

Care journeys: A multi-method exploration of long-term care service users and family caregivers in British Columbia

by

Taylor Hainstock
Bachelor of Health Science (Honours), Western University, 2011

A Thesis Submitted in Partial Fulfillment
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Supervisory Committee

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Abstract

This project focused on developing a more complete picture of the event that most often occurs when an older adult's health care needs can no longer be met in the community setting; the transition from home into a new long-term care (LTC) environment (i.e., assisted living [AL] or residential care [RC]). Informed by a life course perspective (Elder, 1998; Marshall, 2009) and by the health service utilization framework (Andersen, 1995; Andersen & Newman, 1973), this thesis explores the relationship between service users and their social and service contexts in the Fraser Health (FH) region of British Columbia.

Employing a multi-method research design, two studies, one quantitative and one qualitative, were conducted. The goal of the quantitative study was to draw attention to individual, social, and structural factors (e.g., age, gender, marital status, presence of/relationship to primary caregiver, and health variables) that influence the transition from home and community care (HC) services to either AL or RC among older LTC clients (age 65+; N=3233) in three geographic areas (urban, suburban, and rural). Findings revealed that marital status, income, functional disability, and cognitive performance influenced type of transition for both rural and urban clients. However, gender, medical frailty (i.e., CHESS score), number of chronic conditions, and total hospitalizations emerged as significant among clients in suburban areas.

The goal of the qualitative study was to draw attention to the role of family caregivers in the care transition context. Employing thematic analysis, this study drew on a sample of 15 semi-structured interviews with family caregivers who had helped a

family member transition from home into a new care environment in FH. Out of this work, a conceptual framework was developed inductively to illustrate three key phases that seemed important in their care journey: *'Precursors leading to transition'*, *'Preparing to transition into new care environment'*, and *'Post-transition: Finding a new balance'*. Three overarching themes, labelled with direct quotes (*in vivo*), were also developed to capture how family caregivers made sense of their roles and responsibilities: *"I'm just her daughter"* / *"I'm just his wife"*, *"Just go with the flow"*, and *"There wasn't a door I didn't try to open"*.

Overall, the findings from both studies draw attention to the importance of generating a better understanding of the local service and social contexts. Implications for social policy are addressed and highlight the need to continue to invest in efforts aimed at supporting older adults to remain in the community as long as possible, including ensuring appropriate forms of care are available and adequate resources for family caregivers are offered.

Keywords: caregiving journey, family caregiving, long-term care, residential care, transitions in care

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Dedication

To Betty Jewell: The quintessential caregiver.
Your pure, unconditional love continues to inspire me daily.

Chapter 1: Introduction and scope of project

1.1 Introduction

Canadian older adults are living longer and in better health than ever before (Canadian Institute for Health Information [CIHI], 2011). In 2015, we witnessed a historic population shift where, for the first time ever, the number of people aged 65 and over exceeded the number of children under 15 (Statistics Canada, 2015). Furthermore, demographers project that by 2036, one in every four Canadians will be over 65 (Statistics Canada, 2014). The rapidly growing proportion of older adults, combined with their increasing longevity, is unquestionably altering the current and future demographic profile of our nation. These demographic shifts place pressure on the Canadian health care system, but particularly on the long-term care (LTC) sector, as forty-five percent of health care costs per year in Canada are spent on those over the age of 65, despite the fact that they only account for 15 percent of the overall population (CIHI, 2014). With increased recognition of the growing numbers of older adults, concerns have been raised about the sustainability of the healthcare system (Gee & Gutman, 2000). However, Chappell (2011) argues that the popular and negative 'apocalyptic' view of our aging society is oversimplified.

Aging is a unique process that is not uniform across all individuals. However generally speaking, the risk of becoming increasingly frail and in need of care often increases with age. Current health and social policy efforts are largely focused on increasing older adults' independence and quality of life; enabling and supporting them to remain living in the community for as long as possible. The 2011 Census of Canada found that 93% of Canadians over the age of 65 lived at home in private households or dwellings; with their first sources of health and social support typically being a spouse or

co-resident (CIHI, 2011). Despite wanting to age at home and maintain independence for as long as possible, we know that as health care needs advance, remaining at home has its challenges. Access, availability, and use of supportive resources vary widely and are largely dependent on an individual's local and social context, including their location of residence (urban/suburban/rural) and the presence and level of involvement of informal caregivers.

The purpose of my thesis was to generate a more complete picture of movement between or within LTC service and to explore how care transitions link to the larger social policy goal of supporting older adults to remain in the community as long as possible. My research was informed by two theoretical perspectives: the life course perspective ([LCP]; Elder, 1998; Marshall, 2009) and the health service utilization framework (Andersen, 1995; Andersen & Newman, 1973), I employed a multi-method research design (Morse, 2010, Tashakkori & Teddlie, 2010) to explore the relationships between service users and their local service and social contexts. More specifically, I chose to focus on the event that most often occurs when an older adult's care needs can no longer be met in the community; the transition from a home setting into a new LTC environment (i.e., assisted living [AL] or residential care [RC]). By bringing together quantitative and qualitative work spanning three different types of communities (urban, suburban, and rural), I consider how LTC services were used and the experiences associated with organizing and navigating their use. These findings have generated meaningful information to improve our understanding of how local service and social contexts relate to policy efforts to support older adults to age in place.

This first chapter provides an introduction to the main bodies of literature that I drew on for my project and includes: the relationship between aging and geography; transitions in care; and family caregiving. This chapter concludes with a review of my research objectives, my specific research questions, and an outline of the paper-based thesis structure.

1.1.1 Aging and geography

The social determinants of health literature tells us that the conditions in which we are born, grow, work and live influence our health and well-being (Commission on the Social Determinants of Health, 2008). Echoing this, there has been a growing interest in exploring the relationships between older individuals' health and the environments in which aging occurs (Glasgow & Berry, 2013; Hennessy et al., 2014; Keating, 2008; Skinner & Hanlon, 2016). Researchers examining the relationship between health and geography often employ a binary approach, highlighting the significant differences between populations living in rural and urban locations. Researchers who explore differences in population characteristics by geographic location most often suggest that rural populations have lower incomes, less education and lower life expectancies (Allan, Funk, Reid, & Cloutier-Fisher, 2011; Kulig, 2010; Pong et al., 2011). Also, an inverse relationship between health status and geographic remoteness is often reported (Allan & Cloutier-Fisher, 2006; Keating, Eales, & Phillips, 2013; Kitchen, Williams, Pong, & Wilson, 2011), with older adults in rural areas often identified as having poorer health, higher levels of impairment (Forbes & Janzen, 2004), and a higher incidence of chronic disease (Jones et al., 2009) compared to their urban counterparts.

