwhelmed with this aspect of caregiving, Julia responded well and commented that she felt confident in her abilities and had a natural propensity for

learning about and managing complex systems, stating *“I’m interested in how it works”*. However, caring for both Alex and Grace, the demands of Julia’s caregiving role escalated to the point that Julia and William decided to move into the basement suite of Alex and Grace’s home in order to be better situated to provide full-time care.

While Alex and Grace’s health declined, Julia’s caregiving demands increased substantially. Although they received formal home support each day, Alex and Grace required care 24 hours a day. The home support hours the family received allowed Julia time to contribute towards her paid employment. Thus, when Julia was not formally working from home, she was caregiving and had little to no respite time. Julia had remarked that she *“was getting more and more stressed because [she] was trying to cope inside this schedule with no help from family members.”* However, recognizing her need for more support, Julia contacted Alex and Grace’s daughter Maria, who responded to Julia’s call for help by providing more support over the phone and also making trips with her husband to directly assist with physical care.

Complex family dynamics created a taxing environment for Julia to carry out her caregiver role. Julia described Alex as being *“very difficult to deal with”*, and as such, his children, with the exception of Maria, were reluctant to become involved with the physical aspects of providing his care. Each of his children did, however, often voice their differing opinions to Julia regarding how this care should be provided, often resulting in strong disagreements not only between siblings but also between the children and Julia. This atmosphere resulted in a very stressful caregiving context for Julia; however, she often took these disagreements in stride, feeling confident in her own ability to make the correct decision regarding Alex and Grace’s care.

In January, 2011 Alex died peacefully at home surrounded by friends and family members, just as he had wished for. Despite the demands of caregiving and challenging family dynamics, Julia demonstrated resilience as she was able to move past the obstacles of providing care she encountered to successfully provide Alex’s care until the

moment of his death, while continually caring for Grace. Throughout her participation in the study, Julia maintained a cheerful demeanor and often enthusiastically shared examples of her ability to overcome the challenges she faced as a caregiver.

#### **3.4.2. Case study #2 – Claire’s context**

Claire was a 79 year-old English-speaking Canadian citizen, and was the primary caregiver for her husband of 62 years, Colin. Colin was 82 years old and had been diagnosed with lung cancer and had metastases to the sternum. At the beginning of their participation in the study, Colin’s prognosis was unknown, but within one week Colin was deemed palliative. Colin was also diabetic, had one artery 100 per cent blocked, and was beginning to show signs of dementia. Claire had no known health problems, aside from some hearing loss for which she had a hearing aid.

Together, Colin and Claire lived in a newly built independent living home in an urban area that had a grand entrance lined with columns and decorated with a water fountain. They had moved there a few years ago from a more rural area in order to downsize their living space and be closer to amenities as well as their daughter who lived in the city. They had four other children who lived farther away. Claire had remarked that she felt safe and comfortable living there and liked that she could walk to many of the services they needed. They had a car and Colin loved to drive; however, Claire herself never learned. Reflecting a traditionally gendered relationship, Colin looked after all finances for the household, while Claire stated that money was *“something I spend, and that’s all I know.”*

At the beginning of their participation in the study, Colin was relatively independent and administered his own medications. He was also physically strong enough to walk and move about on his own without assistance. However, within one week, he quickly became weaker and began to require assistance walking, so a walker was purchased. Homecare nursing visits became more frequent at this time, offering

Claire the medical guidance and support she needed to keep Colin at home. They purchased bath support bars and had them installed to assist Colin while he bathed.

Rapidly, Colin's strength continued to decline and he began to require assistance to stand and move. Claire began to provide this physical care for Colin, but quickly recognized that she was not physically strong enough, so called upon their son for assistance. A seasonally employed worker who had some months off, their son was able to stay with them for the time being. He conveniently moved into an apartment suite in their building that was available for guests of residents to rent. Their son helped with much of the physical lifting, while their daughter who also lived in the city would come to support Claire and help in providing Colin's care.

Although Colin eventually accepted receiving care from Claire and his son and daughter, he was a very proud man and found it difficult to surrender control. He insisted on administering his own medications for as long as possible. However, within a few weeks he became increasingly confused and his strength declined even further, so Claire took on this role. Claire became responsible for monitoring his diabetes and administering all his medications, but found this task extremely overwhelming. Recognizing her difficulty with this task, she delegated the administration of Colin's medications to their daughter. Claire continued with aspects of care that she felt more confident in providing, for example his physical/personal care and emotional support.

Within the rapid timeframe of one month, Colin went from being relatively independent to completely dependent. This resulted in a highly stressful and demanding care context, however Claire demonstrated her ability to quickly learn and adapt to the circumstances in order to ensure Colin's care needs were met. Recognizing the pace of progression of Colin's decline and Claire's intense caregiving situation, the homecare nurse asked if she wanted to be connected with a social worker for support, but Claire responded *"oh no, I have my family. I don't need that."*

After one month of Claire becoming the primary caregiver, all five children were on-site and took turns providing support for Claire and care for Colin. Together the children rented the suite in their parents' complex to take caregiving shifts. Colin expressed to his family the wish to spend his final days at home. One week later, Claire and their children successfully fulfilled his desire and provided his care until he died peacefully, surrounded by family in their home. Despite the rapid pace of Colin's decline and her high stress and anxiety, Claire demonstrated great resilience through her relatively quick adaptation to the process of her husband dying, her ability to recognize her own strengths and weaknesses, asking for help from others when she needed it, allowing her to ultimately and successfully provide Colin with the home death he desired. On a bereavement visit, Claire demonstrated she found meaning in her caregiving role, proudly stating that she was able to give Colin the death he had wanted: *"it was a very peaceful time."*

#### **3.4.3. Socio-environmental factors contributing to Julia and Claire's resilience**

Although each case conveys a unique experience, both caregivers were able to successfully care for a dying family member until their death. In each case, 'success' meant that they were able to provide care in the care recipient's desired setting (i.e., the home) up to the point of death without developing burnout, and with minimizing or mitigating signs of burden and stress. Regardless of the heavy workload and relatively minimal support received, Julia happily cared for Alex, ultimately granting his wish to have a home death, while continuing to care for Grace. Furthermore, despite the rather accelerated timeframe of Colin's dying process, Claire was able to quickly adapt and successfully provide Colin's care until the end at home, without burnout or significant burden, demonstrating resilience to this adverse situation. Both Julia and Claire's resilience was also demonstrated through their positive expressions of peace and contentment due to their abilities to fulfill their caregiving roles and give Alex and Colin

the peaceful home deaths they wished for, thus finding positive meaning within this challenging circumstance.

Although personal and individual level characteristics played a major role in Julia and Claire's capacities for resilience, their narratives demonstrate that resilience was also influenced by their broader socio-environmental contexts. Thematic analysis reveals six socio-environmental factors that were found to facilitate both Julia and Claire's capacities for resilience: (1) access to social networks; (2) education/knowledge/awareness; (3) employment status; (4) geographic location of residence; (5) housing status; and (6) life course stage. In the following sub-sections we will discuss these contexts specifically.

### **Access to social networks**

Both Julia and Claire had people surrounding them who were able and willing to offer their support and assist with some of their caregiving duties. As such, neither Julia nor Claire was isolated in their caregiving experience. Rather, after recognizing their own need for more support at particular times or with particular tasks, Julia and Claire were able to reach out to those around them for help. Julia was married and received social and emotional support from her husband William and physical direct assistance with caregiving duties when he was home from work. Julia also received support from Alex and Grace's daughter Maria, who would often phone, and near the end, traveled from out of province to offer direct support to Julia and assist with the care of her parents. Claire had her daughter, who lived in the same city, and would often come to assist with her father's care and in the end administer his medications. Claire also had the support of her son, who was able to stay with them and assist her with the physical aspects of Colin's care such as lifting and bathing. Access to this type of support was instrumental in Julia and Claire's resilience to caregiver burnout. Both Julia and Claire also had the support of homecare nurses who provided them with the medical guidance and support needed to fulfill their roles.

### **Education/knowledge/awareness**

Both Julia and Claire were English-speaking Canadian citizens who were familiar with and able to access and navigate the Canadian health care system. Having knowledge of the English language allowed them the opportunity to seek out information they needed as well as comprehend the vast amounts and often complicated written or oral information that was given to them. Furthermore, they were able to communicate easily during health care interactions, allowing them the opportunity to express their needs or concerns. Being Canadian citizens, they not only gained access to the Canadian health care system, but had experiential knowledge of how the system worked, which facilitated their navigation of it to reach and receive the care and support they required. In Julia's case, her ability to navigate the health care system was also fostered by considerable informal medical knowledge that she attributed to her mother, aunts, and uncles, who had all been public health nurses or doctors. This knowledge was further enhanced by her education and natural propensity for managing complex systems, such as the healthcare organizations involved in Alex and Grace's care. In an interview Julia described herself as being very experienced and very interested in complicated systems. Such knowledge allowed her the opportunity to make informed decisions regarding Alex and Grace's care and act on them without having to seek out professional medical guidance each time an issue emerged. Together, Julia and Claire's educated, English-speaking status, experiential knowledge of the medical system, and resulting awareness of the services and supports available to them played a major role in facilitating their resilience to caregiving burnout.

### **Employment status**

Julia and Claire's employment statuses allowed them the opportunity to be at home to fulfill their caregiving duties without experiencing any employment or financial consequences. For example, neither of them experienced the financial stress of having to take unpaid leaves from employment, or had to cope with the dual responsibility of

simultaneously providing palliative care while maintaining paid employment outside the home. Claire was retired, which allowed her the time and flexibility to be at home without concern for lost income, while Julia held part-time employment status, but was able to work mainly from home. Thus, their employment statuses permitted them with the time required to be at home without experiencing any financial and/or professional stress or consequences.

### **Geographic location of residence**

Julia and Claire both lived either in, or relatively close to, large urban areas, which means that palliative supports and home medical services were available to them – which is not the case for much of rural and remote Canada. As such, they were able to access formal homecare nursing support as well as other community-based hospice services without having to travel vast distances. Access to these supports allowed Claire and Julia to successfully provide palliative care in the home and receive the support and care *they* needed in a timely manner. Furthermore, the locations of their residences were within close proximity to many of the services they regularly used, providing Julia and Claire with convenient access to places like pharmacies and grocery stores. For Claire, such proximity allowed her access to the supplies she needed despite not being able to drive. Their geographic locations allowed for comfortable access, without having to endure the stress of travelling or commuting vast distances in order to acquire needed goods or services. Furthermore, Claire resided in an area where she felt safe and comfortable, as well as close to a park where she enjoyed taking leisurely walks, which provided her with a space conducive to reducing stress and thus an environment that facilitated her capacity for resilience.

### **Housing status**

Julia and Claire each had safe and secure housing statuses and, therefore, did not have safety concerns that other caregivers may face, or the financial stress associated with meeting mortgage or rental payments. Additionally, both caregivers

lived at the same residence as the care recipient, mitigating any potential stress associated with the financial costs of travel and travel time, as well the worry associated with a possible emergency situation occurring during their absence. This housing stability also permitted them the freedom to carry out their caregiving role in a familiar environment and the ability to comfortably take moments of respite if/when the occasion arose. Furthermore, as they provided their care in owned homes, not rental suites, they had the freedom to install any required equipment or make any structural renovations they deemed necessary to meet their needs and improve the safety or comfort of the home, for example, when Claire had bathing support bars installed in their bathroom. As such, their safe, stable, and secure housing status was supportive of their resiliency.

### **Life course stage**

Julia and Claire were both in the later stages of their lifecourse. Their lived context was one where they had no young children to care for at home. Rather, for example in Claire's case, she had children who were independent adults and provided her with support as she carried out her caregiving role. The stage in life where Julia and Claire were situated allowed them the time and energy to devote their care provision solely to the care recipients, without having to manage and balance caregiving responsibilities between the care recipient and young children. As such, they were free from the demands, stress, and responsibilities that some other younger family caregivers may face. Lastly, although in a spousal palliative caregiving relationship, both Claire and Colin were in their retirement and so did not suffer from any employment loss or financial consequences that younger families, who are still actively in the workforce and dependent upon dual incomes, may experience.

### **3.5. Discussion**

Julia and Claire's narratives demonstrate that resilience in the context of palliative family caregiving is influenced not only by individual and family variables, but also by broader socio-environmental contexts, such as: access to social networks, education/knowledge/awareness; employment status, housing status, geographic location of residence, and life course stage. Drawing upon intersectionality scholarship, it is important to emphasize that these socio-environmental factors were not experienced in isolation, but rather were relational and simultaneously experienced (Hancock, 2007; Hankivsky et al., 2011; Van Herk, Smith, & Andrew, 2011), together impacting Julia and Claire's capacities for resilience. For example, it was not simply because Julia's employment allowed her to work from home that she was resilient, but rather it was the combined effect of all six identified factors that each intersected to create her unique lived context, which in turn shaped her opportunities, access to resources, and capacity for resiliency. It is also important to emphasize that the six identified factors are themselves dynamic and interrelated (Hancock, 2007; Hankivsky et al., 2011), for example, their life course stages and employment statuses, or education/knowledge/awareness and access to social networks. It is through acknowledging these complex ways in which various factors, such as the abovementioned, intersect to shape real lived contexts that a more sophisticated understanding of caregiver resilience in the palliative context can be attained (Monroe & Oliviere, 2007).

Although much existing palliative caregiving research is focused on vulnerabilities to and risks of experiencing caregiver burdens (Bialon & Coke, 2012; Grunfeld, 2004; Sharpe et al., 2004), this study has aimed to identify those socio-environmental factors that are associated with facilitating resilience in the context of two palliative caregivers' lives. Importantly, these two areas of research inquiry are not divergent, but rather are inextricably linked in an iterative process that occurs over time

and is influenced by individual and family-level variables as well as social contexts and structures (Monroe & Oliviere, 2007). In Julia and Claire's narratives, this iterative process was illustrated through the difficult moments of stress and fatigue that were experienced during the caregiving process (e.g., Julia balancing her work and heavy care schedule; Claire with administering medications), resulting in experiences of caregiver burden. However, each woman was able to acknowledge her experienced difficulty, adapt, find a solution, and ultimately overcome the challenge in order to continue fulfilling her caregiving role. As such, their narratives exemplify how resilience is an active process (Bluglass, 2007; Monroe & Oliviere, 2007; Payne, 2007) that requires dynamic moments of adaptation throughout the complex and unpredictable dying process. The multi-level influences of resiliency were also apparent in the presented narratives. For example, on an individual level, Julia and Claire both maintained energetic and optimistic personalities, but this simultaneously intersected at a broader level with their lived socio-environmental context, which together shape their caregiving experiences and resiliency.

Generally, critical explorations of broader social contexts and structures within caregiving research are focused on issues of burden, burnout, and inequities in accessing supports, while research on caregiver resilience tends to focus on the individual and family-level variables. As such, the current analysis contributes towards addressing a significant gap in existing resilience-focused research. Our findings empirically demonstrate that resilience is not only shaped by socio-environmental factors, but is also interrelated with risks of caregiver burden found in previous studies. For example, previous studies have attributed increased risk of caregiver burden or burnout to those who are actively in the workforce and unable (financially or professionally) to take a leave of absence in order to provide care (Bialon & Coke, 2012; Canadian Policy Research Networks, 2009). Other examples include studies that have found new immigrants to be vulnerable to caregiver burden, (Stewart et al., 2006), as well as those who are in the early adult stages of the life course and have young children

to care for at home (Burns et al., 2010; Charles, Stainton, & Marshall, 2012). Therefore, our findings contribute an important dimension that is missing from such research by emphasizing that resilience is also influenced by such socio-environmental factors. Thus, these findings emphasize that resilience is dependent upon the *opportunities that exist* for caregivers to overcome challenges and develop coping strategies, which ultimately are influenced by their lived socio-environmental contexts. As such, the findings presented herein empirically contributes to contemporary theory on resilience, building upon notions that it is a multi-dimensional, complex, process influenced by numerous related variables that intersect to create either positive or negative experiences (Bluglass, 2007; Monroe & Oliviere, 2007; Payne, 2007).

### **3.5.1. *Implications for palliative homecare nursing practice***

Findings from this study suggest that informal or family caregivers of dying people are resilient despite sometimes challenging circumstances. Indeed, many caregivers in the larger study, including the two cases presented herein, demonstrated an innate capacity to ‘rise above’ the challenges of caregiving. Contemporary understandings of resiliency suggest that resilient individuals have the capacity to adapt to adverse conditions and to develop or refine coping strategies to deal with such conditions (Allen et al., 2011; Bluglass, 2007; Coon, 2012; Monroe & Oliviere, 2007). This may suggest the possibility for family caregivers to be targeted for individual-level interventions by homecare nurses that are designed to enhance caregivers’ capacities to be resilient. For instance, educational interventions could be developed by homecare nursing units to provide family caregivers with the needed skills to manage caregiving at home and to alert them to local services available for support. Knowledge of the socio-environmental aspects of resiliency could also be included in homecare nurses’ assessments of family caregivers in order to better identify those family caregivers who are more likely to live in contexts that would facilitate resiliency and those who may be more vulnerable. At the same time, there will be situations where individual or socio-

environmental adaptations may not be able to be made and homecare nurses and other providers are cautioned against assuming that all family caregivers have the capacity to become resilient.

### **3.5.2. *Limitations***

First, ethnographic data is largely based upon subjective observations (Rose, 1997; Savage, 2000a). However, our use of observational guides focused the collection of fieldnotes while conducting interviews with participants allowed for clarification of events observed, both of which added rigor. Second, this is a secondary analysis that asks a question that differs from those initially posed in the original study's objectives (Heaton, 2008). However, this analysis fits beneath the overarching qualitative/critical methodological positioning of the primary study. Also, the first two authors collected the primary ethnographic data, thus allowing for first-hand familiarity with the field contexts, which facilitated the secondary analytic process. Third, it is important to mention that the two cases do not reflect the full scope of diversity that exists among caregivers. Application of this method to a broad range of cases is necessary to further expand our understanding of the socio-environmental influences on caregiver resilience.

### **3.6. Conclusion**

This analysis advances the concept of resilience towards a more sophisticated assessment of palliative family caregiving that acknowledges the broader socio-environmental context. The case studies presented demonstrate the simultaneous interactions of multiple factors that played a role in Julia and Claire's capacities for resilience, which ultimately shaped their care choices, opportunities, and outcomes, and thereby capacities for resilience. This demonstration reveals how resilience at the socio-environmental level influences the foundation from which personal levels of resilience can be developed in the context of palliative family caregiving in the home.

The concept of resilience is receiving increasing research attention as we seek to understand the complexities of lived contexts and the ways that humans respond to difficult circumstances (Monroe & Oliviere, 2007). Future research should continue to explore the complexity and multi-dimensional aspects of resilience in palliative family caregiving. Gaining a better understanding of the critical role such factors play in the process of resilience can help to improve homecare nurses and other professionals' abilities to identify those caregivers who may be vulnerable to burnout, and also encourage the development of socio-environmental factors that lead to greater capacity for resilience. Such knowledge can be used to inform palliative programs and policies on how to better provide meaningful and equitable support for all family caregivers.