At the same time, researchers have drawn attention to significant differences in the utilization of health services between urban and rural populations (Cloutier et al., 2016; McDonald & Conde, 2010; Kitchen et al., 2011). Both the Romanow Report (2002) and the Kirby Report (Kirby & LeBreton, 2002), for example, drew specific attention to the challenges that rural and remote populations face in accessing health services due to limited local services (e.g., number of hospitals, physicians, specialists, home and community care resources, AL and RC facilities). However, research that explores health status and health service utilization in comparative geographical contexts often offers mixed results (Kitchen et al., 2011). This is largely based on different approaches to defining urban versus rural environments (du Plessis, Beshiri & Bollman, 2001) and the diversity of each community type (e.g., distance from urban center, volunteer base, social engagement, and physical activity opportunities; Jeffery et al., 2013; Keating et al., 2013).

With the increasing likelihood of experiencing cognitive and physical decline with age, LTC services are fundamental in supporting older adults and their families as they cope with changing demands and needs (Chappell & Hollander, 2013). Despite growing awareness of the importance of these services, there has been little attention in the existing literature to differences in LTC service use by geographic area (Cloutier et al., 2016). Because community capacity to meet the needs of an aging population is both highly variable and context dependent (Wiles et al., 2012), further research is required. Generating a better understanding of LTC service users and their local service context can help generate meaningful information to meet the diverse and changing needs of

our population. Thus, exploring the implications of geography for LTC service use is a chief interest of my work.

1.1.2 Transitions and trajectories in care

Changes in health care needs and increased health complexities over time often lead to multiple interactions with health professionals across a variety of care settings (Coleman, 2003). This is particularly evident among older adults (Dilworth-Anderson & Palmer, 2011; Sato et al., 2011). Transitions in care (e.g., movement within or between care settings) can occur as a result of a variety of factors, but are particularly significant because it is at these points that older adults are often considered to be most vulnerable (e.g., due to factors such as older age, living alone, female gender, and being unmarried/widowed; Gaugler et al., 2007).

Studies looking at care transitions predominantly focus on specific populations (e.g., dementia, cancer, stroke or hip fracture patients) and on the adverse outcomes and personal experiences associated with these moves (e.g., hospital readmission and medication errors; Arbaje et al., 2008; Coleman, 2003; Gozalo et al., 2011; Manderson et al., 2012; Reid et al., 2013). Most care transition literature focuses on single transitions to/from the hospital setting (e.g., from home to hospital, hospital to AL/RC, AL/RC to hospital, or hospital back to home). However, less care transition research focuses on movement specifically between LTC services including the transition from home and community care (HC) to RC or HC to AL (Chen, 2011; Fischer et al., 2003; Rockwood et al., 2014). More recently, there has been some attention to the movement from AL to RC (Maxwell et al., 2013; McGrail et al., 2012; Rosenberg et al., 2006).

Many researchers have identified significant predictors of care transitions, often applying the health services utilization framework (Andersen, 1995, Andersen & Newman, 1973) to quantitative analyses. Researchers use this framework to draw attention to individual, social and structural factors that influence entry into a new LTC care environment such as AL or RC. Studies have consistently shown that age, functional status (e.g., dependencies in activities of daily living [ADLs] such as eating, bathing, and dressing) and cognitive status (e.g. presence of dementia) are the most significant predictors of entry into AL or RC (Gaugler et al., 2007; Luppia et al., 2010; Rockwood et al., 2014). However, despite ongoing interest in predicting health service use, there is a limited body of knowledge, and no definitive consensus, on the role of geographic location in influencing transitions between LTC services. Studies that do include place of residence as a predictor of health service use typically limit their focus to the main effects of geographic location, thereby overlooking interactions between geography and other predictors (Akamigbo, 2006; Eska et al., 2013).

With social policy efforts largely focused on meeting the needs of older adults and their families, a central goal of my research was to explore service use and the local social context for individuals who transitioned between key LTC services. Based on identified gaps in the literature, the quantitative component of my thesis specifically contributes to building a better understanding of the intersection between geographic location (i.e., urban, suburban, rural) and factors that influence individuals' transitions between care environments (e.g., HC to AL and HC to RC).

1.1.3 Family caregiving

Transitions in care are often identified as being critical junctures not only in the lives of the individuals experiencing the move, but also for families and friends (Coleman, 2003). Transitions are often made more difficult due to the “siloes” nature of our health care system that results in health services being delivered independently of one another, often leaving the older adult and their family as the only common thread journeying across the health care system (Coleman, Parry, Chalmers & Min, 2006).

Family caregivers play an instrumental role in supporting and maintaining the well-being, functional independence, and quality of life of older adults (Chappell & Hollander, 2013; Kemp, Ball, & Perkins, 2013; Naylor & Keating, 2008). Over the course of their caregiving journey, family caregivers take on a variety of activities; caregivers often seek, obtain and coordinate formal care services for their family members (Brody, 2004; Cranswick & Dosman, 2008; Gitlin & Wolff, 2011; Milligan, 2009; Keating et al., 1999; Sinha & Bleakney, 2014). Sinha and Bleakney (2014) report finding that 31 percent of Canadian caregivers engaged in scheduling and coordinating appointments for their family members and 27 percent managed their finances. Further, we know that when an older adult’s care needs reach a point where they can no longer live safely or independently at home, family caregivers take on distinct caregiving activities to help navigate the transition from home into a new LTC environment (Ashbourne, 2015; Giosa, Stolee, Dupuis, Mock & Santi, 2014). Only a small body of research focuses on the ‘care management’ activities within a larger family caregiving role (e.g., care-related dialogue with other family members or the care recipient about the arrangements for formal care services and financial matters, doing relevant paperwork, and seeking information; see Rosenthal et al., 2007). The provision of this type of ‘managerial care’

is a valuable component of caregiving, particularly so over the course of a care transition, however these tasks have been largely overlooked within the existing family caregiver literature. Exploring these caregiving activities was a key focus of my research.

Currently in BC, there are two Ministry of Health mandated assessment instruments (RAI-HC and RAI-MDS 2.0) used by health professionals to evaluate individuals' need for care in all HC and RC environments. These assessment instruments collect different types of information about the presence and level of involvement of family caregivers in the care of the older adult client. Specifically, while the RAI-HC captures very limited information on family caregivers (14 questions total out of approximately 300 items related to the client; Carpenter & Hirdes, 2013), and is predominantly comprised of yes/no questions such as: "lives with client?" and "provides advice or emotional support?", the RAI-MDS 2.0 used in RC facilities does not include any questions on family caregivers. This is problematic. We know family caregivers are instrumental in supporting older adults throughout their care journeys and yet, we have little data we can use to explore their level of involvement in relation to the older adult particularly when they enter a new LTC environment.

To address these limitations and capture such information, an emerging body of literature focuses on experiences and satisfaction of clients and caregivers with LTC services and transitions in care from the perspective of the family and caregivers (Ashbourne, 2015; Giosa et al., 2014). However, within this literature only limited attention has focussed on family caregivers' roles, responsibilities, and subjective

experiences (e.g., challenges and/or joys and care management activities) in helping family members transition between care environments.

1.2 Project objectives

As noted above, despite the growing attention this topic has received, there remains a gap in our understanding of the local service and social context factors associated with transitions in care. Yet, based on the changing demographics of our nation and the goals of social policy to keep individuals in their homes for as long as possible, there is a need to better understand transitions from home into a new LTC care environment, including the role of geographic location and of family caregivers.

To address these gaps, my thesis focussed on developing a more complete picture of movement across the LTC system in the Fraser Health (FH) region of BC. Using a multi-method approach (Morse, 2010; Tashakkori & Teddlie, 2010), my project was comprised of a quantitative study and a qualitative study. First, I worked with the quantitative administrative data to produce a broad, analytical understanding of two key transitions in care: home care to assisted living or home care to residential care. The main goal of these quantitative analyses was to draw attention to individual, social, and structural level factors (e.g., age, gender, marital status, presence of/relationship to primary caregiver, and health variables) of those who make the transition from HC to AL or HC to RC. The specific research questions for the quantitative component were:

1. What patterns exist in the transitions from HC to AL and HC to RC in urban, suburban, and rural areas of FH?
2. How do individual, social, and structural factors influence the transition from HC to RC as compared to AL, in urban, suburban, and rural contexts?

Following the quantitative work, I completed a qualitative study that explored the unique timeframe in a family caregivers' caregiving journey when they help a family member through the transition from home into a new LTC environment. I focussed on generating more in-depth information on the complex array of activities (e.g., care management and system navigation) that family caregivers engage in before, during, and after a transition between care environments. The specific research questions for the qualitative component were:

1. How do family caregivers manage and navigate a key transition in care for a family member and what are their experiences (e.g., the kinds of activities involved, decisions needed to be made, joys, and challenges faced) in doing so?
2. How do family caregivers make sense of the many layers of their caregiving roles and responsibilities?

Bringing together insights from both the quantitative and qualitative analyses supported the development of a more rich and complete picture of care transitions. This exploratory thesis project provides new insights into individual, social, and structural factors that influence service use and experiences in system-navigation from both aggregate data and personal experience perspectives. As such, it has generated valuable information that can help support the care of vulnerable populations. This project provides a more in-depth understanding of what happens when individuals' health needs change and exceed their family caregivers' and their local service contexts' caregiving capacities. Subsequently, by exploring the multi-dimensional nature of care transitions, findings from this project can help to inform current social policy efforts aimed at supporting older adults to remain in the community as long as possible.

1.3 Paper-based structure of thesis

This thesis features seven chapters. Through discussions with my supervisory committee, I present the quantitative and qualitative studies as two manuscripts that are intended to be submitted for publication. However, similar to a more traditional non-paper-based format, I have still structured my work as a cohesive unit with a logical progression from one chapter to the next. Using a paper-based approach resulted in some areas of unavoidable overlap in terms of chapter content, particularly in regard to the background and context (Chapter 3) and methods (Chapter 4) sections. The literature I discuss in Chapters 1 and 3 is intended to provide an introduction to the main topic areas (i.e., geography and aging; transitions in care; and family caregiving). For Chapters 5 and 6, the literature reviews are refined to provide more detail on factors that influence care transitions (Chapter 5) and family caregiving roles and responsibilities (Chapter 6).

In this first chapter, I have provided a brief overview of the topic areas and introduced the overall objectives of my project. In Chapter 2, I introduce the theoretical perspectives that informed my work: a life course perspective (Elder, 1998; Marshall, 2009) and the health service utilization framework (Andersen, 1995; Andersen & Newman, 1973). The focus of Chapter 3 is to provide background and context-specific information to help set the scene to understand LTC and the range of services it captures. In this chapter, I start by providing the operational definition of LTC that I used for my project and then outline the specific LTC services I focused on. In Chapter 4, I discuss the multi-method research design and my rationale for selecting this approach. I also introduce the larger research project (British Columbia Trajectories in Care Project) within which my thesis is set; including the project area

(Fraser Health) where the data was derived. Ethical considerations are discussed, followed by a description of the process for gathering data. Lastly, I outline the data management and analytic techniques and strategies I used. The chapter concludes with a statement on my role as a researcher in this work.

Consistent with a multi-method research design Chapters 5 and 6 present key findings from the quantitative and qualitative work. Chapter 5 reports on the quantitative analyses of the FH administrative health data addressing the individual, social, and structural factors (i.e., predisposing, enabling, and need) that influence the transition from HC to either AL or RC, and how they vary by geographic location (urban, suburban, and rural) for vulnerable older residents. In Chapter 6, I focus on the unique timeframe in a family caregivers' care journey when they help a family member to transition from home into a new LTC environment. One of the outcomes in this paper is the development of a guiding conceptual framework to help illustrate this distinct period in an individual's caregiving journey, including how they managed, navigated, and made sense of their roles and responsibilities across their family member's care transition. Building from and reflecting on the experiences captured by the framework, this chapter concludes with a discussion of three overarching themes (Braun & Clarke, 2012) that emerged from the study. In Chapter 7, I bring together the quantitative and qualitative findings with a summary of the key insights and a discussion on the potential contributions a multi-method project like this has for long-term care policy and programming.