## 4. Examining the language-place-healthcare intersection in the context of Canadian homecare nursing<sup>8</sup>

### 4.1. Abstract

Currently, much of the Western world is experiencing a shift in the places where care is provided, namely from institutional settings like hospitals to diverse community settings such as the home. However, little is known about how language and the physical and social aspects of place interact to influence how healthcare is delivered and experienced in the home environment. Drawing on ethnographic participant observations of homecare nursing visits and semi-structured interviews with Canadian family caregivers, care recipients and nurses, the intersection of language, place, and healthcare was explored in this secondary analysis. Our findings reveal four themes: (1) homecare nurses view themselves as 'guests'; 2) home environments facilitate the development of nurse-client relationships; 3) nurses adapt healthcare language to each home environment; and 4) storytelling and illness narratives largely prevail during medical interactions in the home. These findings demonstrate the spatiality of language and how the home environment informs decisions regarding language use. Furthermore, these findings exemplify how language and place mutually influence the experiences and delivery of home healthcare. We conclude by discussing the importance of considering the language-place-healthcare intersection in order to gain a

<sup>8</sup> This chapter has been published as: Giesbrecht, M., Crooks, V.A., Stajduhar, K.I. (2012). Examining the language-place-healthcare intersection in the context of Canadian homecare nursing. *Nursing Inquiry*, [Epub ahead of print] doi: 10.1111/nin.12010. Copyright © 2012 Blackwell Publishing Ltd.

better understanding of medical exchanges *in places* and the associated implications for optimizing best nursing practice.

## 4.2. Introduction

Language is the mechanism by which we communicate and the means by which we convey emotion. It informs our thinking, comforts our feelings, and excites our spirits while at the same time it can rattle our nerves or shatter our confidence. Language is a powerful tool for communication, carrying the ability to shape beliefs, behaviours, feelings, and actions (Gesler, 1999; Vranceanu, Elbon, & Ring, 2011). Considering this, language plays a significant role during healthcare interactions, particularly because these meetings are critical points where health/medical knowledge must be communicated, exchanged, and transferred (Finlay, Sarangi, & Keith, 2006; O'Connor, Davis, & Abernethy, 2010; Vranceanu et al., 2011)<sup>9</sup>. Language can be used in therapeutic ways to transform patient attitudes, thereby aiding in the healing process (Gesler, 1999). Furthermore, the use of particular words by healthcare providers can affect patients' understanding of medical procedures and influence how illness is coped with. For example, powerfully emotive words like 'Alzheimer's', 'cancer', or 'palliative' used by healthcare providers can generate dramatic responses among patients, which can affect their health-related decision-making (Jonas-Simpson & McMahon, 2005; Vranceanu et al., 2011).

Barriers to developing shared understandings between healthcare providers and patients during healthcare interactions often arise due to the differences in the language used. The dominant language used in Western healthcare settings is disease-

<sup>9</sup> For this analysis, we understand language as a broad historically and culturally situated system of communication that is comprised of a variety of formalized symbols, sounds, and gestures used to convey meaning to others (Carbaugh, 2007)

directed and biomedical (O'Connor et al., 2010), which is rife with medical jargon and terms. Often, this language is not part of a patient's everyday vocabulary, and as a result can cause anxiety or confusion when used (Gesler, 1999; Roberts & Sarangi, 2005). It is also important to acknowledge the power associated with various types of language, and particularly that biomedical language used by healthcare practitioners is often constructed as authoritative within healthcare settings. This is because the biomedical model is generally considered in Western society as being rational, objective, and scientific, and therefore valued as representing truth (Gesler, 1999; Taylor, 2003). Patients, meanwhile, often convey knowledge through narratives or stories that express their personal, subjective experience (Gesler, 1999; Taylor, 2003). Thus, within biomedical interactions, formal care providers and patients are often positioned differently, with language serving to reinforce this power differential (O'Connor et al., 2010).

While language is considered an important tool used during healthcare interactions, it is also recognized to be inherently linked to 'place' (Tuan, 1991). For example, we actively create meaningful places through interactions and conversations with others, while places become the settings that shape social interactions and the ways that language is used within them (Johnstone, 2010; Stokowski, 2002; Tuan, 1991). Furthermore, contemporary definitions of place have evolved considerably in recent years. Place was traditionally understood as a fixed, bounded, and passive space where events occurred; however, today it is considered to be complex, dynamic, and fluid as people attach meanings to places through their own experiences and understandings (Bender, Clune, & Guruge, 2009). As such, place matters to our health because it shapes, and is shaped by, lived experiences and how we *feel* when we are in them (Bender et al., 2009; Milligan, 2005). Definitions of 'health' have also evolved in recent years, expanding from the biomedical conceptualizations of health being the absence of disease, to today where health is understood to encompass the state of complete physical, mental, and social well-being (Kearns & Collins, 2010). As such, we understand

'healthcare' in this article to involve not only the prevention, treatment, and management of illness, but also the preservation of mental and social well-being through the support provided by others (Milligan & Power, 2010).

Although it is recognized that language is linked to place and plays an important role in healthcare delivery, there has been relatively little research that explicates the language-place-healthcare intersection. Instead, studies in this domain have tended to focus more on exploring language-healthcare, language-place, or healthcare-place relationships (e.g., Andrews & Crooks, 2009; Carolan, Andrews, & Hodnett, 2006; Kearns, 1993; Liaschenko, 1994; O'Connor et al., 2010; Vranceanu et al., 2011). However, in 1999 Gesler shed light on the language, place, health tripartite by emphasizing how language plays an important role in the delivery of healthcare *in places*, explaining that "specific features of rooms in healthcare facilities such as the color of walls, amount of light and the arrangement of furniture, could affect what is being said and how it is interpreted" (21).

The above mentioned connections between language, place, and healthcare is becoming ever more relevant considering that in many Western nations, including Canada, the places in which healthcare occurs are becoming increasingly diversified (Andrews & Moon, 2005; Poland et al., 2005). Neoliberal restructuring has resulted in the deinstitutionalization of care, resulting in care increasingly taking place within community-based settings, especially the home (Burge et al., 2003; Lilly et al., 2007; Skinner & Rosenberg, 2005). With care increasingly taking place in the home, the responsibility for providing care is largely being given to those who live in the home, namely informal (i.e., unpaid, untrained) family caregivers, who according to the Canadian Caregiver Coalition involves approximately four to five million Canadians (CCC 2011). Importantly, in order to effectively enable care in the home on an ongoing basis, family caregivers depend upon the assistance of formal homecare nurses for technical and medical care support (Giesbrecht et al., 2009; Stadnyk, 2002; Stajduhar et al.,

2011a). Homecare nursing is a field of nursing practice that focuses on the provision of nursing care outside institutional settings (Stadnyk, 2002). Due to trends in care increasingly taking place at home, coupled with Canada's rapidly aging population, the Canadian Nurses Association predicts that 67 percent of all nurses in Canada will be working in community-based settings by 2020, compared to 30 percent in 2006 (Villeneuve & MacDonald, 2006). This will inevitably lead to an expanding range of diverse Canadian healthcare settings and an increasing shift in the patterns of healthcare provision and use (Poland et al., 2005).

Gaining an understanding of how language and care interact within community-based settings, such as the home, is significant given the expanding scope of care provision outside formal institutions and the acknowledged importance of language to healthcare interactions. We contend that such understanding can help shed light on the language-place-healthcare relationship and how it ultimately shapes health and healthcare outcomes. Specifically, in this analysis we ask: how does the place of the home influence the language used during Canadian homecare nursing interactions? Our purpose is to bring to the forefront the unique context of the homecare environment for healthcare interactions in order to optimize interventions for best practice. To do this, we undertake a secondary analysis of findings from an ethnographic study.

### **4.3. Study overview**

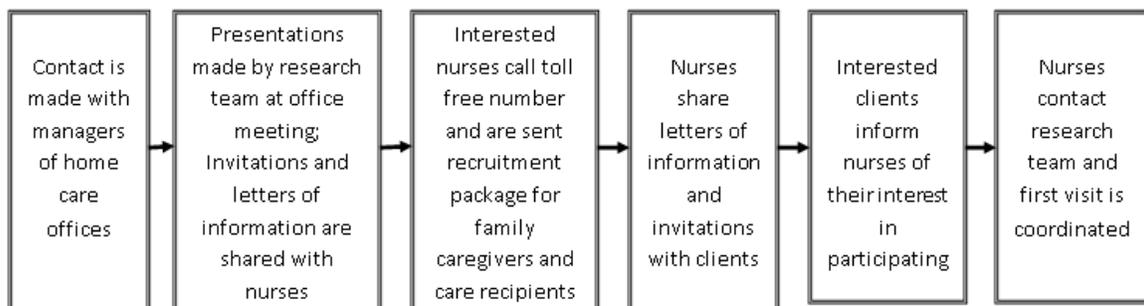
The ethnographic study from which this secondary analysis is drawn aimed to gain a better understanding of how 'family empowerment' is enacted, interpreted, and experienced within the Canadian homecare nursing context. Ethnographic methodologies are used when researchers seek to deeply understand behaviours within their own environmental context (Fetterman, 2003; Schensul et al., 1999). Ethnographers working from critical perspectives are concerned not only with how power, social structures, and ideologies constrain individual experiences, but also with

how to generate practical knowledge that can influence change (Thomas, 1992, 2003). The study design was informed by Dorothy Smith's (2004) critical 'standpoint' perspective, which advocates for linking the micro and macro processes that shape everyday experiences, situating these lived experiences into broader social, political, historical, and economic processes. Our interdisciplinary research team was comprised of academics as well as Master's trained clinical nurse specialists who work in homecare. The team worked collaboratively throughout the design and implementation of recruitment strategies and data collection. Ethics was approved by the University of Victoria.

#### **4.3.1. Data collection and participant overview**

The strategy for recruitment is summarized in Figure 1, where we sought triads of homecare nurses and their clients (family caregivers and care recipients) to participate in the study. Homecare offices in the province of British Columbia whose managers were known to the team were purposely sought ( $n=3$  offices). Participation of homecare nurses involved the recruitment of their clients for participation and having a researcher observe their interactions in the home environment. Participating nurses were informed to recruit family caregivers and care recipients whose health, they believed, was stable enough to allow for multiple consecutive visits.

**Figure 4.1- Strategy for recruitment**



The analysis presented herein is based upon the ethnographic observations and interviews that were conducted by the first author, who is one in a team of three ethnographic observers for the larger study. Thus, this analysis is based upon a sub-set of the larger study's dataset, but importantly draws upon the first author's first-hand observational experience, which allows for greater depth in the interpretation and analysis of the data. However, because this analysis is based upon a sub-set of data and asks a new question than those initially described in the original study's objectives, it is considered as secondary (Heaton, 2008). The data were collected through observing participating homecare nurses during their workday by shadowing them on visits into participating clients' homes during their homecare nursing visits. Outside of interactions with particular patients, observational time was also spent with these homecare nurses in their community offices, where participating clients' cases were often reviewed, over lunch breaks, and in car rides to and from scheduled homecare visits.

On the first visit with a new triad, a brief overview of the study was presented and questions were answered prior to acquiring consent. Then, the homecare nursing visits began and observations were hand recorded. The observations focussed on the interactions between homecare nurses, family caregivers, and care recipients in the context of the home environment. A guide was used to direct observations, which is shown in Table 1. The method for recording observations involved using a small notepad to jot down fieldnotes as inconspicuously as possible, however all participants were informed and aware that fieldnotes were being recorded. Conversations were also hand recorded as much as possible, however, during more emotionally intense interactions, the writing of fieldnotes ceased for ethical considerations. Immediately following each visit, full fieldnotes were written and organized by sections: 1) observational, 2) methodological, 3) theoretical, and 4) reflexive. Additionally, face-to-face semi-structured interviews were conducted with participating homecare nurses, family caregivers, and care recipients in order to elicit interpretive meanings of their own behaviours observed during interactions and inquire into more general issues regarding

the larger study's aim and purpose. All interviews were digitally recorded and lasted on average 20 minutes with care recipients and one hour with caregivers and homecare nurses.

**Table 4.1 - Ethnographic Observation Guide – Setting the context**

- Describe the neighborhood in which the home is positioned
- Describe the physical space of the home (use a diagram)
- Describe who is present during their encounters with one another (e.g., patient, other family members/friends)
- Describe who interacts with the family caregiver: describe if other family members/friends are present and how the home care nurse interacts with the family caregiver and with others present
- Describe where the interactions occur (e.g., in front of the patient, in the hallways, kitchen, bedroom)
- Describe the position of the home care nurse and the position of the family caregiver or others during interactions (e.g., sitting down facing each other, standing in the hallway)
- Describe the length of the interactions, comprehension barriers, who initiates/ends conversations
- Describe any non-verbal communication patterns
- Describe any physical contact between home care nurses and family caregivers (e.g., gestures of support or comfort such as touching one's shoulder)

Table 2 provides an overview of participants, which involve five family 'case' triads (including the homecare nurse; care recipient; family caregiver). Four homecare nurses visiting five families were involved, totalling 36 hours of recorded observation and seven interviews. We were unable to conduct interviews with family members in two of the five cases. In one case (Family #1), the care recipient died during participation in our study, and although a bereavement visit was observed, the family caregiver declined to be interviewed. In the second case (Family #3), the care recipient died and had no family caregiver who could be interviewed.

**Table 4.2 - Participant Overview**

Family	Homecare Nurses (HCN)	Care Recipients (CR)		Family Caregivers (FCG)	
1	HCN-01 Years as HCN: 7	CR-01	Age: 82 Sex: Male Diagnosis: Cancer Prognosis: Palliative	FCG-01	Age: 79 Sex: Female CR Relation: Spouse
2		CR-02	Age: 72 Sex: Male Diagnosis: Multiple Sclerosis Prognosis: Chronic	FCG-02	Age: 62 Sex: Female CR Relation: Spouse
3		CR-03	Age: 67 Sex: Male Diagnosis: Cancer Prognosis: Palliative	None	
4	HCN-02 Years as HCN: 7	CR-04	Age: 46 Sex: Female Diagnosis: Cancer Prognosis: Palliative	FCG-03	Age: 47 Sex: Male CR Relation: Spouse
				FCG-04	Age: not given Sex: Male CR Relation: Brother
5	HCN-03 Years as HCN: 5	CR-05	Age: 80 Sex: Male Diagnosis: Cancer Prognosis: Palliative	FCG-05	Age: 72 Sex: Female CR Relation: Spouse
	HCN-04 Years as HCN: 5				

### 4.3.2. Analysis

The important role of language and its spatiality within the context of home healthcare nursing emerged as a significant finding during the process of the first author's ethnographic observations. Following recognition of this emerging finding we

adopted an 'ethnography of communication' approach in pursuing this secondary analysis, which is a technique used to examine interactions among members of a specific community (Carbaugh, 2007). To enact this analytic technique, ethnographic fieldnotes and interview transcripts were entered into NVivo 7<sup>TM</sup> software, coded, and then analyzed thematically. Thematic analysis involves reviewing and coding data inductively and deductively to explore emergent issues through identifying patterns, which ultimately become categories for analysis. These categories and the findings held within them are compared to the existing literature or framework, which in this case involved the aims of ethnography of communication (Fereday and Muir-Cochrane 2006).

Development of the coding scheme involved reviewing three randomly-selected fieldnotes, each from different family cases, in order to identify initial themes. These themes were translated into 'codes', which were then applied to three other randomly-selected fieldnotes. Following this, the coding scheme was then refined and applied to the remaining fieldnote entries and interview transcripts. Throughout this process regular conversations were held among the investigators to confirm the interpretation of emerging themes and findings and to apply the findings to the aims of the ethnography of communication approach. It was through this process of investigator triangulation that consensus was achieved over the main themes that characterize the language-place-healthcare intersection, which are discussed in more detail in the following section.

#### **4.4. Findings**

Using an ethnography of communication framework, thematic analysis of the data revealed that language used during health care interactions in the home was spatially influenced, while at the same time the environment of the home tends to influence the language used, thus influencing the experience and delivery of home healthcare. More specifically, our analysis revealed four main themes that we found to

capture this complex connection between language, place, and healthcare in Canadian homecare nursing: 1) nurses understand themselves as ‘guests’ in the home and use language to reinforce this; 2) the social space of the home environment facilitates the development of the nurse-client relationship; 3) nurses tend to adapt their healthcare language to each home environment; and 4) storytelling and ‘illness narratives’ largely prevail during medical interactions in the home. We explore each of these findings in the following section.

#### **4.4.1. Nurses as ‘guests’**

Commonly, the homecare nurses commented about and acted as though they were ‘guests’ in the home, which shaped their language use. For example, on one homecare visit a family caregiver explicitly asked the nurse about her choice of words, as described in this observation:

*[FCG-03] said that it was interesting that [HCN-02] just referred to [CR-04] as her ‘client’. [HCN-02] said that she uses the word ‘client’ because she is “in their home” and is “a guest” and so thinks of them as her clients. She goes on to explain that in a hospital, “people become patients” and that the power dynamic is different there. [HCN-02] continued to explain that she prefers to use the word client as she is a guest in people’s homes and that it is up to them if they want to see a nurse or “shut the door.”*

In a follow-up interview, HCN-02 elaborated further by stating: *“Hospitals are patients; homes are clients... It took me a while to get used to that. But because we are in their home, we’re a guest in their home, we’re on their territory, they’ve invited us to provide care so the roles are kind of reversed”*. Such a finding demonstrates how the place of the home may allow some families greater power during healthcare interactions, which is explicitly reflected in the wording used. However, more complexly, it was also found that nurses simultaneously used their formal position to direct conversations during the visits and often came with a predetermined agenda regarding what needed to be done and what information needed to be gleaned or followed up on.

As such, it was found that the nurses' role carried great complexity as they understood themselves as both a guest and a professional and used language during the visits to reinforce this. On the other hand, this complex understanding was also reflected in the greetings and language used by families, emphasizing their roles as both 'hosts' and also 'patients'. For example, demonstrating characteristics of a host, some family caregivers offered to hang our coats or provide refreshments. On one visit, we were invited for lunch, as noted in this observation: "[HCN-01], in the kitchen, told [CR-03] that we brought his Chinese take-out. [CR-03] was absolutely thrilled... He asked us to have a seat at the table with him... We sat down and he offered us something to drink".

#### **4.4.2. Social space of the home environment**

Developing a trusting relationship with clients was indicated as important to the homecare nurses, family caregivers, and care recipients. In the home, this was often expressed through small actions of respect by the homecare nurses, which assisted in the development of this relationship. Commonly, these actions involved nurses acknowledging particular boundaries within the home, and reinforcing these boundaries through language, as noted in this observation:

*[FCG-02] told [HCN-01] and I [first author] to go make ourselves comfortable and have a seat in the living room. [HCN-01] went and sat on the large sofa and I sat next to her. [FCG-02] ran over, and waving frantically, insisted that [HCN-01] sit in a large comfy armchair, not on the sofa... [HCN-01] shook her head saying "no", and smiling said that she could tell it was her [FCG-02's] throne. [HCN-01] told [FCG-02] that she would stay on the sofa and that [FCG-02] should have a seat on her throne.*

Here the homecare nurse conveyed what she saw as a boundary demarcating the use of space in the room, particularly that between the private and public. Her choice of language also conveys recognition of power associated with these spaces by referring to the family caregiver's chair as a throne (a seat reserved for persons of power, such as a

queen). Interestingly, in the follow-up interview with this family caregiver, a number of comments were made about the homecare nurse's consistent respect in her home, relating it to quality of care: *"Yeah, well [HCN-01] is absolutely amazing because she's very very respectful of the fact that we're in our home. I mean you can tell that just by her actions... She's just on top of things. She's pleasant and I know she's got our best interests in mind."*

The homecare setting allows families to inform and convey to nurses their emotional and cognitive states through how they used space. For example, upon arrival the nurses typically asked families where or in which room they wanted the visit to occur in as they were aware that location preferences can shift in response to changes in clients' health status. Also, during emotionally tense conversations, it was observed that family caregivers had the ability to retreat into their homes, away from the care space, in order to collect themselves:

*[The son] points at [FCG-01] and told [HCN-01] "I'm worried about her"... [The son] looked at [FCG-01] and asked if she has eaten today, and [FCG-01] answers yes, that she had some toast with jam this morning. Seemingly worried he told her "it's almost 3:00"... Noticeably upset, [the son] stood up and walked to open the patio door, stepped outside in his socks, and closed the door behind him.*

Several instances of family caregivers taking conversation breaks on patios, balconies, in hallways, and bathrooms were noted.

Nurses used their own observations of clients' home environments to raise questions or make comments on what they saw, helping them to develop deeper relationships and learn more about the social environment in which they resided. For example, it was observed that the nurses would frequently inquire into photos they saw on shelves, walls, and fridges:

*[HCN-03] looked over at the fridge and asked if the photos were [FCG-05] granddaughter. [FCG-05] smiled and said that they were, one was her graduation photo and two others when she was five. She shared how she loved those photos of her, especially the one where she had her face painted and was eating an ice cream cone.*

These types of discussions, sparked by objects displayed in the home environment, helped nurses understand the context of their clients' lives, enabling them to better tailor care, including the language they used to provide it with.

Caring for persons in their home informs the ways in which people use language to convey wishes, fears, and/or desires. It was observed, for example, that sometimes nurses started conversations with discussions about personal objects or photos in order to build trust, which allowed clients and family caregivers to share their emotions, hopes, and/or worries about the future:

*[HCN-01] smiled and told [CR-03] that the roses on his table looked beautiful. [CR-03] solemnly replied that he has had a bad couple of days lately and received the roses from a friend... He then began to share thoughts about his own impending death and listing all the things he still had to get done before he died.*

This conversation, sparked by commenting on roses at the table, led to the care recipient expressing his own fears and stresses, which in turn allowed the homecare nurse to attempt to address them through language while also attending to the practical hands-on care that she was also there to deliver.

#### **4.4.3. Adapting language**

The home influenced the way language was used during medically-oriented discussions, such as conversations about symptom management, test results, and/or managing medications. Generally, the nurses were strategic in how they framed and

worded such details. In an interview, HCN-02, who previously worked in a hospital setting, shared her thoughts on this issue:

*You know, in the hospital you can tell somebody what to do. In the home you don't do that. You bring them onside to your way of thinking... So, it's much more working with them as far as being a team, whereas in the hospital they become the recipient.*

Interestingly, this nurse remarks that she is unable to “tell” families what to do in their homes. Although she is working towards the same outcome whether in the home or hospital, the way she approaches the situation and uses language to align families with her way of thinking differs between these care settings. The distinction here may be due to the pace of interactions, whereby in the home there is more time for concerns and issues to unfold and be absorbed, while in the hospital there is less time due to bed space pressures and generally more acute health issues of patients.

Each home, as a social space, was seen to influence the way language was used within it. It was observed that language was used differently within and between homes depending upon the social dynamic of the home, who the clients were, and who was present in particular rooms. Typically, the nurses adjusted language to their clients, which largely was dependent upon perceptions of their clients’ educational background, English comprehension, illness trajectory, and knowledge regarding the diagnosis. For one example, it was observed that HCN-01 used the formal names of medications when speaking with FCG-02 because she knew that she had a background in nursing, but when speaking with FCG-01, HCN-01 would refer to medications as “the little one” or “the big yellow pill.”

As clients were considered by nurses to be part of the care team, it was seen as critical that they understood diagnoses and/or prognoses and be able to discern when something was normal or if action was required. Language was central to achieving this understanding. For example, HCN-01 stated in her interview:

*They [clients] have to be able to understand what's going on in their language. A medical language... (gasp of frustration?) ...you know, I saw someone who had a mastectomy and she hands me her pathology report and she says, "Can you explain this to me?"... it says 'extensive' and 'aggressive' and 'invasive', all of these words. So I said, "This sounds like it's not the best cancer to have." I still try to be optimistic and not scare the heck out of them. And I said, "It sounds like you're going to need some treatment". Those kinds of things, just ....making it English. Because there's one thing knowing the medical words, but it doesn't help anybody when you want them to learn something.*

It was observed that a large component of homecare visits involved nurses teaching family caregivers and care recipients medical practices and procedures they could perform themselves at home. Homecare nurses used the cues they had obtained from observing the home environment and speaking with clients and family caregivers in order to language such discussions appropriately. For example, on one visit HCN-01 understood that FCG-01 was feeling confused about medications, so HCN-01 asked to see where and how FCG-01 stored CR-01's medications. From seeing how the medications were organized in the home, particularly that current medications were chaotically mixed together in an overflowing shoe box with expired and older medications that were no longer needed, HCN-01 was able to discern how confused and overwhelmed FCG-01 was feeling and language her guidance accordingly.

#### **4.4.4. *Storytelling and illness narratives***

Language used by nurses in the home tended to involve a number of strategies to facilitate the clear exchange of knowledge and information. Generally, the home environment seemed to prioritize the use of families' illness narratives in conversations and nurses seemed to make great efforts to adapt their language to clients' own explanatory models of health/illness. For example, nurses would often reply to a client's stress or fear with a story of another client who was going through a similar situation and in doing so drew upon language that was familiar to the client's own

narrative. In some cases, nurses would share stories from their own personal experiences to display empathy and understanding as well as suggest coping strategies, as observed on this bereavement visit:

*[HCN-01] explained that there will always be days, like this weekend – Father’s Day – which will be difficult... [HCN-01] then told [FCG-01] a story about her own mother-in-law who lost her husband and she recently called her on the telephone because it was their anniversary and she knew that it would be a difficult day for her.*

Storytelling was also commonly used by the nurses to justify suggestions for what they thought should be done or to initiate more difficult discussions, for example about advance care planning. It was observed that the home environment, and in particular its informal nature, seem to enable these story- and narrative-based conversations to happen organically.

Many instances of storytelling being used to respond to clients’ emotions, encourage humour, and clarify medical jargon, among other purposes, were observed. A common feature of these stories was the use of analogies and metaphors. Metaphors were often used as a strategy to lighten conversations and mediate embarrassing situations. For example, when asking CR-02 how his catheter and urinary infections were doing, HCN-01 asked how his “waterworks” were treating him. Metaphors and analogies were also used during more difficult conversations, for example how HCN-01 ritualistically told her different clients that “*everyone is on the same journey, just in different vehicles, and each with their own luggage.*” Metaphors and analogies were observed to offer a strategy by which homecare nurses could draw on a non-medicalized vocabulary to convey complex details to clients and family caregivers while at the same time demonstrating that they understood clients’ needs and comprehension levels.

## 4.5. Discussion

The findings shared above demonstrate that complex connections between language, place, and healthcare exist. Particularly, the findings illustrate how power shapes social spaces like the home and thus influences the relations, practices, and language used within this healthcare setting. In other words, the power associated with particular places influences the language used and whether people are either valued or de-valued during healthcare interactions (Liaschenko, 1994). Although not a comparative study, such findings may help to provide insight into differing power dynamics that exist between the homecare setting and more institutional settings such as hospitals. Such findings build upon Liaschenko's (1994) work, which emphasizes the power of the 'biomedical gaze' in institutional hospital settings and how the moral nursing work of protecting patient agency will differ depending if care is provided in the hospital or the home. In hospitals, biomedicine is the dominant discourse, which informs constructions of what hospital spaces are, namely focused on anatomical bodies and establishing cultural boundaries and biological norms (Gilmour, 2006; Kontos, 1998; Liaschenko, 1994). In the home environment, however, our findings demonstrate that nurses commonly self-identified as being guests, which shaped their roles, behaviours, and language choices when providing formal care in this informal setting. These nurses' understanding of being invited into clients' homes creates a unique power dynamic with regard to healthcare interactions, wherein they were often considerate of household norms and associated language use. Thus, in the home, families tend to hold more power regarding who enters the care space and how care is directed, which differs from an institutional setting where the continued presence of staff largely manage and direct the care routine and style of language used (Gilmour, 2006; Liaschenko, 1994; Milligan, 2003).

In clinical settings, patients and family caregivers are on unfamiliar territory while formal staff determine who has access to particular rooms or spaces (Andrews,

2003; Andrews & Moon, 2005). In the context of homecare nursing, our findings show that the use of space is largely directed by families who determine where they want visits to occur, while nurses must navigate the boundaries delineated by the families. This notion of having to carefully navigate the complex public-private divide of providing care in the home has been examined in other research that explores these blurred boundaries. Such research has consistently shown that caregivers feel as though they must struggle to maintain control in these care contexts (Andrews, 2003; Milligan & Power, 2010; Stajduhar, 2003; Williams & Crooks, 2008; Yantzi & Rosenberg, 2008). Our study offers new insight into this carefully communicated negotiation through examining how the public-private divide is managed and languaged in the home from multiple perspectives in the formal and informal caregiver-care recipient triad, most particularly by showing these homecare nurses' awareness of the need to respect family caregivers' and clients' spaces and desires.

Roles are formed by and reproduced in specific places and power operates within these places to reinforce the dominant language used within these roles (Dolan & Thien, 2008). This reality was reflected in our findings, where the prevailing explanatory model that informed clients' and family caregivers' language use was the illness narrative rather than disease-oriented discussions. Our findings show that nurses make great attempts to adapt their positioning and language to the personal, experiential position of their clients, which is informed by the context of the home environment. This may be unique to the homecare setting as the nurses and families use language to co-create a healthcare place in the home. In a study looking at nurses' willingness to adapt to their environments, Rytterström and colleagues (2009) found that although nurses felt the need to adapt to the culture of particular institutional wards in hospital environments, they did not feel the same need to adapt to the patients. However, because clients in our study were often seeking biomedical knowledge from nurses during the observed visits, they continued to hold power by virtue of their knowledge regardless of their consideration of household norms and use of language and space.

Participating nurses often adapted their language, frequently shifting between different types of language during single homecare interactions. For example, a single visit could shift between informal banter and deep discussions about how to administer medications properly a number of times. Even during more medically-focused conversations, the language used by nurses was sensitively adapted to the particular home environment and who was present, which both considered clients' emotions and potential for comprehension. Humour was also used by the nurses as a strategy, not only to lighten tensions but also to hinder potential embarrassment or awkwardness, especially regarding more intimate care procedures. This finding is reflected in other research that found humour to be integral to the development of the client-nurse relationship, while allowing the nurses a moment to rest and cope (Åstedt-Kurki et al., 2001). Overall, our findings indicate that language used in the homecare setting varies dramatically between and within visits, which implies it is collectively shaped by the home environment, those who are present, and linguistic strategies that are informed by the goals of particular visits.

#### ***4.5.1. Implications for best practice in homecare nursing***

Our observations of homecare nursing practice can contribute to gaining a better understanding of care work in diverse settings, which can assist with informing interventions to optimize best nursing practice. Relevant to our findings, Canadian nurses are ethically required to assume responsibility for ensuring therapeutic and professional relationships with clients based on trust, respect, and professional intimacy (CRNBC 2006). The development of this relationship was of great importance to participating nurses; however, the setting of the home environment was found to create a unique dynamic in regard to the roles and expectations associated with these relationships. Specifically, the homecare nurses seemed to hold two positions at once: that of guest and professional. Families, too, held dual positions serving as both host and client. Thus, the home creates a challenging environment for care provision for

nurses and clients alike because of the sometimes competing expectations of their dual positions. Homecare nurses must make a choice regarding which role to assume when and where during a visit, which was also found in Oresland and colleagues' (2008) study where the ethical demands placed on nurses required them to perform according to the norms of both guest and professional. This dual positioning is also reflected in the language used during interactions and may help to explain the continuous shifting from more informal, personal styles of discussion to formal, medically-based conversations associated with their differing roles. By acknowledging the complexity of homecare nurses' shifting roles in the home setting and the additional challenges created for nurses who are attempting the development of trusting and respectful relationship, interventions for best practice may gain insight.

By virtue of the need to develop a therapeutic and trusting relationship, nurses are compelled to consider clients' expectations in regard to which roles they should perform and when to switch from one to another. With this in mind, it may be beneficial for nurses to be aware of families' understanding of being a host and any additional stress or burden they may experience in assuming this role. In regard to spatial boundaries within the home, our findings demonstrate that families find it important for nurses to enact respect, while using their language as an illustration of this. Drawing from our own observations, it may be the case that instances of nurses overstepping spatial and spoken boundaries demarcated by families create barriers in developing trusting relationships. Thus, navigating these spatial (e.g., rooms, cupboards, closets) and spoken (e.g., identifying which stories are okay to repeat again and which ones are not) boundaries within the home is critical in best practice nursing if the development of trusting relationships is the goal. Indeed, given the increasing numbers of people who will require care at home in the future, nursing education programs should be directed toward assisting student nurses and nurses working within community health settings to better understand the conditions that will facilitate trusting relationships within the homecare context.

Best practice in nursing emphasizes that nurses should provide clients with the information required to make informed decisions with consideration being given to their emotional and cognitive states (CRNBC 2006; Liden, Ohlen, Hyden, & Friberg, 2010). It is also expected that nurses will provide information in a timely and appropriate manner, taking into account the individual's abilities, age, culture, language, and preferences (CRNBC 2011). This task demands high skills in communication and knowledge translation by nurses to ensure that clients have the necessary information to give their informed consent to care. As our study has shown, through engaging with the home environment, nurses may be able to discern clues to assist them with this task. Each style of language used in the homecare context provides a purpose and gaining a better understanding of these different styles may help inform strategies to enhance knowledge translation. Furthermore, with greater attention paid to the role of language in the homecare (and other healthcare) settings, nurses may become better aware of the power associated with language and its potential to influence clients' decisions.

#### **4.5.2. *Future research directions***

The methodology used in this study can be meaningfully applied to other health and social care settings outside the clinical environment (e.g., residential homes, community centres, mental health or addictions centres, telehealth) to further explore the language-place-healthcare intersection. In examining these other settings, there are a range of ethnographic methods that can be used to provide insights to inform theoretical and methodological advancement or applied knowledge aimed at optimizing best practice for healthcare professionals. Discourse analysis, for example, could be performed on video recordings of healthcare interactions in various settings, while arts-based methods such as visual ethnography or ethnographic filming may bring new meaning as verbal knowledge and visual representation in specific places work alongside one another (Kindon, 2003; Lorenz & Kolb, 2009; Pink, 2006). Such research has the potential to further advance knowledge on how language, place, and healthcare

are mutually shaped by one another and how they shape the use of power in providing and receiving care within particular settings. The findings of these types of studies would assist in confirming those shared herein.

#### **4.5.3. *Limitations***

The findings of this analysis should not be generalized or understood as representative of all Canadian homecare nursing interactions. First, nurses were aware that this study would observe interactions between them and their clients. As such, those nurses who were confident in their work may have been more likely to participate than those who were not. Second, it was within the nurses' power to share information about our study and they may have acted as gatekeepers, inviting only those families to participate with whom they had already built good relations. Third, most care recipients in this analysis were receiving palliative care. It has been found that nurses tend to be more accommodating to families experiencing death and dying and so the findings might not be reflective of other care contexts (Ward-Griffin & McKeever, 2000). Fourth, like all research methods, ethnography faces limitations as the collection of fieldnotes depends largely upon the subjective observations of the researcher (Rose, 1997; Savage, 2000a, 2000b). However, our use of observational guides streamlined the focus of fieldnotes, while conducting interviews with participants allowed for clarification regarding what was observed, both of which contribute to the rigour of our data collection process.

#### **4.6. Conclusion**

The intersection of language, place, and healthcare within the Canadian homecare nursing context has been explored in this study. This was accomplished through conducting observations of homecare nursing practice and interviews with nurses, clients, and family caregivers. Findings brought to the forefront the uniqueness

of the homecare environment for healthcare interactions and contribute to our understanding of the connections between language, place, and healthcare.

The findings empirically illustrate that the place of the home shapes language use during healthcare interactions, which ultimately informs the experiences of receiving and delivering healthcare services. Importantly, this analysis can be used to inform strategies and optimize interventions for best nursing practice, such as those pertaining to the development and maintenance of trusting and respectful relationships with clients in the homecare setting through highlighting the significance and power associated with the language used. Gaining a better understanding of language used in particular healthcare settings can provide insight into how conversations should occur 'in place' in order to enhance the meaningful exchange of information and encourage compassionate healthcare interactions.

## 5. Intersectionality and the ‘place’ of palliative care policy in British Columbia, Canada<sup>10</sup>

At some time, in some way, we must all face the end of life. Many of us share the common desire that when death comes to us or a loved one, it will be peaceful and dignified and that we will be surrounded by those we love, feeling safe, comfortable and cared for. The ultimate goal of palliative care is to support and care for the most vulnerable in society: the dying and their family members. *Who* will be providing this care, however, is largely shaped by embedded socially- and politically-defined sets of expectations and practices regarding rights and responsibilities (Dyck, 2005; Milligan, 2010). Within Canadian policy, concerns have increasingly emerged due to Canada’s rapidly aging demographic and the inevitable expanding need for palliative care in the coming years. What continues to go unseen, however, is that those who require palliative care are not simply an homogenous group of ‘aged’ Canadians, but a diverse group who are complexly situated within a web of intersecting social, economic, cultural, political, historical, geographic and physical contexts that will dramatically shape their palliative care needs, the types of services and supports required, and ultimately their access to these supports and services.