Chapter 2: Theory

In Chapter 2, I discuss the theoretical perspectives, used heuristically, that informed my thesis. These included: a life course perspective (Elder, 1998; Marshall, 2009) and the health service utilization framework (Andersen, 1995; Andersen & Newman, 1973).

2.1 Life course perspective (LCP)

Over the last 45 years, a LCP has become widely adopted by researchers exploring aging. There are six interrelated, core themes of a life course perspective (Elder, 1998; Shanahan, 2000). These include the interplay of human lives and historical time, the timing of lives, linked or interdependent lives, human agency in making choices, diversity in life course trajectories, and developmental risk and protection (see Table 2.1 for definitions; Hutchison, 2011).

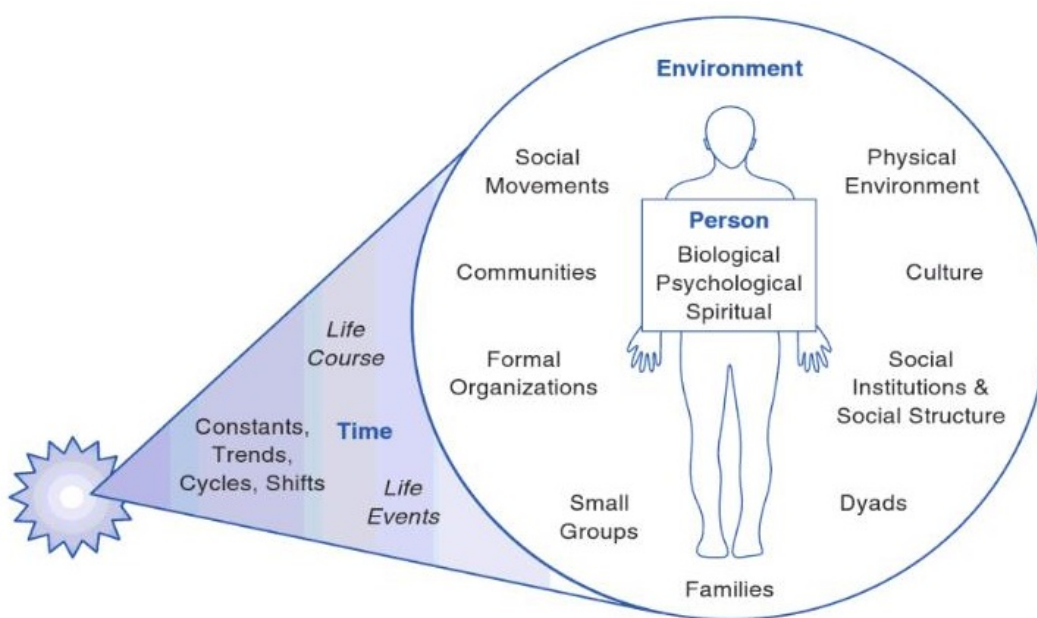
Table 2.1 Central themes in a life course perspective

Interplay of human lives and historical time	Individual and family development must be understood in historical context.
Timing of lives	Particular roles and behaviours are associated with particular age groups, based on biological age, psychological age, social age, and spiritual age.
Linked or interdependent lives	Human lives are interdependent, and the family is the primary arena for experiencing and interpreting wider historical, cultural, and social phenomena.
Human agency in making choices	The individual life course is constructed by the choices and actions individuals take within the opportunities and constraints of history and social circumstances.
Diversity in life course trajectories	There is much diversity in life course pathways as a result of cohort variations, social class, culture, gender, and individual agency.
Developmental risk and protection	Experiences with one life transition or life event have an impact on subsequent transitions and events and may either protect the life course trajectory or put it at risk.

Source: Hutchison, E. D. (2011). Central themes of a life course perspective. *Dimensions of human behavior: The changing life course* (4th ed., p.21). Thousand Oaks, CA: SAGE Publications, Inc.

These core themes focus on the lives of individuals over time (Elder, 1998; Marshall, 2009) and emphasize the “continuities as well as the twists and turns in th[eir] paths” (Hutchison, 2011; p.38). This perspective recognizes the importance of individual level biographical and social structural characteristics such as age, gender, and health status in shaping life course trajectories, as well as the broader social contexts within which older adults and family caregivers are situated (e.g., geographic location, family, and work worlds; see Figure 2.1; Hutchison, 2011).

Figure 2.1 The relationship between person, environment, and time



Source: Hutchison, E.D. (2011). The relationship of person, environment, and time. *Dimensions of human behaviour: The changing life course* (4th ed., p.9). Thousand Oaks, CA: SAGE Publications, Inc.

A LCP is often used to explain developmental changes over the life course at an individual level. However, Marshall (2009) suggests that it is also a useful analytical approach to inform and guide the development and analysis of public policy. He

suggests that the LCP can look beyond the individual to more thoroughly focus on exploring how individuals, their families, and broader social networks interact and change over time (Marshall, 2009). More recently, applications of the LCP have moved past exploring the relationships of age and family, extending to more empirically based studies (e.g., longitudinal studies with large data sources and more opportunities for advanced quantitative analysis; Dannefer & Kelly-Moore, 2009; Penning, Cloutier et al., 2016). I chose to use a LCP to inform my work as it is a theory that guides a substantial portion of the existing literature and research exploring family caregiving, yet is considered a more novel way to consider LTC trajectories using administrative data.

Principles of the LCP are reflected in both the quantitative and qualitative components of my thesis. The quantitative study explores transitions between one LTC service to another (HC to AL or HC to RC) using core variables embedded in this perspective (e.g., the influence of age, gender, marital status, health status; presence of/relationship to caregiver). Stratifying my analytic cohort by geographic area (urban, suburban, and rural) also helps to highlight differences in service users and their local service contexts. Geographic area is also embedded in a LCP, as it is recognized as having influence on individuals' lives over time. Applying a LCP to the quantitative work helped to highlight the differences in individuals' care trajectories as they move through the health care system.