The implicit goal of Canadian health care policy is to enable universal access for all through publicly insured and extended services, yet there exist great disparities in service access and provision (Romanow, 2002). Not only does place of residence determine levels of access to services due to underlying geographic, economic,

<sup>10</sup> This chapter has been published as Giesbrecht, M. (2012). Intersectionality and the ‘place’ of palliative care policy in British Columbia, Canada. In Hankivsky, O (Ed) *An Intersectionality-Based Policy Analysis Framework*. Vancouver: Institute for Intersectionality Research and Policy.

demographic and cultural realities of particular regions Romanow, 2002; Robinson et al., 2009; Milligan & Power, 2010), but access is also highly dependent upon one's intersecting lived context and positions of privilege and disadvantage within the social hierarchy of power. Such positionality can shape one's opportunities, choices, beliefs, decisions and access to care and support services. Thus, policies that do not consider such lived realities, particularly *who* needs *what kinds of* supports, will only result in reinforcing existing inequities in access to care. Given the complexity of lived experience and how embedded issues of power influence access, intersectional theory and the concept of 'place' have much to offer when examining policies that define and determine health and social care services. However, little research has applied intersectionality and the concept of place to palliative care policy research, or health and social care policy research more generally.

This chapter uses an intersectional lens and the concept of place as analytic tools to explore palliative care policy in British Columbia (BC), Canada, through reporting on the findings of key informant interviews conducted with palliative care providers and administrators in the province. Importantly, I did not set out with place as the pre-determined category of analysis for the interview data, but found that it continually emerged as a primary theme when exploring palliative care policy through an intersectional lens. The purpose of this study is to shed light on BC's current palliative care policy landscape while uncovering inequities in access to services and supports for those needing such care services. My relationship to this study lies in my academic background, which is in human/health geography and is informed by theories of feminism, political economy and social constructivism. Indeed, as feminists have long noted, private and public spaces are inherently interlinked and deeply political. As well, I see significant value in applied approaches to research. My interest in palliative care stems not only from personal experience, but from a desire to shed light on the often overlooked, yet invaluable work of both informal/family and formal palliative care providers in Canada. I begin this chapter by introducing the concept of place and how it

relates to intersectionality. I then provide a descriptive overview of palliative care policy in BC, followed by a discussion of how I grounded my research and then present the findings from the key informant interviews. Overall, I seek to show the relevance of intersectionality and place to the study of palliative care policy in BC.

## **5.1. Intersectionality and ‘Place’**

The complex notion of place has garnered much attention from geographers since those inspired by the cultural turn in the discipline cast their gaze upon the concept during the 1990's. Today, place is commonly described as “a bounded entity, containing a unique assemblage of characteristics and within which, people forge profound attachments and identities” (Bondi and Davidson 2005, p16). This description signifies that place is doubly constructed: built physically, but socially interpreted, narrated, perceived, felt, understood and imagined (Easthope 2004). Thus, places are not simply physical constructs, but are infused with social dimensions. Building upon this definition, place, in the physical sense, can also be understood as a material artifact, a literal location or a setting for social relations, while the social dimensions of place include the meanings people attribute to places, the ways they engage in place-making activities or place-specific behaviours, how they understand their place in the social hierarchies, how they develop a sense of place, and how they create emotional attachments to places (Castelden et al., 2010). Although places hold significant meanings for people, a person's history and experiences will influence her/his perceptions and experience of places, while at the same time, places will affect that same person's opportunities and activities (Easthope, 2004). Therefore, places are complexly linked together in unequal ways through social relations of power (Easthope, 2004).

With this understanding of place, it becomes apparent how the concept could easily lend itself to intersectional research, particularly that which focuses on health and

social care delivery; however, this link has received little attention from researchers. Intersectional scholars have long recognized the significance of 'geography' or 'place' in their research, yet the understanding and application of these dimensions tend to be relatively singular, usually denoting a 'physical' geographic location, while overlooking the infused social dimensions and relations of power embedded in these places. While feminist and critical geographers have often looked at particular socio-spatial interconnections (e.g., see Kobayashi 1994; Pratt 1998; Dolan and Thien 2008), the wider theoretical paradigm of intersectionality has not been widely adopted (Valentine 2007).

For geographers, understanding place through an intersectional lens can enhance the sophistication of the concept by raising questions about how geographers situate themselves in their research and develop, categorize and understand relationships between various types of places. Intersectionality also enhances the complexity surrounding the extent to which identities are understood, made, unmade and simultaneously experienced in particular places. As well, a more sophisticated application of the concept of place to intersectional research may enhance intersectionality's appreciation of the social constructions and meanings of place and its role in shaping the processes of oppression and subject formation, while also showing how oppression and subject formation in turn shapes places. Furthermore, as places are infused with social constructions of meaning and power, they are also characterized and situated within a complex web of intersecting categories of difference (e.g., cultural, economic, historical, and political, among others) and are shaped by various intersecting macro-micro processes, which ultimately will shape social experiences and contexts for social interactions.

In this chapter, the intersectional approach I use is grounded in lived experiences, while providing a theoretical foundation for the pursuit of social justice (Hankivsky et al, 2009). My study aims to "consider simultaneous interactions between

different aspects of social identity as well as the impact of systems and processes of oppression and domination” (Hankivsky et al., 2009 p. 3). In the following section, I provide a contextual backdrop by explicitly addressing four descriptive questions drawn from the IBPA framework: 1) *What is the policy ‘problem’, or how has the need for palliative care been represented in BC policy?*; 2) *How has this representation of the ‘problem’ come about?*; 3) *How are groups differentially affected by this representation of the ‘problem’?*; and 4) *What are the current policy responses?* I have chosen to address these four questions as they provide an excellent starting point from which to explore palliative care policy in BC, to unpack underlying assumptions regarding who is experiencing death and dying, and to uncover existing beliefs surrounding their palliative care needs. I have chosen another IBPA question to direct the actual analysis of this study. This question was selected to assist in uncovering the real diversity that exists among families who require palliative care services and any unjust issues that may be overlooked in BC palliative care policy. This transformative guiding question is: (4) *What inequities actually exist in relation to the problem?* In order to answer this question, I have sought the valuable perspectives of those who are actively delivering palliative care support and services on the front lines in B.C. In my conclusion, I address one final IBPA question, which asks: (6) *Where and how can interventions be made to improve the problem of achieving equitable access to meaningful palliative care services and supports for all British Columbians?*

## **5.2. BC’s palliative care landscape**

When using an intersectional framework, it is important to simultaneously consider the multiple levels of systems and structures related to a particular ‘problem.’ At an international level, among ‘developed’ nations, neoliberal policies and resulting health care reforms have recently shifted the responsibility of care from the state to the voluntary and informal sector (e.g., voluntary organizations, family caregivers)

(Chouinard & Crooks, 2008; Skinner & Rosenberg, 2005). This shift has had a profound influence on *where* such care now takes place. Specifically, the *place* where care occurs has been increasingly deinstitutionalized, moved out of formal institutions (e.g., hospitals) and into the community, especially the home (Burge et al., 2003 ; Skinner and Rosenberg, 2005; Lilly et al., 2007). These reforms and policies directed at shifting care into the home and thus into the domain of private citizens, are based on a conventional division of labour that underpins policy and informal social expectations of who will bear the primary burden of care work (Dyck, 2005; Stajduhar & Davies, 2005; Milligan & Conradson, 2006). Providing care in the home means that those who formally and informally work within the home, largely women (who are often unpaid), are filling the gaps in labour and services that have been left by such neoliberal policy shifts (Dyck, 2005; Armstrong et al. 2008; Williams, 2002). But more complexly, the responsibility to provide this care is falling heavily upon the shoulders of untrained and unpaid informal caregivers (commonly referred to as ‘family caregivers’) who are not only primarily women, but complex beings who simultaneously inhabit other distinct socioeconomic, cultural, political and historical locations (Bondi, 2008; Dolan & Thien, 2008).

Within Canada, family caregivers and the care they provide have become the backbone of the health and long-term care systems (FWCBC, 2003; CCC, 2009; Stajduhar et al., 2011). Various estimates indicate that 75% to 90% of all home care is now provided by family members, who save the formal health care system an estimated \$6 billion a year in human resources costs and contribute up to \$26 billion of unpaid care work (Hollander et al., 2009). In palliative care, it has been estimated that family caregivers contribute \$6000 worth of unpaid hours in the last four weeks of life alone (Hollander et al., 2009). In this paper, I use the commonly referred-to definition of palliative care developed by the World Health Organization (WHO, 2011), which describes this care as:

*an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the*

*prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (n.p.).*

Within Canada, palliative care is offered across a range of sites, including nursing homes, acute care hospitals, respite facilities and hospices, and by a variety of providers, who can include family doctors, nurses, specialists, community volunteers, spiritual leaders and family members (Carstairs, 2005).

By 2036, British Columbia will have the oldest population west of Quebec (HRSDC, 2013). It is expected that approximately 24% of British Columbians will be 65 years of age or older, an increase of 9% in the next 24 years, which will have dramatic impacts on the need for palliative services. The Ministry of Health in BC has responded to this concern by identifying palliative care as an area of health policy priority (BCMh, 2006). The challenge the Ministry faces is how to “ensure quality services are consistently available so that British Columbians with a life-limiting illness, and their families, can experience the best possible quality of life during the transition to death” (BCMh, 2006, p.16). The direction the Ministry is taking to achieve this goal, however, is towards enhancing services and policies that enable palliative care to be provided in the private homes of British Columbians, which is reflective of overarching neoliberal trends. The ‘problem,’ according to the Ministry, is that while the majority of British Columbians would prefer to spend their final days at home, 60% still die in hospitals (BCMh, 2006). Thus, this definition of the ‘problem’ sees a disjuncture between British Columbians’ preferred place of death (i.e., in the home or hospice) and where most deaths actually occur (i.e., in the hospital), and perceives that this disjuncture must be addressed while palliative care policies and practices are developed, modified, or enhanced in the face of impending increased need.

In 2009, a study by Crooks developed a timeline of palliative care policy and practice in BC. She found that the development of palliative care services in BC has been

shaped by various social, political and geographical factors, and that government concerns and priorities regarding this care have shifted dramatically over time (Crooks, 2009). Beginning in the 1980s, messages about palliative care were brought forth in the provincial legislature and, interestingly, personal stories about those who were not receiving needed palliative care were often used to initiate dialogue in legislative sessions (Crooks, 2009). In the 1990s, questions revolved around where palliative care should take place, who should be responsible for it, and how it should be funded (Crooks, 2009). In the 2000s, priorities shifted again towards developing and implementing specific initiatives, such as the BC Provincial Framework for End-of-Life Care (2006), the federal Compassionate Care Benefit Program, and the BC Palliative Care/Pharmacare Benefits Program. These programs mark a dramatic shift in government priorities away from building freestanding hospices, towards facilitating home-based palliative care (Crooks, 2009).

Considering current health care spending in BC, it should come as little surprise that the downloading of palliative care responsibilities onto communities and families is an attractive policy option (Hankivsky, 2004). Such a shift is seen as key to controlling health care spending by governments and is justified as a way to alleviate demand on the formal health care system while improving quality of care for recipients (Armstrong et al., 2008; Hankivsky, 2004). The provincial government's repeated tax cuts and aim of meeting deficit targets have resulted in major decreases in public health care spending. These cuts force regional health authorities to determine what they will trim, which directly and indirectly affects communities and social services that enable palliative care provision. As such, availability/eligibility of particular palliative services varies dramatically across BC, resulting in vast spatial inequities, especially when comparing BC's rural health authorities to more urban ones (Milligan & Power, 2010; Crooks et al., 2011). General trends, however, include the province-wide cutting of hospice beds, adult daycare and respite facilities, which ultimately increase the responsibilities of family caregivers (Canadian Centre for Policy Alternatives, 2005; BC Nurses Union,

2009). At the same time, support for family caregivers of the frail, elderly, (dis)abled and dying is also being cut, for example, formal home care (e.g., nursing) and support (e.g., bathing, laundry, vacuuming, shopping and meal preparation) (Friends of Women & Children in BC, 2003).

Although family caregiving can be an empowering, inspirational and fulfilling role, it is important to acknowledge that the demands and responsibilities may also come with associated burdens (e.g., mental stress, compromised physical health, financial costs). Like all populations, caregivers are complexly situated within intersecting socioeconomic, cultural, political and geographic realities. Thus caregiver burdens and associated stressors may weigh more on the shoulders of some than others. Choices, opportunities, decisions and ultimately one's ability to cope with the highly demanding caregiving role are complexly interrelated with one's place in the world and the access to resources one can draw from. For example, those who live in poverty may face greater stresses and challenges in meeting the financial costs associated with dying (Wakabayashi & Donato, 2006), while women face stronger societal expectations to take on the role of caregiver and its associated burdens (Dolan & Thien, 2008), and those who may be more geographically or socially isolated are likely to experience greater fatigue leading to an increased risk of anxiety and depression (Spencer, 2004).

Although BC has recognized palliative care as a core service in the provincial health care program, those who are providing the majority of palliative care, namely family caregivers and front-line workers, remain invisible in policy initiatives (Yantzi, 2009). This may be due in part to an inherent neoliberal 'expectation' that families and charitable community organizations are responsible for fulfilling this role. It may also be due to the constructed divide of the public and private spheres and, rooted in familialism, assumptions by policy makers that the family will automatically take over responsibility for care (Hankivsky, 2004; Siltanen, 2006). Such policies also assume that

all citizens have a safe and healthy home environment suitable for caregiving (McKeever et al., 2006; Milligan & Power, 2010) and that dying British Columbians have family members who are both willing and capable (e.g., financially, physically, mentally, emotionally) to successfully take on this role (Seale, 2000).

As this section demonstrates, palliative care in BC has advanced over recent years, yet it remains an often overlooked and undervalued component of health care systems. Based on BC's current palliative care landscape, it is apparent that an intersectional approach could generate more accurate information to inform policy about who needs what kind of palliative services and supports. Thus, it is important to investigate palliative care in BC in order to shed light on how lived social/physical places impact opportunities, choices and decisions related to providing and accessing palliative care supports and services.

### **5.3. Study Overview**

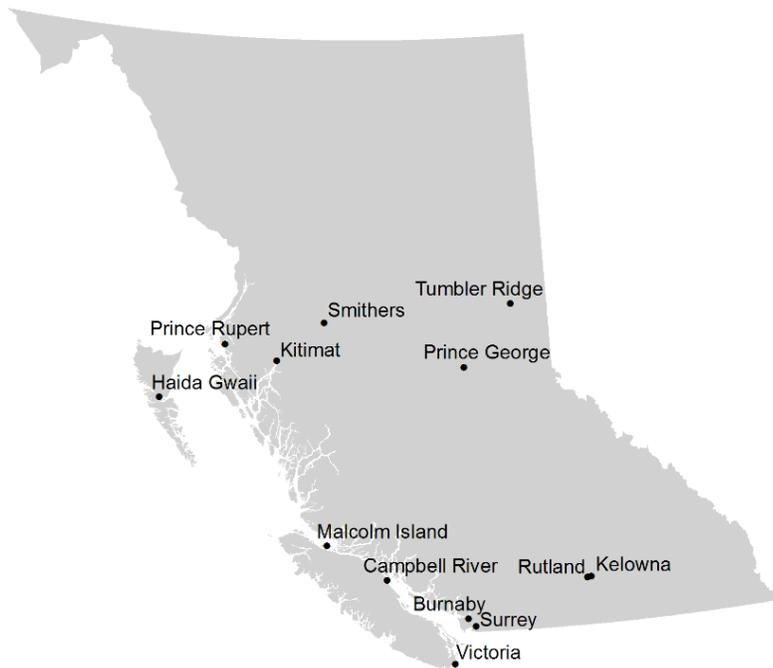
My exploratory study seeks to examine the perspectives of those working on the front lines of palliative care provision across BC. Twenty front-line workers were interviewed and purposely recruited from a variety of employment backgrounds, occupational settings and geographic regions across BC in order to capture employment and geographic diversity and bring about diverse discussions of experiences working with families with various needs. The inclusion criterion required participants to be actively providing direct palliative care to family caregivers and/or care recipients through their formal employment. Recruitment involved disseminating an information letter summarizing the study's purpose and inclusion criterion. The letter was sent via e-mail to a number of hospices, palliative organizations and hospitals across BC. Additionally, telephone calls were made to inform potential offices/organizations/participants about the study.

### **5.3.1. Data Collection**

Semi-structured interviews were conducted by telephone in May/June, 2011. The interviews lasted on average 45 minutes and inquired into participants': 1) experiences of working with families experiencing death and dying; 2) perspectives on the diversity of families in need of palliative care supports and access to these supports; 3) perspectives on current palliative care policy in BC; and 4) suggestions for policy improvement. All participants were informed of their rights in the research study and provided verbal consent prior to the interview. Ethics approval was granted by Simon Fraser University's research ethics board.

The interviews were conducted with front-line workers from across BC, as shown in Figure 1. They worked in a variety of occupational groupings, including: home care/community nurses; social workers; social work consultants; acute care/emergency social workers; spiritual care providers; physicians; counsellors; and pharmacists. Participants' workplace settings were also varied, crossing hospice, hospital, clinic and community spaces. In order to protect anonymity and meet ethical standards, further demographic information (e.g., age, ethnicity, gender, etc.) of participants cannot be shared due to some of the low populations and rural/remote communities involved.

**Figure 5.1 - Participants' workplace locations in BC, Canada**



### **5.3.2. Analysis**

The interviews were digitally recorded, transcribed verbatim and entered into N8™ data management software, after which thematic analysis was conducted. Thematic analysis involves reviewing and coding data both inductively and deductively in order to explore existing research goals as well as emergent themes from the dataset through the identification of patterns that become categories for analysis (Fereday and Muir-Cochrane 2006). After reviewing three randomly-selected transcripts in order to start the analytic process, it became apparent that place, in both the physical and social sense, was a major emergent theme from the dataset. Considering the thematic finding of place, I decided to anchor my intersectional analysis here and to employ a framework developed by Castleden et al. (2010) that uses place as a tool for analysis in palliative care research. As such, development of the coding scheme was not only informed by intersectional-based themes, such as 'power', 'experienced injustice' and 'hierarchies of

care’, but also by Castleden et al.’s (2010) framework, which draws upon aspects of place, including ‘location’, ‘proximity’ and ‘rural’ or ‘urban’.

## **5.4. Findings**

In keeping with intersectionality, ‘place’ did not carry a singular meaning or experience for participants. Three themes regarding place were found to be most prominent in the dataset: (1) site; (2) distance/proximity; and (3) location. Site refers to the actual places where palliative care occurs, while distance/proximity refers to the relational aspect of place, for example, in terms of being near or far to services. Location refers to a socially ‘positioned’ or ‘situated’ sense of place. Although I have attempted to disentangle these into three thematic categories for organizational purposes and clarity, the theory of intersectionality reminds us that these categorical findings are highly fluid, relational and complexly interrelated across a variety of scales stretching from the body to overarching economic and sociopolitical structural systems.

### **5.4.1. Site**

The main sites of palliative care discussed by participants were the hospital, hospice and family home. However, their preferences for each site varied. Generally, the home and hospice were preferred, while the hospital was commonly perceived as being only a “*last option.*” For example, participants described the hospital environment as being “*impersonal*” and not a comforting place conducive to quality palliative care. Intersecting with access to social resources, some participants stated that the “*people who end up in hospital are only the ones who have no support.*” Interestingly, however, it was also stated by some participants that some families choose the hospital over others sites due to intersecting economic, cultural, geographic or social issues that influence their beliefs, choices and decisions (which will be discussed more in the following sections). Furthermore, some participants located in rural and remote regions

where hospitals are very small (in some cases only 7 rooms) viewed the hospital as the most preferred site for palliative care, as the social environment there was more similar to a “family” than an institution. However, overall there seemed to be a general consensus among participants that palliative care in larger and more urban hospitals is not to quality standards.

Using an intersectional lens, I found that access and the preference for the hospice as a site of care varied among population groups. In general, hospices were seen as a more suitable site than hospitals, as their policies and culture are rooted in the philosophy of palliative care, which aims to ensure that all individuals die with dignity. Hospices also provide an alternative for families who do not wish to have a home death or do not want to spend their final days in a hospital. However, a number of barriers were mentioned by participants that limit some people’s access to hospices in BC. First, as there are many BC communities that simply do not have a hospice house nearby, families in those areas are required to travel (in some cases, hundreds of kilometers from their home) for this service, which can create major social impacts, as families may be forced to separate and live at great distances during these time periods. Second, to be eligible for hospice, the care recipient must score below 40% on the palliative performance scale (which measures for functionality). Using such strict medically-based eligibility requirements that do not consider other social contexts were a source of frustration for some participants:

*...they [hospice houses] use the palliative performance scale...like it is gospel! And if you are 40% or less on the palliative performance scale, you can go to hospice. If you are anything above, doesn't matter any other extenuating circumstances, doesn't matter the context—nothing—zero—end of story, you don't get to go. So yeah. It's hard. I mean I know all about rules but there are people that do not fit into ticky boxes.*

Third, if and once care recipients become eligible for hospice they may face long waiting lists to be transferred, a concern that was raised by many participants. In

addition to the physical location of hospices and individual medical prognoses, socioeconomic status was also found to intersect with and create barriers in accessing hospice care. Participants commented on the out-of-pocket hospice costs for patients and their families, which are tied to assisted living rates. Hospice costs in BC are roughly \$30 per night, which was seen by many participants as unjust and an attack upon the dignity of dying individuals who cannot afford these rates.

Besides the hospice, the family home was the other preferred palliative care site of participants, as care in the home was generally believed to be more compassionate, while the environment was familiar and comforting. Importantly, however, any preference given to this site of care was largely dependent upon a range of intersecting contextual factors. In order to stay in the home, for example, participants stressed that care recipients need to have family members or friends who are willing, available, and capable to provide care. Some families simply do not have someone like that. As one participant put it, *“I mean ...we see it all the time - you have two people just propping each other up - and that is more common when they are elderly, but it can also be if there is drug addiction, or alcoholism, or mental illness.”* Importantly, families also require access to formal supports and services to stay at home, like home care nurses, home support workers and palliative physicians who will make house calls, which was deemed by participants as most critical for making palliative care at home a reality. As mentioned previously, due to recent budget cuts and resulting spatial inequities in the distribution of resources, the limited availability and provision of formal care in the home in some regions of BC has greatly affected families’ choices, as another participant remarked, *“Okay, here is your choice, either go to hospice or stay at home—If you stay at home we can only put in two hours [of support] a day. How much of a choice is that?”*

Although favouring the home as a site of care, participants believed that private houses were not always safe and/or suitable sites for palliative care. For example, one participant explained that *“Sometimes you go in and someone’s got lung cancer...and*

*there is black mold all over the windows.*” Safety issues were also a concern with regard to social dynamics within the home:

*I’ve had people who are dying and they are in a home where numerous drug addicted people share the space and so their pain control drugs become capital and so the patient doesn’t get the drugs they need.*

Making houses safe as a site of palliative care sometimes requires making modifications to spaces or bringing in equipment, changes that depend on various intersecting contexts, such as socioeconomic status and access to particular material resources like vehicles: *“I sometimes have a bit of a challenge getting the right equipment in place in homes and then I have a lot of families who aren’t in a position, they don’t have a truck, to move the equipment and so... that can be a bit of a challenge.”* Based on the data, the most concrete barrier to providing palliative care in the home is faced by those who do not have secure housing: *“there is a lot of housing insecurity—people who have lived on their own, you know, and then they are too sick, what do they do when they are too sick but they are not quite ready for hospice?”* Additionally, taking into account the intersection of care with cultural/spiritual issues, some families do not wish to have death occur in the home. As one participant stated, *“I find the Haidas [a First Nation] are definitely more spiritual. They tend to believe...if they die in the house, the spirit stays in the house, that kind of thing, and they don’t like that by any means.”* Because of their spiritual beliefs and lack of hospices in the area of their Aboriginal reserve territories, these families have little choice but for death to occur in a hospital setting.

#### **5.4.2. Distance and Proximity**

The physical distance between palliative care services and users, and/or between formal palliative care providers and their clients was commonly raised by participants as a major factor influencing their abilities to provide effective support. A participant from northern BC discussed some of the spatial inequities that exist in

distribution of services throughout the province, claiming *“there are places out there that don’t have doctors, don’t have hospitals, so I doubt that those places have a hospice, and I don’t even know if they have people kind of trained in that area [palliative care] to give the type of care that might be needed.”* Importantly, participants commented that because some regions lack formal palliative services, families have no choice but to move closer to the nearest hospital or hospice (again, sometimes hundreds of kilometers from home), which can be quite distressing for families, especially for those who do not have the finances to simply move and/or take a leave or find new paid employment in the community where the hospital/hospice is located.

While participants discussed issues of physical distance and proximity, it became clear that their concerns were also infused with social meanings and issues of belonging. As intersectionality reminds us, belonging, inclusion and exclusion are inherently linked with social justice. Some participants stated that people in remote regions feel *“lost”* and that *“some communities are just so remote and isolated, both geographically and socially”* that their needs for palliative supports are not heard or valued. However, it was also commonly noted that these remote and isolated communities are generally more ‘socially’ close and connected internally, which is a great strength for families experiencing death and dying: *“...the smaller places make up in personal caring and concern for the family and patient in ways that perhaps, places that may appear to have a lot more services don’t.”* These close connections within smaller communities were seen to be extremely valuable in terms of support for families.

Participants were careful not to make cultural generalizations and acknowledged intersectionality’s claim that diversity exists within each culture; however, some general differences were raised with regard to sociocultural issues and their relevance to proximity. For example, a participant explained that *“First Nations have all sorts of family around...they usually have friends or somebody that is there for them so it is quite a close-knit community that way.”* Participants from northern BC commonly remarked

on the sense of community with regard to death and dying among First Nations, and particularly the Haida, including how this was often enhanced through close physical proximity. Meanwhile, another participant from northern BC explained that, *“out of all my white clients, I would say probably at least 40% of them are here all by themselves with no family. Closest family would be out-of-province.”* These observations pertain to social and physical distance and proximity, which are relevant factors for intersectionality and point to experiential differences in death and dying across BC. They also expose particular needs in regard to addressing spatial inequities in palliative care supports.

#### **5.4.3. Location**

The most dominant place-related theme raised by participants was in reference to how both the physical and social locations of care of recipients and family caregivers determine their access to palliative services and supports. In the physical sense, participants whose employment reaches beyond a health authority boundary found the bureaucracy and *“enormous variations and permutations”* in service provision extremely frustrating. As one participant commented, *“the palliative benefits program, it is supposed to be a provincial program...but what happens is that it’s doled out to various regions to be administered and those regions apply their own rules around what is covered, what isn’t, and how it gets covered.”* Therefore, the provision of and access to palliative services is largely dependent upon where one is geographically located in BC, which intersects with overarching regional demographic, historical, cultural and socioeconomic differences among communities. During the interviews, many participants situated in rural areas compared their palliative services to those in urban locations, often emphasizing the spatial inequities that exist:

*“I think in places like Victoria and Vancouver, they are doing a very good job. But when they make policies...all you have to do is come and spend*

*three months working in a location like this [remote] and you will realize that we fall off the map all the time.”*

Spatial inequities in palliative care services and supports across BC have a number of implications. One of these is economic, thereby connecting access and socioeconomic status. One participant remarked on the extra costs and stresses associated with accessing care in rural areas:

*the financial burden in a rural area versus in a city is huge... you know, the cancer centre is in [city name] so if you live in [smaller community] per se, it is a four hour drive through pretty treacherous mountain passes to get to your appointment...it is just so much more stressful to have to travel for treatment.*

In recent years, there have been considerable funding cuts that have affected access to palliative care services, particularly in BC's north. One participant stated that the hospice/palliative care program there *“is essentially disintegrated,”* while another explained that *“Northern Health initiated a hospice/palliative care program and has let it wither to almost a point of non-existence.... The working conditions are impossible.”* Additionally, in some locations there may not be access to a family physician due to shortages, which makes it *“a nightmare”* for families to access services, as eligibility for palliative care programs in BC is typically dependent on a physician's assessment of the prognosis and a referral.

All participants believed that one's social location shapes access to palliative services and supports in BC, along with experiences of death and dying. During the interviews, participants emphasized that each family and each death is unique; however, some patterns with regard to inequities in choices, opportunities and access to supports and services were mentioned. Issues of culture, spirituality, language, education, gender, sexuality, marital status, life course position and socioeconomic status were all mentioned by participants as being complexly intertwined within clients'

lives and affecting palliative care outcomes. Here, issues of social processes of power and subject formation results in effects of privilege and penalty for those in need of access to palliative care supports. Access was largely understood by participants to be related to issues of isolation, culture, gender, unresolved colonial injustices and ongoing experiences of poverty. There were many examples provided, however, I will present only some of the main themes that arose. Firstly, First Nation people's, but particularly those living off reserve and who are socially disconnected from their cultural communities, were said to face extreme barriers in accessing needed social and spiritual supports. Meanwhile, participants felt that the Aboriginal population as a whole lacks representation in palliative care policy and access to formal services. One participant stated that *"the First Nations are a significant part of the population... but, they are significantly, significantly underrepresented in palliative care."* Another said, *"I know for a fact that the First Nations people are falling through the cracks in terms of palliative care... there is just terrible inequality given the distribution of resources and funding."*

Unsurprisingly, participants thought that women tended to be family caregivers more often than men, while the degree of expectation for women to take on the role of caregiver varied depending upon other intersecting dimensions of language, culture and socioeconomic position. For example, one participant explained that *"in the Indo-Canadian community, often it is the daughter-in-law who is looking after the dying mother-in-law, plus her own parents, plus there is very little support, and she might be the only one that speaks English."* It was also stated that women are more likely to take on the dual responsibility of family caregiving while maintaining paid employment, which participants said creates tremendous stress on women. And while some women face these extra challenges by maintaining these 'dual responsibilities,' others experience great pressure to leave their paid employment in order to fulfill caregiving responsibilities. As one participant observed, *"either the woman is still working, or she has been forced to leave her job because women usually make less than men, so often*

*their jobs are the ones that are given up because, you know, someone has to give up something, so take the least paying job.”*

Socioeconomic status was seen by participants as greatly affecting access to palliative services. As one participant described it, *“without a doubt... accessing palliative care programs is so much harder for people who live in poverty.”* Much of the time this diminished access is associated with the out-of-pocket costs families are expected to incur and the loss of wages from taking time off paid employment to provide care. One participant explained that *“we have so many people living paycheque-to-paycheque and then... it sounds funny, but there are so many expenses associated with dying and people that are not financially well resourced for that, it’s really tough.”* Further, and intersecting with the issue of physical location, participants also recognized that those living in more rural areas face greater challenges in achieving job security and stable financial standing, especially rural women.

Marginalized population groups were thought to face severe challenges accessing palliative services, especially the homeless, those with stigmatized diseases and those who live in unsafe places. Elaborating on this, one participant commented that *“Street people—I mean stigma—you know, you need a referral [to access palliative care] and a lot of people when they are dying they don’t go to doctors.”* Those with particular illness and diseases also were seen as significantly underrepresented in palliative care, especially those with stigmatized diseases like HIV. Further, those suffering from mental illness face major barriers in accessing palliative services. One participant claimed that, *“mental health is a huge one... We struggle with mental health. Trying to get the mental health team involved when people are dying? Oh, it is almost impossible.”* Some participants expressed concern that there is no place for those with mental illness to go when they are dying because, *“Anybody who has behavioural issues that would impact on the other clients is not somebody that would be suitable [for hospice] and yet we do not have anything in place - and this is especially for, I would say,*

*people with addictions.”* Participants argued that because these population groups are sometimes more difficult to house and often not trusting of people in the health field due to bad experiences in the past, they are not accessing the formal supports they may need.

## **5.5. Advancing new perspectives on BC palliative care policy**

In 2006, the BC Ministry of Health published a framework for palliative care with the vision that end-of-life care in the province

*...will feature high quality services that are competent, compassionate and respectful of all people who are dying and their families. Patients and families will have choices, including a range of options to support death with dignity and comfort in the setting that best meets the needs of patients and family caregivers (BCMh, 2006, pg 4).*

Although this is admirable, the findings of this analysis indicate that there is much to be done to actualize this vision. Great inequities exist in choices, options and access to palliative supports and services in BC. Emerging from this intersectional analysis, findings indicate that these inequities are dependent upon relational aspects of ‘place’ and where people are physically and socially situated within these contexts. Site, distance and location in both the physical and social sense were found to greatly influence palliative care access and outcomes. Looking more closely at the issue then, it becomes apparent that these contexts complexly intersect in each individual’s lived reality, from micro (e.g., illness or disease prognosis) to macro levels (e.g., neoliberalism).

The physical places discussed in the participant interviews (e.g., rural BC, the home, the hospital, among others) are themselves characterized by intersections of sociopolitical, economic, cultural and historical processes, as well as relations of power. Although BC policy is directed towards enabling palliative care in the home, the findings

point to the home as a highly contested site for palliative care, one characterized by intersecting political, cultural, economic, social, geographic and historical dimensions. By gaining a better understanding of these intersectional aspects of the home, we are better able to uncover particular inequities, especially with regard to access and the associated relational processes of power that will simultaneously shape, and be shaped by, those who live there. By shifting the intersectional gaze to the site of the home, we gain a deeper understanding on the social fields that frame everyday life experiences. Reflecting on intersectional theory, Moss (1997), called for more research to recognize a relational view of place. Such an approach would not be limited to the physical boundaries of the home itself, but would emphasize how the intersecting social relations of daily lives, in turn, shape home environments and, in regard to this study's topic, access to palliative care.

The findings demonstrate that current BC palliative care policy, which is currently directed towards assisting families in the home, is based upon a number of assumptions that create major obstacles to the achievement of the Ministry of Health's vision. These assumptions include that all dying British Columbians have: 1) the willingness and desire to have a home death; 2) access to a family caregiver who is willing and has the time, capabilities and resources to provide care; and 3) families that have the physical resources and/or local medical support available to assist them through the palliative care process in the home. By unpacking the Ministry's policy directive towards enhancing supports for palliative care in the home, it also becomes apparent that the house, home and family have become conflated in the policy realm and are based on an ideologically laden perspective where families are seen as white, middleclass, heterosexual and nuclear. Mallet (2004) emphasizes that governments of capitalist countries, like Canada, tend to conflate the house, home and family as part of a broader ideological agenda aimed at increasing economic efficiency and growth, which is reflected in the shift in responsibility of palliative care from the state and its institutions to the home and nuclear family. Furthermore, this study's findings disrupt

the common policy discourse, which tends to assume that those in need of palliative care are a homogenous group of middle class, Anglo-European (white western) elderly British Columbians. The findings demonstrate that great diversity exists among dying British Columbians and their families, which in turn results in diverse needs for palliative support.

The present study also shows that some groups face higher barriers and experience greater stresses and burdens than others. For example, those who are located in rural and remote areas in BC, who are at great distances from services, who are socially isolated or stigmatized, and who may be complexly located under any of the existing arms of oppression (e.g., cultural minorities and/or First Nations, among other groups) face greater barriers to accessing palliative supports, and ultimately, achieving a death with dignity. On the other hand, this analysis also exposes characteristics of those who are situated in relatively privileged social and physical positions, for whom such policies are working, namely, those who have a relatively predictable prognosis and middle to high class status, who are located near a larger urban/town area, are home owners, and socially connected, married, and/or have an educated (preferably with a medical background) woman friend or family member who is healthy, willing, capable and available to take time to provide care in the home. Considering these findings, it is apparent that deeply embedded components are resulting in, and reinforcing, inequities in palliative care. Applying the IBPA framework in this study has brought these components to light and generated information that can potentially be used to inform policy directions towards more equitable and inclusive palliative care policy options.

The site of the home for palliative care may be a viable and desirable option for some, yet the findings point out that this may not always be the case due to a range of complex issues (e.g., lack of access to outside formal supports, spiritual beliefs, housing security and associated costs). The social role of the home is important in reifying identities and values, desires and fears, traditions, and memories, all of which will shape

opportunities, choices, access and decisions regarding palliative care. Underlying motives behind some British Columbians' preference for the home as a site for palliative care must also be considered, particularly if such preferences are based upon perceptions that hospital care is inadequate and should only be a "last resort." Perceptions of low-quality palliative care in hospitals may leave some British Columbians feeling as though they have no choice. Stajduhar and Davies (2005) found that some BC families choose to provide care in the home because they do not see the hospital as an option at all due to the paternalistic approaches to care imbued in this space, and the tendency for a biomedical environment to depersonalize and decontextualize the experiences of dying and of giving care. Exemplifying this, Pesut et al. (2011) emphasize the significant role of spiritual care providers employed within hospital settings and how multi-faith chaplains are able to address issues of diversity. Yet, their unique contribution to modern health care is not being recognized or valued by the dominant biomedical culture, and especially in the face of constraining budget cuts. Unfortunately, this only exacerbates the depersonalization and decontextualization of the hospital environment as a site for palliative care. Considering this, and that hospices often have long waiting lists, cost \$30/night, and are not available in many communities, it is not surprising that the home is often identified as the preferred site for palliative care. Links between these issues and families' preferences and decisions regarding sites of care should not be overlooked in policy creation and implementation.

## **5.6. Conclusion**

This study has been exploratory, however, it does begin to shed light on BC's current palliative care policy landscape while uncovering inequities in access to services and supports for those in need. Using an intersectional framework and my selected IBPA questions as a guide, I have been able to uncover how policy has developed and represented the 'problems' associated with palliative care in BC. I have also unpacked

underlying assumptions about who is experiencing death and dying, and what are believed to be their associated palliative care needs. The study also disrupts the current policy discourse that the home is singularly the optimal and preferred site for palliative care. Further, I have uncovered the kinds of population groups that are actually affected by such policies, what inequities exist, and how issues of privilege and power are currently being reinforced.