A LCP recognizes that chronological age, relationships, common life transitions, and social change all contribute to shaping individuals' lives (Hutchison, 2011). For the qualitative study, I collected more in-depth information on the ways that core LCP themes influence individual experience. In particular, I focused on exploring the role and

experiences of family caregivers as they journeyed alongside their family members' transitions into a new care environment (i.e., from home into AL or RC). Care transitions are often seen as junctures in time when family caregivers experience changes in their care responsibilities and relationships with their family members (Levine & Feinberg, 2012). These role and relationship changes often reflect linkages between early life experiences and later experiences in adulthood (Hutchison, 2011). A LCP helps to make sense of how family caregivers are interconnected as they journey alongside their family members as they transition. Further, this perspective helps us to think about how the nature of these familial relationships frame the way caregivers conceptualize their roles, responsibilities, and experiences in navigating their family members' care transitions.

2.2 Health service utilization framework

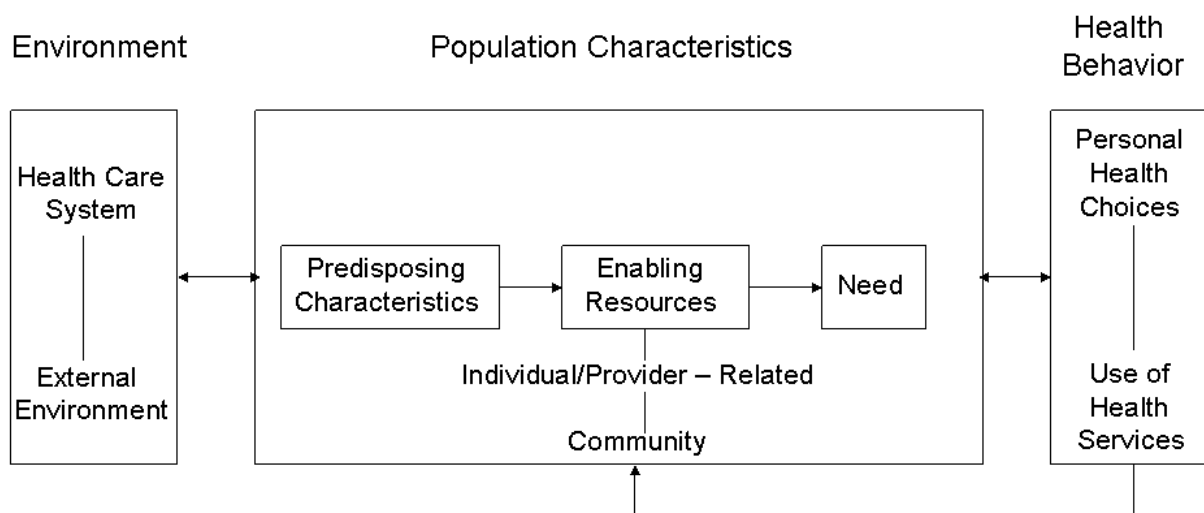
The health service utilization framework, often known as the Andersen-Newman Model (Andersen, 1995; Andersen & Newman, 1973) also guided the organization of the data analysis in the quantitative study, including the selection of variables and set-up for the analyses. The original framework was developed in the late 1960s to help understand the 'how's' and 'why's' of health service use among families (Andersen, 1995). However, this framework has since been expanded and become one of the most widely applied approaches for investigating the use of health services by individuals and populations.

Over the years, a number of variations of this framework have emerged, but the main premise remains that an individual's utilization of health services is predominantly related to three broad categories of societal and contextual factors including:

predisposing (e.g., age and gender), enabling (e.g., marital status, income, geographic location, presence of informal caregiver), and need characteristics (e.g., health status) that either facilitate or impede health service use. Emerging from the recognition that the broader determinants of health (i.e., environment, lifestyle, and healthcare organization) can impact an individual's health (Lalonde, 1974), 'Phase 3' of the framework (1980s-1990s) introduced the external environment (e.g., geography, political, and economic contexts) as being important elements that contribute to building a better understanding of health service use (Andersen, 1995). In the "Emerging Model – Phase 4" (see Figure 2.2), Andersen and colleagues emphasize the "dynamic and recursive nature of health services' use", which is portrayed by the multiple influences on health service use and the feedback loops between the predisposing, enabling, and need variables and the individuals' health outcome (Andersen, 1995, p.7).

We know that health service use is strongly related to an individual's 'need'. However, the rationale for applying the health service utilization framework to the quantitative analysis is based on the framework's ability to explore how other important contextual factors influence an individuals' health service use. Grouping factors into predisposing, enabling, and need categories allowed me to explore how these variables operate in influencing an individual's transition from one LTC service to another. This framework was also useful because it was easy to adapt to my data set (e.g., the predisposing, enabling, and need factors selected for my analysis were based on what variables were available in the administrative data set and not pre-defined by the model). For these reasons, I felt the health service utilization framework was the appropriate model to help organize and structure the quantitative study.

Figure 2.2 The ‘Emerging Model – Phase 4’ of health service utilization



Source: Andersen (1995). An Emerging Model – Phase 4. From “Revisiting the behavioral model and access to medical care: does it matter?” *Journal of Health and Social Behavior*, 36(1), 1-10.

2.3 Linking a LCP and the health service utilization framework

Principles from both the LCP and health service utilization framework highlight the importance of bringing a multi-dimensional approach to health services research. Both theoretical perspectives draw attention to individual, social, and structural factors (e.g., age, gender, health status, and service use) that are often identified as having an influence on individuals’ care trajectories. They also address the ways in which individuals’ care trajectories are linked to their local service and social contexts (e.g., families and communities). For example, a core theme of the LCP is the idea of ‘linked or interdependent lives’ which suggests that “family is the primary arena for experiencing and interpreting wider historical, cultural, and social phenomena” (Hutchison, 2011, p.22). In the health service utilization framework, presence of and relationship to an informal caregiver is often identified as an enabling variable that either

facilitates or impedes the use of health services. Another core theme from the LCP, “diversity in life course trajectories” (i.e., diversity in life course pathways as a result of cohort variations, social class, culture, gender, and individual agency; p. 22) is reflective of the variability we see when exploring predisposing, enabling, and need variables using the health service utilization framework.

Applying these perspectives to my thesis work, offered a way to think about the nature and complexities of health service use and the interconnected factors that can influence individuals’ abilities to remain in the community as long as possible.