Future efforts should be made to conduct intersectional research on palliative care in order to inform policy of more equitable ways to deliver this care (e.g., policy makers must understand who is affected by what barriers and why). More concretely, communities need to be included in the palliative care policy process and provided with committed supports and resources necessary to achieve a dependable level of quality palliative care. Also, rather than directing all policy efforts towards assisting families to stay at home, the Ministry of Health must simultaneously provide families with an option of sites for palliative care, particularly by encouraging and supporting the construction of hospices and enhancing education and improving the quality of palliative care in hospital settings. Furthermore, efforts should be made to include the knowledges of disadvantaged groups and to target these groups for services. For example, attention should be paid to cultural/spiritual diversity through the development of sensitized, inclusive programs, particularly for Aboriginal populations. Lastly, due to the complexity of death and dying, there is a need for multiple governmental sectors to become involved in palliative care, for example, Medicare, employment insurance and family allowance, and at multiple levels, such as the local, provincial and national levels, in order to adequately address the complex needs of families experiencing death and dying. This multi-sectoral approach will require coordination, a shared vision and political commitment from local to national leaders in order to be successful.

Ultimately, this study advances the concept of place within intersectionality theory, a concept which, to date, has not received adequate attention within this theoretical domain. At the same time, I have attempted to intersectionalize the concept of place and, as such, to reveal extensive possibilities and expansive uses of intersectionality in other fields. More specifically, my study emphasizes that ‘choice’ at the end of life is not merely a matter of individual preference, but is related to complex issues of socioeconomic status, service provision, cultural discourses, and emotional, spiritual and relational factors, which are all infused with the physical and social aspects of place (Morris & Thomas, 2007). In light of an expanding need for palliative care services in the coming years, it is imperative that BC policy acknowledge these existing inequities in order for all British Columbians to have access to “quality services” that will support family caregivers and allow for the best possible quality of life during the transition to death.

## 6. Conclusion

In this dissertation, I have presented four analyses (Chapters 2-5) that were each informed by unique aims and objectives. As a whole, this dissertation has been collectively informed by three overarching objectives: (1) to contribute a novel geographic perspective to the existing body of Canadian palliative care research; (2) to determine the diverse, yet interrelated, axes of difference that shape Canadian palliative caregivers' experiences in the context of the homecare environment, and; (3) to gain a better understanding of how Canadian palliative caregivers' opportunities, choices, decisions, and outcomes are shaped by where and how they are situated. My research goals were to disrupt the common notion in policy and practice that Canadian palliative caregivers are a homogeneous group who have similar needs and thus require similar supports, and generate knowledge that can inform decision makers of ways to provide Canadian palliative caregivers with the most meaningful and equitable supports.

In this chapter, I synthesize my research findings and revisit the above-mentioned objectives, discussing each separately and describing how they have been met. I also examine the contributions and implications these analyses offer to the field of geographies of care and caregiving, palliative care policy in Canada, and best palliative care nursing practice, while speaking to the overarching goals of this dissertation. I conclude this chapter by acknowledging some limitations of this research and providing suggestions for potential future research directions.

## 6.1. Revisiting My Research Objectives

### 6.1.1. **Objective One:** *Contributing a novel geographic perspective to the existing body of Canadian palliative caregiving research*

The analyses presented in this dissertation offer a geographic perspective to the field of palliative caregiving research in Canada, particularly by employing a *relational* conception of place. For example, in Chapter 2, while identifying those axes of difference that shape family caregivers' experiences of providing palliative care, and their associated implications for the Compassionate Care Benefit (CCB), place emerged as an important thematic finding. Here, place encompassed the locations where family caregivers resided, whether they resided in rural or urban communities, and the site in which care and ultimately death occurred. Importantly, however, this place-based finding is but one axis of difference among four others (i.e., culture, gender, lifecourse stage, and material resources) that shape caregivers' potential uptake of the CCB. Thus, this analysis, as well as the three others included in this dissertation, emphasized that place is not experienced in isolation, but is relationally experienced alongside other axes of difference simultaneously.

Together, all four analyses presented herein illustrate the *range of ways* in which place can be conceptualized and experienced, contributing a unique geographic perspective to the field of Canadian palliative caregiving research. For example, in Chapter 3, the concept of place not only referenced geographic location (such as proximity to services and amenities), but also considered the broader socio-environmental locations of two palliative family caregivers. These situated locations were found to influence their capacity for resilience (i.e., access to social networks, education/knowledge/awareness, employment status, housing status, and life course stage). Chapter 4 explored the role of place in relation to the use of language during healthcare interactions in the home environment. More specifically, place in this analysis was understood as both a social and physical construct that shaped the home

as a health care setting. It was found that the social and physical place of the home shaped power relations between formal and family caregivers, influencing their relationships, practices, and language choices. Finally, in Chapter 5 place, as a multi-dimensional social and physical construct, was found to shape opportunities, choices, and decisions related to providing and accessing palliative care supports and services in British Columbia (BC). More specifically, aspects of the social and physical dimensions of the site where palliative care occurs, distance from or proximity to supports and services, and location were found to play a critical role in shaping palliative caregiving experiences and inequities in access to meaningful supports in BC.

Taken together, these analyses meet my first objective and address a current gap in Canadian palliative caregiving research by offering a critical geographic perspective (Andrews & Crooks, 2009; Mackinnon, 2009). They also confirm that place does not carry a singular meaning or experience (Easthope, 2004; Bondi & Davidson, 2005; Kearns & Collins, 2010 ), but instead show that place is shaped in relation to the lived context in which palliative family caregivers are situated. For example, again in Chapter 2, differences among caregivers and access to the CCB program were revealed through applying the abovementioned conception of place and by focusing the analysis on understanding caregiver experiences from the perspective of their everyday lived realities. Thus, by employing the concept of place from this standpoint, findings were able to reveal different experiences of place, which were in turn shaped by its relation to the lived context. Furthermore, and reflecting another understanding of place, the differences found among lived contexts were shaped by *where* the caregivers were socially and physically situated (i.e., their culture, gender, place of residence, place in the life course, material resources). Similarly, in Chapter 5, palliative caregivers' experiences of places (e.g., the home, hospice, and hospital) differed depending upon where caregivers, care recipients, and their families were socially and physically situated (e.g., their culture, living in rural BC, access to material resources, etc.). Thus, applying a relational and multi-dimensional understanding of place from the perspective of

everyday lived realities allowed for the above-mentioned findings to emerge, enhancing our understanding of the numerous ways that place can be experienced, and in turn, how place shapes experiences of palliative caregiving.

By employing a conception of place that stretches beyond singular dimensions (e.g., that encompasses factors ranging from the micro-scale of the body to macro-scale structures of neoliberalism) and encompasses a multitude of meanings defined by its relation to other factors (e.g., life course stage, material resources, gender), a diverse range of palliative caregiving experiences have been uncovered in the analytic chapters. Such a perspective is valuable to the study field of palliative caregiving as it emphasizes the significance of place in the provision of care. It also allows for a nuanced understanding of how palliative caregivers' 'place-in-the-world' is interconnected with structures of power, thus shaping opportunities, activities, and outcomes.

**6.1.2. *Objective Two: Determining the diverse, yet interrelated, axes of difference that shape Canadian palliative caregivers' experiences in the context of the homecare environment***

Across the analytic chapters the findings reveal valuable information that can contribute to a better understanding of the diverse, yet interrelated, axes of difference that shape Canadian palliative caregivers' experiences in the context of the homecare environment. Most importantly, the findings confirm and underscore that family caregivers are a diverse group with different needs for support. Acknowledging such diversity is critical in order to ensure all health care, including palliative care and supports, are delivered in an equitable, meaningful, efficient, and effective way (Ballem, 1998; Hawkins, 2002; Hankivsky et al., 2011). More specifically, by recognizing the diverse lived realities of family caregivers, the delivery of palliative care supports can be designed to mitigate barriers to access while at the same time ensuring that services are in fact meeting the real needs of all caregivers. Acknowledgement of diversity promotes

social justice, respect (Hulko, 2009; Hankivsky et al., 2011), and allows Canadian families to access the supports they need to face death and dying with dignity.

Most explicitly aligned with objective two, Chapter 2 aimed to identify, among palliative family caregivers across Canada, what differences exist in shaping caregiving experiences and access to supports. Thematic analysis of 50 interviews with front-line palliative care providers revealed five axes of difference: culture, gender, lifecourse stage, geography, and material resources. It was found that each axis intersects in the lives of individual palliative family caregivers, resulting in unique lived contexts that bring associated strengths and/or vulnerabilities to caregiver burdens. As such, this analysis emphasized that acknowledgment of diversity among Canadian family caregivers is an important aspect of understanding caregiving experiences. These findings reflect an argument offered by Hsuing and Nichol (2010) that emphasizes that a recognition of diversity is critical in order to fully capture the complexity of caregivers' experiences. It is only through understanding these complex lived experiences, which will ultimately be different for different population groups, that strengths, challenges, needs for support, and barriers to access can be identified. As Hankivsky (2005) states, it is through acknowledging diversity within lived experiences that a more sophisticated, complex, and dynamic understanding of equity and social justice can emerge.

In Chapter 3, an ethnographic in-depth case study analysis of two palliative family caregivers demonstrated that different lived contexts influence vulnerability to caregiver burnout and capacity for caregiver resilience. Similar to Chapter 2, it was found here that lifecourse stage and geography played an important role in caregiver resilience; however, access to social networks, employment status, and housing status were also found to shape the capacity for resilience against caregiver burnout. Interestingly, this level of social difference has been acknowledged in studies pertaining to caregiver burden with regard to employment status (Canadian Policy Research Networks, 2009), lifecourse stage (Charles et al., 2012), and access to social networks

(Sharpe et al., 2004). However, to my knowledge, the ways in which these axes of difference facilitate resilience has yet to be considered outside of this dissertation. Thus, the findings from this study encourage reflection on resilience beyond individual-level factors and promote a more multi-dimensional understanding of how differing socio-environmental contexts can influence caregivers' capacities to cope.

In Chapter 4, an analysis of ethnographic fieldnotes and interviews with homecare nurses, family caregivers, and care recipients revealed that each home, characterized by those who resided within it, influenced the way that language was used during homecare nursing visits. Typically, nurses adapted their language depending upon their perceptions of family caregivers' education level, English comprehension, and the illness trajectory of the care recipient. Therefore, these differences influenced the language used, the type of relationship built, and ultimately the way decisions were made during the caregiving process. Although different languages have been recognized as an important component when considering the delivery of health care to diverse populations (Wilson, 2006), the nuances between the differing ways the same language (e.g., English) is used in the context of homecare nursing had not been previously explored. Therefore, these findings highlight the significance of language during healthcare interactions in the home environment and bring forth a new understanding of how caregiver diversity influences the use of language, and ultimately, the caregiving experience.

In Chapter 5, an intersectional analysis of 20 semi-structured interviews with front-line palliative care providers revealed that great differences exist with regard to family caregivers' choices, opportunities, and access to palliative caregiver supports and services across BC. Particularly, site, distance/proximity, and location, in both the physical and social sense, were found to influence caregiver experiences through the relational and intersecting political, cultural, economic, social, and geographic dimensions that characterize them. For example, it was found that the preferred site of

care, whether hospital, home, or hospice, was largely dependent upon various other intersecting axes of difference such as culture, rural or urban residence, and the availability of formal homecare supports. As such, the application of the intersectional concept of place has revealed findings that exemplify the range of ways that place is experienced as well as how power is infused in these locals, shaping differing experiences and access to palliative care. These findings offer a new understanding regarding the complexity and diversity of everyday lived caregiving experiences and provides insight into how such diversity will shape the meaning of and experience of place.

Together, this research underscores the importance of recognizing diversity (Hawkins, 2002; Duffy et al., 2006; Pinqart & Sorensen, 2006) and that palliative family caregivers are not a homogenous group with similar support needs. Ultimately, these findings suggest that implementing ‘blanket’ style policies and programs that are targeted towards an ‘imagined-average’ person are not efficient, effective, or equitable. Rather, such approaches result in many supports and services being rendered inaccessible, irrelevant, or inadequate. Thus, in order to actualize the BC Ministry of Health’s goal, which is to ensure universal access to health care for all Canadians (Health Canada, 2010), more diversity and flexibility in regard delivery and types of supports offered must be considered in regard to the real lived experiences of those who can benefit from using them.

Based upon the findings of this dissertation, there are a total of 15 axes of difference found to be relevant to palliative caregivers’ lives and situated locations, which are listed in Table 1 on the following pages along with descriptions of the scope of each, which are informed by Hankivsky et al. (2009) and the WHO Commission on Social Determinants of Health (2008). It is important to emphasize here, once again, that the listed axes of difference in this table are not static or fixed, but are context specific, dynamic, and relational.

**Table 6.1: Interrelated axes of difference that shape palliative caregiving experiences in the home**

<b>Axis of Difference:</b>	<b>Scope of the Axis:</b>
<b>Access to social networks</b>	The availability of, and ability to draw upon, family, friends, neighbours, colleagues, community members, and/or other personal close others for support and assistance when needed
<b>Access to material resources</b>	The ability to acquire the tangible goods and consumables and the means by which they are purchased, wherein an absence of these resources can result in material deprivation
<b>Availability of formal palliative homecare support</b>	The presence of formal palliative services and programs, within meaningful proximity to the location of residence, that are able to provide support in the home
<b>Culture</b>	The totality of the ideas, beliefs, values, knowledge, and way of life of a group of people who share certain historical, religious, linguistic, ethnic, and/or social backgrounds
<b>Education and literacy</b>	The knowledge and skills available to reason, make judgments, and problem solve. Also the ability to access and understand health system and medically-related information, which at times may be relatively complex
<b>Employment status</b>	The state of being actively employed, part-time employed, self-employed, unemployed, or retired
<b>Gender</b>	The manner in which a society defines the array of socially constructed roles and relationships, personality traits, attitudes, behaviours, values, relative power, and influences based on a differential basis of being a 'woman' or a 'man'
<b>Health/Ability</b>	The state of physical, mental, and social well-being as well as having the physical, mental, and emotional capacity to carry out duties
<b>Housing status</b>	The state of residence and whether this is relatively stable and/or secure (e.g., home ownership) or unstable and/or insecure (e.g.,

	homelessness)
<b>Illness trajectory and prognosis of care recipient</b>	The course of illness over time and whether it is relatively predictable (e.g., some types of cancer) or unpredictable (e.g., chronic illnesses)
<b>Language</b>	The method of communication, either spoken or written, consisting of the use of words in a structured and conventional way
<b>Lifecourse stage</b>	The sequence of socially defined events and roles that individuals enact over the progression of their life from birth until death
<b>Relationship Status</b>	The state of being single, widowed, separated, divorced, married, in civil union, or in domestic partnership
<b>Rural/urban residence</b>	The geographic location of residence and whether it is within a rural area (i.e., relationally greater distance from services and supports) or an urban area (i.e., relationally closer proximity to services and supports)
<b>Site of care</b>	The physical place in which palliative care occurs

The findings of the four analyses bring us a step closer to identifying what differences exist *and matter* among palliative family caregivers in Canada, thus contributing valuable knowledge regarding who palliative family caregivers really are and the need to deliver and provide services in more flexible and diverse ways. For example, in Chapter 2 it was found that young, spousal palliative family caregivers with young children at home require particular supports, such as child care, employment security, and higher income assistance. These support needs would differ greatly from an elder, retired palliative caregiver with a secure financial standing. Also, these findings offer data that can inform decision makers about *who* and *what factors* to consider when developing strategies to enhance future palliative care policy and programs in Canada. Ultimately, it is through acknowledging diversity that vulnerabilities to caregiver burden

and inequities in accessing palliative caregivers' supports are able to be revealed, as well as ways forward in identifying interventions to address these inequities. Such information is critical to informing palliative care policy and decision-makers on how to provide more effective, meaningful, and equitable caregiver supports that are based upon the actual *needs* of the population they aim to service.

**6.1.3. *Objective Three: Gaining a better understanding of how Canadian palliative caregivers' opportunities, choices, decisions, and outcomes are shaped by where and how they are situated***

Building from my previous objective that emphasized the diversity among palliative caregivers in the home and their support needs, my third objective pertained to uncovering how these diverse physical/social locations shape opportunities, choices, decisions, and outcomes. Ultimately, the findings of the four analyses presented in this dissertation reveal particular inequities that exist with regard to the opportunities and choices that ultimately affect the decisions made by informal and formal caregivers alike and thus the outcome of providing palliative care in the home.

In Chapter 2, it was found that particular segments of the palliative caregiver population are particularly vulnerable to experiencing inequities with regard to accessing needed services and resources, and the CCB in particular. These groups include non-English or non-French speakers, cultural minorities, rural residents, employed caregivers who are women, caregivers who are men, caregivers with young children, and those who do not have or are unable to purchase meaningful material supports. For example, due to language limitations, non-English or non-French speakers may not be aware of existing local supports for palliative caregivers. This lack of awareness restricts their opportunities to access services such as respite support, volunteer transportation services, or household support services, which in turn restricts their choices, directing their decisions, and ultimately their palliative care outcomes (e.g., whether or not care is given in the home, the caregiver's health, the quality of

death for the care recipient). On the other hand, in Chapter 3, it was found that those who do speak English, have knowledge regarding the Canadian medical system and the services and supports available to them, are retired or work from home, have secure housing, stable economic statuses, live near or with the care recipient as well as relatively close to services and amenities, and have other family members surrounding them who are able and willing to assist in providing support have enhanced capacity for resilience against caregiver burnout. It was found, for example, that having flexible employment status (working from home or being retired) allowed these family caregivers the opportunity to stay at home and provide palliative care with little or no financial or employment sacrifice. This opportunity, in turn, enabled a greater variety of choices, influencing their decisions, and palliative care outcome.

In Chapter 4 it was found that language plays a critical role in influencing the experience of palliative caregiving in the home. Here, the physical/social location of the family caregiver, care recipient, and formal care providers will shape the way language is used. This, in turn, will influence the type of relationships built, the decisions made, and the palliative care outcomes. For example, the development of a trusting relationship and opportunity for clear information transfer can allow for particular concerns or issues to be raised, allowing for suggestions to be offered on how these issues can be addressed, which, in turn, can shape decisions and outcomes. This finding holds implications for the findings in Chapter 2 regarding caregivers' language competencies and how this can serve as a barrier or facilitator to service or support access. More specifically, how information is communicated and the words that are used can be as important to language competency in terms of ensuring that palliative caregivers are adequately and meaningfully supported in the home as language comprehension.

Chapter 5 most explicitly addresses this third objective, as it was found palliative caregivers in BC who reside in rural areas, who live at great distances from services, and who are socially isolated or stigmatized can face particular barriers to accessing

meaningful palliative care services. This results in these population groups having fewer opportunities or choices that will allow them to facilitate a death with dignity. On the other hand, those who have a relatively predictable prognosis, are middle to high class status, who are located near a larger city/town area, are home owners, and socially connected, married, and have an educated, healthy, willing, and able family member to provide care in the home have greater opportunities and choices and thus are situated in a relatively privileged position in relation to the ways that current palliative care supports are provided. These findings, which point to those who face particular barriers, reflect the findings of Chapter 2 (e.g., residing in rural areas, unable to purchase meaningful supports, cultural minorities) and exemplify how particular social and physical locations shape access to palliative supports. However, the findings in this chapter go a step further by also identifying those for whom current palliative care *is* working, which reflects the findings in Chapter 3 regarding caregiver resilience. More specifically, those who are socially connected, educated, and live near a larger city/town, and are of higher class status (which will likely be associated with stable housing status) are better equipped to provide palliative care at home and access required supports to assist them with undertaking this demanding responsibility.

These findings address the third objective and emphasize that where a palliative caregiver is socially and physically located shapes the caregiving process and ultimately the outcomes for caregivers and care recipients alike. Importantly, these findings not only point to specific inequities that exist with regard to accessing meaningful palliative caregiving supports, but also suggest aspects of caregivers' social and physical locations that can put them at either increased or decreased risk of caregiver burnout. As a reminder, caregiver burnout is when caregivers become so physically, mentally and emotionally depleted that they are no longer able to provide care (Carstairs, 2005; Lilly et al., 2012). Caregiver burnout is the potential outcome when the commonly experienced stresses and demands of caregiving - caregiver burdens - are not

addressed. Table 2 synthesizes the relationship between burnout and the findings that inform the third objective.

**Table 6.2: Social and physical locations that influence risk of palliative caregiver burnout**

<b>Increased risk of burnout</b>		<b>Decreased risk of burnout</b>
<b>Caregiver is a non-English or non-French speaker</b>		Caregiver is an English or French speaker
<b>Caregiver identifies as a cultural minority</b>		Caregiver identifies with the cultural majority
<b>Caregiver is a new immigrant</b>		Caregiver is a long-time Canadian citizen with knowledge of the medical system and awareness of local supports available
<b>Caregiver is a rural resident (or those who live far from services and amenities)</b>		Caregiver is an urban resident (or those who live near services and amenities)
<b>Caregiver is employed outside of the home</b>		Caregiver is retired or working from home
<b>Caregiver has young children at home</b>		Caregiver has no young children at home
<b>Caregiver does not have and is unable to purchase meaningful material supports</b>		Caregiver has and is able to purchase meaningful material supports
<b>Caregiver is socially isolated or stigmatized</b>		Caregiver has a social network available for support
<b>Caregiver or care recipient (depending on site of care) has unstable housing status</b>		Caregiver or care recipient (depending on site of care) has stable housing status
<b>Care recipient does not have a clear prognosis (e.g., chronic disease)</b>		Care recipient has a relatively predictable prognosis (e.g., some forms of cancer)
<b>Caregiver faces mental health/addiction challenges</b>		Caregiver is physically/mentally healthy and capable

It is important to emphasize that the social and physical locations listed in Table 2 are not dualistic, but are situated along a continuum (e.g., horizontally across the table). In addition, they are co-located or simultaneously experienced, sometimes across rows. More specifically, some aspects of a caregiver’s social and physical location may act against burnout while at the same time others may put them at risk of exposure. The interaction between these locational variables will inform capacity for resilience and

ultimately outcomes for all parties involved. Furthermore, those caregivers whose social and physical locations overlap across multiple segments of these population groups (e.g., vertically across the table) may be exposed to even greater risk or lesser risk of caregiver burnout. For example, a rural resident who does not speak English and has young children at home may be at greater risk of caregiver burnout compared to an urban resident who is retired, physically and mentally healthy, and has a stable economic status. It is apparent from these findings that some groups are at an increased risk of caregiver stress, burden, and negative health outcomes, which again may be amplified for those whose location overlaps multiple segments of these particular population groups.

## **6.2. Contributions and Implications**

Together, the findings from the four analyses previously discussed offer research contributions for and suggest implications in three domains: theory, policy, and practice. In the following section I speak to my overarching dissertation goals and objectives and discuss the contributions and implications this research raises for: (1) the geographies of care and caregiving; (2) palliative care policy in Canada; and (3) best practice in homecare nursing.

### **6.2.1. *The geographies of care and caregiving***

In 1997, Moss stated that more “critical medical researchers must take into account individuals’ multiple positioning in various sets of power relations based on gender, class, sexual orientation, race, ethnicity, ability, lifecycle, citizenship, and so on, for they set the context within which individuals live out their daily lives” (Moss, 1997 p31). More recently, there have been calls from intersectional scholars, as well as some human geographers, to recognize the diversity that exists *within* such commonly constructed categories of difference (Hancock, 2007; Valentine, 2007; Hankivsky et al.,

2011). The theoretical framework of intersectionality is experiencing increased uptake in some research circles, such as in women's health and policy (Weber & Parra-Medina, 2003; Hankivsky et al., 2009) and psychology (Cole, 2009) as well as in regard to particular issues such as violence against women (Crenshaw, 1994), mental health (Banks & Kohn-Wood, 2002), and aging (Hopkins & Pain, 2007). However, this theoretical positioning has yet to be applied in the geographies of care and caregiving field and thus, little is known regarding how individuals' multiple positionings and associated relations of power shape the role of caregiving, particularly palliative caregiving. Thus, the findings from this dissertation address these concerns and calls, and contribute to the field of health geography, and more specifically the geographies of care and caregiving, by considering the multiple positions of palliative caregivers with regard to needs and access to existing supports and services.

This research contributes to advancing intersectionality scholarship by providing numerous examples as to how geography and/or place is a multi-dimensional and relational construct and how these places are infused with relations of power. Although intersectional scholars have long recognized the significance of 'geography' or 'place' in their research, the application of these dimensions tend to simply denote a 'physical' geographic location, while overlooking the how places can evoke multiple meanings and experiences depending upon the perspective taken. The findings from the four analyses demonstrate the diverse experiences of place among palliative family caregivers in Canada, and also how their situated social and physical locations shape experiences of physical places (e.g., the home, hospice, region, etc.), as well as their needs, access to, and use of palliative care services and supports. This particular type of diversity was especially investigated in Chapters 2, 3, and 5, and the findings from these chapters show that without considering individuals' positionings within the broader web of socially constructed categories of difference that inform the determinants of health, essential aspects of palliative caregivers' experiences will remain hidden. Importantly, it is not unless real lived experiences of caregivers are revealed that the delivery of

palliative care can be enhanced to ensure equitable and meaningful support that meets caregivers' *real needs*. Considering the importance of focussing on the everyday lived reality of caregivers in order to understand their real needs, the analytic approach taken in this research is reflective Dorothy Smith's (2004) feminist standpoint perspective, which advocates for linking the micro- and macro-processes that shape everyday experiences. However, rather than focussing on gender perspectives, this research focusses on *place-based* perspectives and thus offers a unique and innovative approach for exploring how everyday experiences are inextricably linked with place, while simultaneously considering the context of overarching power relations and processes.

A goal of my dissertation research has been to address calls from health geography scholars to better acknowledge and consider complex lived realities specifically through the application of a relational conception of place. As such, the findings of this dissertation also address calls made by an increasing number of health geographers to move research laterally and explore the *relations* between people, place, and outcomes in regard to belonging and access to social support (Kearns & Collins, 2010). More specifically, Chapters 2, 3, 4 and 5 all work towards advancing perspectives regarding relational conceptions of place by employing place in a fluid and boundless way, while acknowledging its relation to the wider socio-political, economic, and cultural conditions that simultaneously shape lived experiences. This was done by grounding the analyses in the lived realities of caregivers and by not employing pre-determined definitions or boundaries regarding categories of difference, including 'place'. What emerged were findings that demonstrated various ways place was significant at particular times and in specific contexts, as well as how it was related to the various other facets of reality that are simultaneously being experienced by caregivers. In doing so, these analyses emphasize that place is not experienced in isolation, but rather is always experienced from the perspective of one who is socio-culturally, politically, historically, and economically situated. Thus, when exploring experiences of place, it is critical to *simultaneously* acknowledge lived contexts in order

to better capture complex realities and the multiple and diverse ways that place can be experienced. Although this framework was applied in the context of palliative caregiving in Canada, it can be meaningfully applied in many other geography of care and caregiving research areas, for example caregiving for children with (dis)abilities in the home or for those with chronic illness and/or disease in the home. This framework could also be applied to gain a more in-depth understanding of place-based experiences in other settings, such as the hospital, long-term care facilities, prisons, hospices, and drug rehabilitation centres. Future research in these contexts may help to shed light on how diversity within situated lived experiences results in various experiences of place and how these experiences are shaped by multiple relational dimensions ranging from the body (e.g., prognosis) to overarching socio-political structures (e.g., neoliberalism).

The findings from the analytic chapters affirm Kearns' (1993) contention that individuals' social and physical experiences of place are dynamic and shift in relation to their needs. Building upon this notion, these analyses add that family caregivers' needs are also dynamic and will shift according to context and each caregiver's unique lived physical and social reality, which will influence experiences of place. Wiles' (2003) research recognizes that care and caregiving is a dynamic, temporal process from which a variety of social and environmental factors come into play to shape the caregiving experience. For example, her research into the geographies of caregiving showed how differences and relations between people and locations affect access to resources. The current dissertation research contributes to Wiles' (2003) findings and Kearns' (1993) ideas by suggesting that experiences of place are relational, multi-dimensional, dynamic, and temporal and are influenced by circumstantial and situational lived contexts that, in turn, *shape support needs* in addition to access to resources. As such, this dissertation addresses Kearns' request for health geography research to shed light on place in light of one's 'place-the-world' (i.e., using a standpoint perspective) while also considering how place is experienced in relation to other broader social variables (i.e., applying an intersectional approach) (Valentine, 2007; Dolan & Thien, 2008).

This dissertation research addresses a significant gap in existing palliative care research: the lack of research that looks at palliative family caregiving from a critical perspective (Exley & Allen, 2007; Mackinnon, 2009). To date, much critical analysis has focused on issues of home care from a feminist and/or political economist perspective, addressing concerns about the implications of the (re)domestication of care for unpaid carers and the significance of the home as a social feminized space (Exley & Allen, 2007). These analyses have also emphasized issues regarding the feminization of care, whereby caregiving is predominately associated with women, and thus how policies directed at providing care in the home are resulting in disproportional expectations for women to take on this role. Similar to the topic of this dissertation, Exley and Allen (2007) apply a critical approach to palliative care in the home and argued that current policies have led to an “over-romanticised” notion of care, which privileges the value of caring relationships without acknowledging the actual work of caring. They further argue that the home is not always the ideal place for this care, but that relationships may be better maintained and nurtured if people have a “realistic” choice of care in institutional settings. This dissertation research, particularly Chapter 5, builds upon Exley and Allen’s (2007) work by further disrupting the ‘gold-standard’ ideal that the home is best place for palliative care to occur for all citizens. Additionally, this dissertation research casts a critical intersectional lens regarding which people current policies and programs are working for and which people are falling through the cracks in terms of accessing meaningful palliative care. Situated lived contexts and their associated power relations were found to result in social and spatial inequities in access to care. Overall, I am confident that this research contributes knowledge that can help build a more nuanced understanding of how health and social care are experienced by different individuals and groups by considering place in relation to the other socio-economic, political, cultural, and historical locations that also shape lived realities (Moss, 1997; Dolan & Thien, 2008).

### **6.2.2. Palliative care policy in Canada**

Within Canada, a rapidly aging population and associated increase in chronic disease prevalence are putting significant pressure on the health care system, long term care system, and ultimately family caregivers (Williams et al., 2010; Carstairs & MacDonald, 2011). During the time that Canada had a federal Minister with special responsibility for palliative care and public policy directives like the Canadian Strategy on Palliative and End-of-Life Care, concerted policy leadership and targeted funding led to great successes in improving palliative care awareness and infrastructure (Carstairs & MacDonald, 2011). In particular, this Strategy led to many policy improvements, including in the areas of research and data collection, education for health care professionals, and support for caregivers (Carstairs & MacDonald, 2011). However, since 2007 when the Secretariat supporting this Strategy was defunded and disbanded, progress in palliative care improvement both nationally and provincially/territorially has slowed (QELCCC, 2010; Carstairs & MacDonald, 2011). This raises many concerns as there exists the inevitability of an expanding need for palliative care in Canada's future (QELCCC, 2010; Carstairs & MacDonald, 2011). Considering this, it is apparent that major barriers and challenges exist in ensuring that all Canadians, present and future, have equitable access to meaningful palliative care.

One critical direction for overcoming the challenges outlined in the above paragraph lies in the production and continuation of research and data collection on palliative care in Canada (Carstairs & MacDonald, 2011). Thus, this dissertation contributes to this important cause by exploring the grounded experiences and perspectives of those working on the front-lines in palliative care in Canada, namely formal providers and family caregivers. This serves as a complement to research undertaken by other Canadian teams on topics such as palliative care in rural and remote areas (Crooks et al., 2009; Castleden et al., 2010; Lockie et al., 2012; Novik & Maclean, 2012; Pesut et al., 2012), with First Nation communities (Kelley & Prince, 2006;

Kelly & Minty, 2007; Castleden et al., 2010), access to palliative services (Cinnamon et al., 2008; Schuurman et al., 2010; Collier, 2011; Cohen et al., 2012), and palliative care policy (Crooks, 2009; Williams et al., 2010; Carstairs & MacDonald, 2011).

Considering the emergent findings regarding the complex lived realities and associated needs and challenges in accessing meaningful palliative services, it is apparent that there is much room for policy improvement in ensuring that all Canadians have equitable access to palliative care supports and services. In keeping with the analytic findings, it is essential that a “one size fits all” approach – an approach that tends to dominate Canadian policymaking (Williams & Kulig, 2012) – is not employed when making these improvements. This might necessitate employing a multi-sectoral or inter-sectoral approach in order to enable those agencies that can collectively speak to the axes of difference that inform caregivers’ experiences to shape action and intervention together. For example, in the concluding section of Chapter 2, and due to the complexity of death and dying, it was emphasized that there is a need for multiple governmental sectors (e.g., Medicare, employment insurance, family allowance) to become involved at multiple levels (e.g., community, municipal, provincial, national) in order to address the complex needs of families experiencing death and dying.

Chapter 5 brought forth explicit policy implications with regard to informing decision makers of ways to provide palliative caregivers in BC with the most meaningful and equitable supports, stressing the need to consider diversity and especially ‘who needs what kinds of supports’ when developing palliative care policy. Findings here stressed the need for a ‘systems approach’ to palliative care: one ensuring that high quality care is available in a variety of settings and that people and families have the information and support to move from one setting to another based on their needs. This same analysis also emphasized the important role that local communities can play in the palliative care policy process, contending that they must be provided with committed supports and resources necessary to achieve a dependable level of quality care. In order

to address inequities, it is argued that palliative care policy should be gender sensitive and informed by cultural factors. The knowledge of disadvantaged groups must also be included in the development of palliative care programs, and these groups should be also targeted for services (e.g., Aboriginal; mental health). Furthermore, findings in Chapter 5 point to the need for families to have more options in regard to the places where palliative care occurs. This can be done by encouraging and supporting the construction of more local hospices and enhancing the quality of palliative care provided in hospitals, particularly by implementing palliative care education programs for formal care providers in these settings. Complementing the systems approach advocated for in Chapter 5, Chapter 3 emphasizes that, due to the valuable role palliative family caregivers play in the health care system, efforts should also be directed towards valuing their work, facilitating resilience, and developing particular supports for those who are most vulnerable to caregiver burnout.

### **6.2.3. *Best practice in homecare nursing***

Homecare nursing is a highly spatial and place-based practice as it is based upon a unique understanding of how the environmental context influences health (CHNAC, 2008). As mentioned in Chapter 1, Canadian community health nurses (including homecare nurses), are registered nurses whose practice takes them to diverse settings including schools, shelters, churches, community health centres, and especially homes (CHNAC, 2008). Most generally, their professional goals are to prevent disease, as well as protect and promote health, and provide care for people experiencing acute, chronic, or terminal illness (CHNAC, 2008). This is done through the provision of clinical nursing care, health education, and counseling to individuals, families, groups, and populations (CHNAC, 2008). A critical part of their practice is to mobilize resources to support health by coordinating care and planning services, programs, and policies with individuals, caregivers, families and other community organizations (CHNAC, 2008). As such, the findings from this dissertation research provide information that can inform these

services, programs, and policies given its focus on palliative caregiving in the home. Furthermore, these findings shed light on the provision of care in diverse settings, with diverse individuals, which can assist in informing interventions to optimize best nursing practice.

Relevant to palliative caregiving and this dissertation research, a standard of best practice in homecare nursing requires nurses to consider the impacts of the determinants of health and various socio-environmental contexts of individuals and communities, such as financial resources, geography, and culture (CHNAC, 2008). Given that these same dimensions were touched upon throughout the analyses presented in this dissertation, the findings can assist in directing homecare nurses towards recognizing those particular differences that have been found to shape experiences of palliative caregiving and access to services (see Table 1). As has been mentioned several times already, the findings emphasize that such variables are not experienced in isolation, but are relational and often overlap and intersect in each individual's life creating unique contexts for care and support needs. Acknowledgement of this reality can assist homecare nurses in gaining a better understanding of these diverse lived realities, which can in turn help to inform strategies for optimizing best practice.

A standard of best homecare nursing is to facilitate access to services and equity in this access, which involves providing culturally sensitive care, advocating for appropriate resource allocation for individuals, and using various strategies to ensure potential and realized access to services for potentially vulnerable populations (CHNAC, 2008). Specific to palliative care, findings from this dissertation that have been synthesized in the above sections provide detailed examples of various existing inequities in accessing meaningful palliative care (e.g., rural residents, Aboriginal populations, those who do not speak English or French) as well as those population groups who are at increased risk of caregiver burnout (see Table 2). This information can help to assist homecare nurses in identifying those family caregivers who may be at

increased risk of burden and burnout, as well as facilitate more equitable access by advocating for the allocation of resources to these most vulnerable groups.

Findings from Chapter 3 contributed explicit implications for best practice nursing, particularly through identifying those broader socio-environmental factors that play a potential role in facilitating caregiver resilience. More specifically, these findings suggest the possibility for family caregivers to be targeted for individual-level interventions designed to enhance their capacities to be resilient. For instance, knowledge of the socio-environmental aspects of resiliency could be included in health care providers' assessments of family caregivers in order to better identify those family caregivers who are more likely to live in contexts that would facilitate resiliency and those who may be more vulnerable to burnout. Chapter 4 also raised implications specific to communication during homecare nursing interactions. One of the unique challenges of community nurses is building relationships within a complex, changing, and often-ambiguous environment (CHNAC, 2008). This study confirms this and adds that the home creates a challenging environment for care provision because of the sometimes competing roles and expectations of both homecare nurses (i.e., as guests and professionals) and clients (i.e., as hosts and care recipients). This relates to the importance of acknowledging spatial and spoken boundaries in the home, and the need for homecare nurses to successfully delineate and navigate these spaces in order to develop trusting relationships. Overall, this particular analysis points to the value in homecare nurses determining and using language that is appropriate for and relevant to each caregiver's social and physical location, which can be assisted by engaging with the home environment. Together, this information can help to inform interventions for best practice specifically in regard to the development of trusting and respectful relationships.