2.4 Summary

In this chapter I discussed the two theoretical frameworks that have guided my work: a life-course perspective and the health services utilization framework. In Chapter 3, I introduce specific background and context information on the areas in which my research objectives were grounded. I discuss the importance of conceptualizing LTC as continuing care and begin by defining LTC and the specific LTC services and supports my work has focused on (i.e., HC, AL, and RC). Then, I discuss the role that family that caregivers play in supporting a family member who is receiving LTC.

Chapter 3: Social and health services in Canada

This chapter begins with the operational definitions and conceptualizations of LTC that I use to frame my research. I outline the specific LTC services and supports my project focused on notably: home and community-based care, assisted living, and residential care, and discuss the role that family caregivers' play in supporting an older adult through their LTC care journey.

3.1 Defining long-term care (LTC)

It is widely recognized that formal LTC services are instrumental in helping meet the diverse needs of our aging population (Chappell, 2011; Hollander et al, 2007; McGrail, 2011). However, LTC is not a single 'type' of service (e.g., hospital or physician) and does not fall under the Canada Health Act (Alexander, 2002; Chappell & Hollander, 2013), but is widely recognized as being fundamentally comprised of core services that collectively support and care for older adults as they age. These services "address the health, social and personal care needs of individuals who, for one reason or another, have never developed or have lost some capacity for self-care" (as cited in Havens, 2002, p.89). Determined by need assessments, these services most often include: home and community-based care (e.g., home support, rehabilitation, and nursing) or care outside the home (e.g., AL, RC, and group homes; Chappell & Hollander, 2013; Banerjee, 2007; McGrail, 2011; Toles, Abbott, Hirschman, & Naylor, 2012). However, because it does not fall under the Canada Health Act, there is no obligation for provincial government bodies to ensure or provide a standard range of LTC services to their populations (Canadian Healthcare Association, 2009). This has

led to large variation in service provision, policies, and terminology across provinces and has resulted in a wide range of accessibility, cost, quality, and staffing standards (Banerjee, 2007; Chappell & Hollander, 2013; McGrail, 2011).

In BC, a range of care and support options are available from both publicly-subsidized and private pay service providers. Individuals may access private pay services directly from the provider, with the two parties organizing all aspects of service provision. Alternatively, individuals can access publicly-subsidized services through the health authority, but this requires a formal needs assessment to ensure the individual meets the provincial eligibility criteria. Although subsidized services consider individuals' preferences, a person's needs are the primary means of determining service provision (British Columbia Ministry of Health [BCMOH], 2016b). Publicly-subsidized health services and housing are in high demand (BCMOH, 2016c), which has contributed to long waiting lists and 'first-bed available' policies in many care environments (i.e., AL and RC). For the purposes of my thesis, I focus only on publicly-subsidized LTC services for the quantitative study and publicly-subsidized AL or RC for the qualitative study.

Competing visions on how to best organize an integrated and coordinated continuum of care have been characteristic of health care policy discussions since the 1980s and still remain at the forefront of discussions today (CIHI, 2012; Chappell & Hollander, 2013; Cohen, 2012; Organisation for Economic Co-operation and Development [OECD], 2013). Over the last two decades, regionalization and restructuring activities in Canada have focused on 'deinstitutionalizing' care for older adults and improving access to home and community-based supports (British Columbia Ministry of Health Planning, 2002; Cohen, 2012). Although the idea behind the

restructuring activities has been to shift resources from the most expensive health sectors (i.e., hospitals) and focus on bringing people closer to home, the report '*Caring for BC's Aging Population Improving Health Care for All*' (Cohen, 2012), highlights a steady decline in access to key health services (e.g., home health services and RC) between 2001/02 and 2009/10. Restructuring and underfunding has resulted in further fragmenting the health care system, making it challenging to meet older adults' needs. For example, Cohen notes that changes to eligibility criteria (which have become increasingly restrictive) has left older adults waiting until they are in an emergency and have to go to the hospital before they can arrange to receive support at the community level; an impact that "undermine[s] the vital prevention role these services can place" (p.7).

Although hospital care often serves as the entry point for older adults into the LTC system because their need for LTC services occurs unexpectedly (e.g., following cardiovascular problems or a fall), for the purpose of my thesis, I focused on LTC services outside the hospital setting including HC, AL, and RC. Further, in addition to the formal services described above, I extended the definition of LTC to include informal (unpaid) caregiver support, hereafter referred to as family caregiving. Family caregivers are instrumental in maintaining the well-being and quality of life of older adults and often provide a wide range of supports including: personal care, help with activities of daily living, financial matters, housekeeping, social engagement, and emotional). Based on the important role family caregivers play in the lives of older adults, often over an extended period of time, I chose to include family caregiving in the working definition of LTC. Alongside the care recipient, family caregivers are recognized as one of the only common threads moving across the health care system (Coleman, Parry, Chalmers, &

Min, 2006). The following section describes each of the LTC services that my work focused on.

3.1.1 Home and community based care (HC)

Most older adults want to remain in their own home for as long as possible, as 'aging in place' is the most desirable alternative to institutionalization (Kitchen et al., 2011; Martin-Matthews, Sims-Gould, & Tong, 2012; Wiles, Leibing, Guberman, Reeve, & Allen, 2012). In fact, the 2011 report by CIHI, *Health care in Canada, 2011: A focus on seniors and living*, found that 93 percent of older adults were living at home in the community, with the majority (54.1 percent) living with a spouse or common-law partner. Alternatively, they also found that 26.7 percent of older adults live alone in a household dwelling (CIHI, 2011). Further, they found that the proportion of older adults living alone consistently increased with age: 37 percent of older adults aged 75 and older, compared to 49 percent of those aged 85 and older.

With the vast majority of older adults living at home, there is a need to maintain a social policy focus on the planning and delivery of community-based services to support them. Although most older adults are able to maintain some level of independence at home often with the support of family, when their care needs become more complex (e.g., multiple chronic conditions that may affect cognitive and behavioural functioning; Cohen et al., 2006), formal health and social supports are often sought. HC services are designed to help enable older adults to remain at home in the community as long as possible and are available subsidized through the local health authority (for those who qualify) or directly from a private provider. HC typically includes home health services delivered by a health professional (e.g., nursing, physical, occupational and respiratory therapy), as well as home support services delivered by a community health worker

(e.g., help with ADLs/IADLs, homemaking, meal services). HC supports are primarily designed to complement the care provided by family caregivers, not to replace them (Carter, 2012; HCC, 2012). These services can help provide care when a caregiver is unavailable or provide a break from caregiving duties to do other errands/activities.