## **6.3. Encountered challenges**

### **6.3.1. *Writing geographic analyses for a non-geographic audiences***

The journey I've experienced in pursuing the PhD research presented herein has, as expected, brought forth many challenges. One major challenge that I had originally underestimated involved writing up geographic analyses for audiences situated outside the scope of the discipline. Although I could have taken the direction of tailoring my research to geographers and sharing insights about palliative caregiving research, I preferred the idea of exposing those falling outside of geography to the significance of place in health and health policy research. Therefore, each chapter included in this dissertation was written to target differing non-geography audiences. Chapter 2 was published in the *International Journal for Equity and Health*, and thus was tailored to those in political, policy-related, economic, social and health services-related researcher circles, and particularly those interested in systematic differences in distributions of one or more aspects of health in population groups. Chapter 3 has been published in, and Chapter 4 submitted to, journals whose audiences generally are nurses, health care professionals, social scientists and health policy makers. My final paper, Chapter 5, was written as a chapter in intersectionality-based policy analysis framework, with an incredibly varied audience, but primarily including those employed in, or researching, health policies in Canada.

Coming from a social science, qualitative, geographic background, I had become used to writing for those who were familiar with particular key disciplinary concepts. Meanwhile, it was not until my writing of Chapter 5 that I realized none of my intersectionality team members were aware of the difference between space and place, and one had summarized my paper in an introductory chapter of the policy reader using space and place interchangeably throughout the section. This made me realize my own assumptions that others would be aware of this difference and I quickly understood that I needed to be much clearer in defining geographic concepts in my work. It was while

writing Chapter 3 that I realized how difficult it was for me to write about complex, social-science heavy topics like resilience, social locations, and intersectionality for a more medical and policy orientated audience. Overall, I learned that introductions of papers should be structured to provide sufficient background on the geographic concepts used, like place, and also in the discussion, to relate the findings back to a point of relevance for the audience (e.g., implications for nursing practice, advancing palliative care policy). Furthermore, papers should be written using language tailored for the various audiences, which in my case involved the trying to avoid an overly social-science laden language. This challenge created a great learning exercise in translating research, a skill that I will undoubtedly draw upon in my future. Most importantly, successfully disseminating this research for these audiences has allowed me the opportunity to promote the discipline of health geography to those who may not normally be exposed to this area of inquiry.

### **6.3.2. *Conducting intersectionality-based analyses***

The challenge of conducting intersectional research has been widely acknowledged by scholars (for examples, see McCall, 2005; Valentine, 2007; Boleg, 2008; Nash, 2008; Hankivsky & Cormier, 2010). Recognized are the challenges inherent in the complexity of intersectionality, and because it is a relatively new concept there is little methodological guidance available for researchers wishing to use intersectionality in their work. I was well aware of these challenges before embarking on my PhD research journey, and in all honesty, was *very* hesitant to dive into this ‘sea of mud’ while still learning the basics of simply conducting research. However, it was from taking a class offered by Drs. Olena Hankivsky and Marina Morrow in my Master’s program at Simon Fraser University that I was first introduced to this theoretical approach and, ultimately, shifted the way I saw the world. When I decided that my PhD dissertation research would continue exploring diverse experiences of palliative caregiving, I realized that intersectionality would be a perfect fit. Well aware of the previously mentioned

challenges, I would not have had the courage to engage with intersectional scholarship without the support and encouragement of Dr. Olena Hankivsky and the many other researchers and graduate students I have met through my involvement in a Vancouver-based intersectionality reading group and my participation as part of a team working towards creating an intersectionality-based analysis framework for a wide range of stakeholders. Undoubtedly, my use of an intersectional approach in my PhD research has come from their support, which I was fortunate enough to have around me throughout my PhD program. Having access to others who are familiar with the struggles and challenges of conducting intersectional research and who are able to provide their feedback and advice and has been instrumental in me completing and publishing my intersectional-informed analyses.

Unsurprisingly, as there is little guidance regarding how to employ intersectional research, the first major challenge I faced in using such a framework was regarding whether or not it was even acceptable for me to apply intersectionality to my research because I would be using secondary data in three of my analyses (Chapters 2, 3, and 4). Originally I was very hesitant to explicitly associate these analyses with the intersectionality paradigm because they were drawn from larger existing research projects that had their own original theoretical and methodological positioning. This is a limitation of my research; however, applying intersectionality to secondary data is, at the very least, a starting point from which to further intersectional knowledge on palliative caregiving. Further to this, I realized that the lack of structured guidance around how to apply intersectional frameworks, in fact, allows for a great deal of flexibility. Although this application of intersectionality does open the doors for a greater debate regarding what makes a study 'intersectional', I believe as long as the analytic techniques employed were informed by the tenets of intersectionality (i.e., that: social categories intersect; it is concerned with multi-level analyses; it pays attention to power; it encourages reflexivity, emphasizes the importance of time and space; it recognizes the existence of diverse knowledges; and it focusses on social justice

and equity (Hankivsky et al., 2012)) these analyses contribute valuable knowledge that can be used as starting blocks from which future studies can build. Again, it was from the encouragement of those in my professional network that led me to understand that intersectionality comes in many forms and that you can still incorporate intersectionality into research by revisiting an original study, reanalyzing, or performing a secondary analysis.

After learning that it was possible for me to conduct intersectional analyses on secondary data, I spent much time thinking about where and how to begin. There is no guide or list of steps to follow on how to conduct an intersectionality analysis and some argue that the paradigm of intersectionality has only introduced a set of new methodological issues (McCall, 2005; Boleg, 2008; Hankivsky & Cormier 2010). For example, as Boleg (2008) states, although intersectionality theory provides a conceptually solid framework with which to examine the social locations of individuals and groups within the broader interlocking structures of power relations (Collins, 2000; Weber & Parra-Medina 2003), the methodological choices available to do so and/or guidance offered on how to do so are severely limited. I did know *who* would be included in my analyses (i.e., palliative caregivers and those experiencing death and dying), which was a start. However, sitting before secondary datasets consisting of interview transcripts, I was overwhelmed and unsure how to proceed. I was faced with the common challenge reflective of what has become a defining characteristic of intersectionality: acknowledging the complexity of participants' lived experiences, which expands to include multiple dimensions of social life and categories of analysis (Hancock, 2007). Clearly, this is an incredibly intimidating task to take on. As there is little known regarding what differences exist among palliative caregivers in Canada, I chose to begin by conducting an intersectionality-informed critical diversity analysis in order to first determine what kinds of differences existed among palliative caregivers that would affect their experiences and access to the CCB program (Chapter 2). The findings from this paper then inspired Chapter 3, which, using a case study method,

looked to explore what differences existed that placed some palliative caregivers in more 'privileged' positions in terms of their abilities to cope with caregiver burdens and mitigate burnout. Together, these papers and my time spent with and experiences of interviewing homecare nurses and families helped to inform the development and research design of Chapter 5, which was my individual attempt to conduct an intersectional study from the outset of the research process. It was through this iterative process of building upon the findings of my previous studies that allowed me to develop the research design of Chapter 5, create interview questions that I felt participants would be comfortable answering, and ultimately generate meaningful responses while conducting an analysis that I felt captured the complexity of palliative care experiences.

Building upon the previous challenge of how to conduct analyses that embrace the complexity of intersectionality, another challenge I faced pertained to how to actually frame, organize, and articulate findings in a way that was coherent for a reader. I found this incredibly difficult as intersectionality aims to embrace and capture complexity, diversity, fluidity, and the multiple interconnections and relationships that exist; however, academic papers require a very structured and formulaic output. The writing process for these papers, and especially Chapter 5, required a great deal of thought and planning regarding how to balance emphasizing the great complexity and diversity that exists with articulating findings in a clear and meaningful way. For Chapter 5, I believe I was able to overcome this challenge by anchoring my analysis in the concept of place. This technique allowed for me to frame my writing into three categorical findings (e.g., site, distance/proximity, and location), but still allowed me to discuss how each place was experienced in many different yet relational ways by diverse groups of people. In other words, it allowed me to situate and contextualize my analysis, while also providing me with a structure to present findings clearly via an academic paper. Similarly, Rönnblom (2008) uses the geographic concept of space and claims that this concepts anchors the analysis and allows for a more in-depth examination,

while providing opportunities to see concrete implications for dimensions of power and power relations that occur within policy in particular spaces. Considering this, I believe geographers may have much to offer regarding new and innovated ways to frame and contextualize intersectional analyses through the use of concepts such as place and space.

#### **6.4. Limitations**

As mentioned in the limitation section of the analytic chapters, it is worth repeating here that this dissertation is qualitative in nature and therefore does not seek representativeness in order to achieve overall generalizability of all palliative caregivers and palliative caregiving experiences in BC or Canada. Rather, I have sought to qualitatively acknowledge diverse lived experiences within the contexts in which they occur, which allows for transferability of findings. Transferability refers to the process whereby readers of this research are able to infer these findings into their own research situations (Graneheim & Lundman, 2004). In other words, by explaining the context within which the findings of this study emerged, others are to determine whether or not they can “transferred” into another context.

Although the objectives of three chapters (Chapter 2, 3, and 5) were directed towards identifying categories of difference that were not preconceived from the outset, it is important to acknowledge that my own cultural positioning, socialization, and ongoing education has most certainly played a role in identifying the diverse axes of difference that emerged in these analysis. However, the processes of defining these categories involved ongoing input from other researchers and expert scholars during the analytic processes, which broadened the lens with which the data was viewed and allowed for a variety of perspectives to inform the construction of categorical differences found within. I believe that this form of investigator triangulation aided with

undoing the potential for my personal positioning to disproportionately guide interpreting the findings shared in any of the chapters.

The findings shared in this dissertation are not meant to be used towards generating or reinforcing stereotypes based upon particular populations groups that that may be seen as vulnerable and at high risk of experiencing caregiver burnout, or seen as low risk with high capacity for resilience. For example, some population groups listed as being at high risk for caregiver burnout in Table 2 may in fact be at low risk despite socio-environmental contexts due to personal, family, and other factors. Therefore, this research is not meant to dismiss the complexity and unique context of each situation, but rather is intended to bring greater awareness to the multi-dimensional and diverse social and physical locations in which families and family caregivers are situated and how such positioning actually influences palliative caregiving experiences.

Although this research speaks to experiences of informal palliative caregiving, Chapters 2 and 5 rely on the perspectives of formal front-line palliative care providers. As such, these analyses miss out on the experiential perspectives that can be offered by family caregivers themselves, suggesting an important avenue for future research. However, for the purpose of this research, formal palliative care providers' perspectives were purposely sought because of their experiences working with numerous different families across time, allowing them to speak to any trends they witnessed with regard to diversity and inequity.

## **6.5. Potential Future Directions**

There are numerous directions to continue the areas of inquiry examined in this dissertation. Although the analytic findings generated information regarding axes of difference that shape palliative family caregiving experiences, there is much potential

for research to continue exploring relational aspects of family caregiver diversity. For example, there is little known regarding the experiences of palliative caregiving among families from the lesbian, gay, bisexual, or transgendered (LGBT) communities. One guide for care professionals from the United Kingdom acknowledges that these communities may face particular challenges. For example, those who are older and lesbian, gay, or bisexual would have had fewer opportunities to have children outside of heterosexual relationships and/or may have limited inter-generational networks (National End of Life Care Programme, 2012). Therefore, they may have a smaller social network to draw upon for caregiving support, and thus be more reliant upon health and social care services, yet may be reluctant to access them for fear of discrimination (National End of Life Care Programme, 2012). Considering this, there is much to learn about palliative care and caregiving within the diverse LGBT community. For example, do differences in the experiences of the home environment, the dying process, and family caregiving differ across these family structures. A key question is: what impacts do other intersecting social and physical aspects of place have on this experience (e.g., age, gender, socio-economic status)?

Although there is an increasing awareness from researchers regarding the importance of cultural diversity in the palliative care context (Mackinnon, 2009; Pesut et al., 2010; Donovan et al., 2011), health geographers have much to offer here as well in regard to identifying how cultural variables shape meanings and experiences of place and/or the home. For example, spatial frameworks can be employed to examine how individuals and groups use certain beliefs and practices in the home setting during the dying process.

There still exists a lack of research that applies a critical lens to palliative care and caregiving (Mackinnon, 2009). Consideration of social justice theories, with specific reference to equal access and opportunity and equitable supports to all groups, could play a significant role in understanding and addressing the multiple oppressions faced

by individuals (Mackinnon, 2009; Pesut et al., 2012) and how this oppression shapes palliative caregiving experiences and experiences of a sense-of-place. Here, a relational conception of place can be employed to address questions of inclusivity and how individual and systematic barriers can be addressed by considering the multiple scales at which they are constructed (e.g., micro, meso, and macro). There is also a need for more research to explore how discrimination, stigmatization, and/or oppression affect the palliative caregiving process and experiences of providing palliative care in particular settings. For instance, how does the experience and meaning of particular settings change for palliative family caregivers who face social discrimination (e.g., ethnic minorities, same-sex couples, care recipients with stigmatized disease such as HIV/AIDS)? How does this positionality affect choices, access, and use of formal palliative caregiving services? How does this positionality affect the experience of caregiver burden or capacity to cope? Such an approach can also be applied towards gaining a better understanding of differing positions, like the care recipient's experience of palliative care.

Finally, the conceptual framework used in this dissertation can be meaningfully applied to other health and social care issues that take place across a variety of settings other than the home (e.g., clinical, community centres, residential homes, mental health or addictions centres). Here, geographers have much to offer by employing a relational concept of place to such healthcare interactions. One potential direction is to explore how care is intertwined and co-constructed with the physical and social dimensions of place in these settings. More research is also needed to explore how care, among diverse populations, is simultaneously shaped by factors from multiple scales, ranging from the body, the household, the community, region, nation, and beyond. Such research will further advance our understanding of the influence of socio-political and cultural pressures, expectations, and responsibilities on health care experiences. This information can further inform strategies for more effective methods of delivering

health care that aims to provide equitable and meaningful access for all population groups.

## **6.6. Conclusion**

In the context of a rapidly aging population, an increasing number of Canadians are becoming aware that they will be called upon to provide care for a family member or friend approaching the end of life (Canadian Caregiver Coalition, 2011; Canadian Hospice Palliative Care Association, 2012; Canadian Hospice Palliative Care Association, 2013). Although not all dying Canadians will be in need of palliative care, reports about the underutilization of palliative care supports and services are troubling because they point to a critical gap in Canadian health care policy and practice. It is increasingly apparent that the way palliative care is currently being defined, administered, and delivered in Canada is not meeting the needs of and/or reaching its potential users (Carstairs, 2005; Canadian Hospice Palliative Care Association, 2012).

The research presented herein has generated information that can lead to a better understanding of the barriers some family Canadian caregivers face in accessing palliative care services and, through acknowledging diversity, what particular needs exist in order to improve such supports. By grounding this research in lived experiences and seeking the perspectives from those working on the front-lines in palliative care, this research has been able to offer valuable knowledge that sheds light on the complex lived realities of informal, and sometimes formal as well, palliative caregivers in Canada. More specifically, this research has identified particular differences that exist and, importantly, how these differences *intersect* to impact caregivers' access to palliative care services and supports. Furthermore, by acknowledging diversity, specific needs of population groups have been revealed, offering valuable information on how to better direct the delivery and provision palliative care in Canada towards providing meaningful and useful supports for all. Thus, this research contributes knowledge that can inform

decision-makers in palliative care policy and homecare nurses working on the front-lines on ways to improve access, lessen inequities, and better meet the needs of dying Canadians and their palliative family caregivers. Such efforts can assist Canadian health care systems with reaching the aim of universal access while providing all citizens with quality care and support across the entire spectrum of life, from birth until death.

In contemporary Western society, it is common for people to ‘turn a blind eye’ and deny that death is an inevitable event in each of our lives. Yet, at some point, in some way, death will come to us, whether it is when we are called upon to provide care for a dying friend or family member or when we ourselves require care from others. Despite this reality, palliative care remains at the margins in Canadian health care, with only a small number of provinces or territories designating palliative care as a core service under their health plans, and with at least 50 percent of designated palliative care programs being funded solely by charitable donations (Canadian Hospice Palliative Care Association, 2012). In order for palliative care to become a priority in our health care system, it needs to become a priority for Canadians. This presents a challenge as it depends upon the ability and willingness of individuals to talk about death and dying. It is my hope that the translation and mobilization of research findings, including those presented herein, will help to spark such conversations, emphasizing that palliative care is important for everyone, which will in turn result in momentum regarding palliative care advocacy and ultimately an enhanced palliative care system that adequately supports informal caregivers.

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## **Appendices**

## Appendix.

### My role in the larger studies that the analyses presented herein contribute

Chapter	Larger Study	My Role	Data used in analyses
<p><b>2:</b> <i>Critically examining diversity in end-of-life family caregiving: Implications for Canada's Compassionate Care Benefit</i></p>	<ul style="list-style-type: none"> <li>• <i>Primary Investigators:</i> Drs. Allison Williams &amp; Valorie Crooks</li> <li>• <i>Aim:</i> To evaluate Canada's Compassionate Care Benefit from the perspectives of the primary stakeholders</li> <li>• <i>Data Collection:</i> BC, AB, ON, QC, NFLD</li> </ul>	<p>Recruitment of the formal front-line palliative caregiver stakeholder group. Conducted semi-structured interviews with these participants (n=50)</p>	<p>Transcripts of the semi-structured interviews I conducted with formal front-line palliative caregivers (n=50)</p>
<p><b>3:</b> <i>Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: A qualitative case study</i></p> <p><b>4:</b> <i>Examining the language-place-healthcare intersection in the context of Canadian homecare nursing</i></p>	<ul style="list-style-type: none"> <li>• <i>Primary Investigator:</i> Dr. Kelli Stadjuhar</li> <li>• <i>Aim:</i> To explore the understandings and enactment of 'empowerment' among family caregivers within the home care context</li> <li>• <i>Data Collection:</i> Vancouver Island and Fraser Health Authorities, BC</li> </ul>	<p>Recruitment of participants (i.e., home care nurses) in the Fraser Health Authority. Collected observational fieldnotes (36 hours) and conducted semi-structured interviews with these participants (family caregivers, n=5; care recipient, n=5; home care nurses, n=5)</p>	<p><b>Chapter 3:</b> All observational fieldnotes and interview transcripts from the larger study (i.e., Vancouver Island and Fraser Health Authorities)</p> <p><b>Chapter 4:</b> Observational fieldnotes and interview transcripts from the data I personally collected (i.e., Fraser Health Authority)</p>
<p><b>5:</b> <i>Intersectionality and the 'place' of palliative care policy in British Columbia, Canada</i></p>	<ul style="list-style-type: none"> <li>• <i>Primary Investigator:</i> Myself</li> <li>• <i>Aim:</i> To explore inequities in palliative care policy in BC</li> <li>• <i>Data Collection:</i> BC</li> </ul>	<p>Study design, participant recruitment of front-line palliative care providers, and data collection (semi-structured interviews with these participants, n=20)</p>	<p>All transcripts of semi-structured interviews (n=20)</p>