In 2010/11, BC spent approximately \$351 million on publicly-subsidized HC services (Office of the Auditor General of BC, 2013). The BC Office of the Seniors Advocate (OSA) (2015) reports that 40 percent of older adults receiving publicly-subsidized HC are 85 and older; 34 percent had a diagnosis of Alzheimer's disease or other dementia; 85 percent of HC clients need minor assistance ADLs like bathing, eating, and toileting; and 81 percent had mild cognitive/memory impairment.

To enable older adults to remain at home longer, adequate community-based supports and resources for both the care recipient and their family caregivers are essential. Chappell and Hollander (2013) reinforce the importance of these services by highlighting the cost-saving features they can bring to the health care system, suggesting savings can be achieved by “substituting lower cost home care for higher cost hospital and facility care” (p.15). McGrail (2011) further suggests that the availability and uptake of community supports and services, in addition to the provision of a range of alternative facility arrangements (e.g., congregate and supportive housing to provide basic help with moderate/low care needs), will lessen the need for the most ‘intense’ types of health service (e.g., RC) for some older adults. In many ways, HC plays an important role in the spectrum of LTC services and requires continued attention to maintain the current and future sustainability of our health care system.

3.1.2 Assisted living (AL)

With increased care needs, an individual may no longer be able to live safely or independently at home. AL has been described as one of “the most service-enriched forms of supportive housing” available (Canada Mortgage and Housing Corporation, 2005, p.9).

Based on provincial variation for defining and classifying types of supportive care, there is no consistent definition of AL in Canada (McGrail et al., 2012; Wolse, 2004). However in 2004, BC became the first province in Canada to regulate AL facilities, requiring all private-pay and publicly-subsidized residences to be registered under the Community Care and Assisted Living Act (McGrail et al., 2012). In general, AL is described as “a form of housing that combines private units in apartment-style residences with the provision of hospitality and personal care services” (Carter, 2012, p.47). However, unlike RC facilities, they do not offer 24-hour professional nursing care or supervision. AL is largely oriented towards older adults who are still independent, but can no longer live safely on their own (Carter, 2012). In a report comparing AL facilities between Canada and the US, Golant (2001) suggests that:

“Canadian facilities are less likely to be occupied by very frail seniors. They have lower staff-resident ratios and are less likely to provide unscheduled personal care assistance or nursing services. A smaller percentage of facilities have wings or units that can accommodate seniors with Alzheimer’s disease.” (pg. 3)

A report by the BC Office of the Ombudsperson (2012) indicates that in 2010/11, there were more than 4,300 subsidized AL units across the province, with health authorities spending approximately \$74 million on this sector. Individuals’ preferences to remain in the community as long as possible, combined with the high costs associated with RC facilities, has led to AL being an increasingly attractive alternative to

institutionalization (Maxwell et al., 2013; McGrail et al., 2012). However, because of significant regional and national variations in the definition of AL, eligibility criteria, staffing protocols, and services, there have been concerns raised about the quality of care AL clients receive (e.g., poorer detection and management of health issues ultimately resulting in increased use of other health services and hospitalization; Zimmerman et al., 2005). In turn, there has been general uncertainty surrounding the impact AL has on the health of individuals (Golant & Hyde, 2008). For example, Maxwell and colleagues found that the increased prevalence of older adults with dementia and other chronic conditions in AL may negatively affect the facility's ability to provide appropriate and effective care to vulnerable residents. Despite these concerns, there remains limited research that focuses on AL use in Canada.

In a study conducted by the University of British Columbia (UBC) Centre for Health Services and Policy Research, McGrail and colleagues (2012) found that 65 percent of publicly-subsidized AL residents in BC came from the community and had received some form of publicly-subsidized HC services prior to admission between 2004/05 and 2007/08. These residents were older, on average, than HC service users (75 percent of AL residents are 80 or older, compared to 58 percent of HC users); with the largest proportion of these residents (approximately one-half) being over the age of 85 and three-quarters being women. Further, more than half of these individuals had two or more major chronic conditions (e.g., cardiovascular or neurological; McGrail et al., 2012). Although we know that cognitive declines are often associated with increased age, McGrail and colleagues also found that a diagnosis of dementia was relatively uncommon among publicly-subsidized AL residents when they moved in. However, over a period of one year, 24 percent of publicly-subsidized AL residents were diagnosed

with dementia and had much shorter lengths of stay in AL (39 percent exited AL within the first year).

Putting emphasis on fostering a home-like environment, AL facilities care considered a viable middle option between living independently in one's own home and living in a RC facility; and thus, an integral component of LTC.

3.1.3 Residential care (RC)

When an individual can no longer live safely on their own, normally because of substantial changes in medical and functional health, RC is often the next step. RC facilities provide 24-hour professional nursing care and supervision, in addition to hospitality (e.g., meals, laundry, and housekeeping), personal care services (e.g., medication administration, assistance with ADLs), and recreational activities (FH, 2016a). Similar to HC and AL, across most jurisdictions there is a mix of public, private, non-profit RC options (FH, 2016a). In 2011, there were a total of 28,992 RC beds in BC; with the vast majority of them (26,491: 91.4 percent) being publicly subsidized (Carter, 2012). In 2011, BC health authorities spent approximately \$1.6 billion on this LTC sector (Carter, 2012). Although, there is heightened attention on RC in light of our shifting demographics, only 3.7 percent (approximately 30,000) older adults in BC reside in RC facilities (OSA, 2015).

A variety of factors influence a move into RC such as older age, gender, marital status, cognitive and physical health decline, challenges with ADLs/IADLs, and/or increased caregiver burden/distress or lack of informal support (HCC, 2012; Luppá, Luck, Weyerer, König, & Riedel-Heller, 2009; Wu et al., 2014). Comparing publicly-subsidized RC clients to publicly-subsidized HC and publicly subsidized AL clients, the Senior's Housing Report (OSA, 2015) found that older adults living in RC are more likely

to have advanced medical and physical health problems. They found that 82 percent of publicly-subsidized RC clients had a combination of complex conditions that indicated high or very high need for facility level care (compared to 63 percent and 53 percent of AL and HC clients respectively; OSA, 2015). Further, in this same report it was noted that 61 percent of RC clients had a diagnosis of Alzheimer's disease or other dementia (compared to 45 percent of AL and 34 percent of HC clients) and 67 percent of RC clients needed moderate to significant assistance with ADLs (compared to 10 percent of AL clients and 15 percent of HC clients). Older adults in RC were also significantly more likely to be using a wheelchair full-time, and to be on antipsychotic/antidepressant medication compared to AL or HC clients (OSA, 2015). However, comparing RC to AL is largely reflective of the difference in the type and level of care need each facility is positioned to meet.

When health care needs extend beyond the capacities of family caregivers, HC and AL, RC provides an array of fundamental services for older adults and holds an important role in the LTC sector.

3.1.4 Family caregiving

With age-related changes in physical and mental health being the most significant drivers of caregiving need (Turcotte, 2013), family caregivers are often the principal source of support for older adults. A recent report from Statistics Canada found that 88 percent of Canadian older adults relied on help from family and friends in 2012, with half of these care receivers relying on formal (professional) care services as well (Sinha & Bleakney, 2014). Of the approximately 8 million Canadians over the age of 15 providing unpaid care to a family member in 2011/12, the largest percentage was women between the ages of 55 – 64 (38 percent; Sinha, 2013). Most caregivers were

providing support to their parents/parents-in-law (48 percent) and were 2.5 times more likely to be caring for their mother than their father. A much smaller percentage of caregivers were reported to be caring for a spouse (8 percent; Sinha, 2013).

Family caregivers take on a wide range of activities to help support the well-being of their family member. Sinha (2013) found that family caregivers spent an average of three hours a week caring for a family member or friend. However, this increased to 10 hours a week for caregivers caring for a spouse. Care provided by family varies both in type and intensity, but most often includes assistance with daily activities of living (e.g., bathing, dressing, eating, cooking, transportation, shopping; Gitlin & Wolff, 2011). Family caregivers are also instrumental in obtaining, coordinating, and monitoring the provision of formal care services for their family member (e.g., HC services; Sims-Gould & Martin-Matthews, 2010). Further, family caregivers are most often the ones managing finances.

For some, caring for a family member can be a long journey, as it often spans a number of years. Sinha (2013) reported that majority of caregivers (89 percent) had been providing help for one year or longer, with approximately half providing care to a family member for four or more years. However, family caregivers often provide care in conjunction with formal LTC services at each stage of their family member's care journey (e.g., HC, AL, and RC; Gaugler, 2005). Over the course of their caregiving journey, caregivers often juggle other commitments including raising children and their career (Keefe, 2011). Caregivers balancing the physical and emotional support of caring for their family member, alongside other obligations, have been shown to experience negative consequences such as stress and 'caregiver burnout' (HCC, 2012).

As noted, caregivers spend a considerable amount of time and energy supporting their family member. However, there are concerns about the future shortage of caregivers because of smaller families, women's increased participation in the work force, and older adults living longer (Chappell, 2011). To help meet these challenges, initiatives have been implemented to better support caregivers in their caregiving tasks; including financial and social resources available at the federal, provincial, and municipal levels (Keefe, 2011). However, there lacks consistency in the eligibility criteria or the kinds/levels of supports available (Alliance for a National Seniors Strategy, 2015).

Despite their central role in supporting older adults across their care trajectory, family caregivers are situated outside the formal LTC system. The concern that the demand for family caregiver support may soon exceed supply (Keefe, 2011) reinforces the importance of maintaining a focus on family caregivers and their crucial involvement in their family members' care journeys. For these reasons, I included family caregiving as one of the fundamental elements of LTC.

3.2 Summary

As presented, LTC is a complex, fragmented network of health services aimed at supporting the health and well-being of Canadians as they age. Although I have reviewed the 'types' of services independently, older adults often use multiple services over their life course and in many cases in combination with one another (Chappell & Hollander, 2013; Coleman & Barenson, 2004; Covinsky et al., 2003).

Conceptualizing LTC services as 'continuing care' is well-suited to my thesis objectives. The quantitative component of my project explores transitions between LTC services (i.e., HC to AL or HC to RC), which speaks to the 'continuing' nature of health care utilization among older adults as their care needs change. The qualitative

component of my project (investigating informal caregivers' experiences in supporting a family members' transition across LTC) highlights the complexity and 'siloed' nature of health service delivery system from the perspective of the person who is most often navigating it. Chappell and Hollander (2013) argue for the need for policy makers to 'take up' and apply the well documented evidence that suggests the "integration and coordination" (p.30) of health service delivery systems can contribute to the sustainability of the health care system. Further, collaborative efforts between delivery systems may contribute to the social policy goal of enabling older adults to remain in the community as long as possible.

To conclude, in this chapter I introduced the definition of LTC that I used to frame my research, including the specific LTC services and supports that were a focus in my work (i.e., HC, AL, and RC). I also discussed the role family caregivers' play in supporting an older adult and how their care activities are situated within LTC. In Chapter 4, I outline the research methods I apply in my project.

Chapter 4: Research methods

This chapter outlines the research methods that guided this project. I begin by discussing the research design (multi-method), the rationale for selecting this approach, and how I applied it to my work. Following this, I introduce the larger project that I was fortunate to be part of, and in which my project was nested. Then, I provide a description of the area in which my research took place and the rationale for dividing the health authority into three geographic areas. Next, I present the ethical considerations for the project, followed by a description of the process for gathering data. Lastly, I outline the data management and analytic techniques and strategies that I applied. A statement on my role as a researcher concludes the chapter.

4.1 Research design

With an interest in exploring how care transitions research links to the larger social policy goal of supporting older adults to remain in the community as long as possible, I employed a multiple method research design (hereafter referred to as ‘multi-method’; Morse, 2010; Tashakkori & Teddlie, 2010). Using this approach, I explored the relationship between service users and their local service and social contexts. To generate more in-depth information on how to better support older adults in the community, my thesis was comprised of two components including a quantitative study and qualitative study.

Although a multi-method design is synonymous with ‘multiple method design’, it is different from ‘mixed-methods¹’ (Morse, 2010). In Tashakkori and Teddlie’s *Handbook*

¹ “Mixed method design consists of one project, known as the *core* project, which is a complete method in itself, and a second project consisting of a different type of data or analysis, using a strategy (and there may be more than one) that is incomplete: that is, that is not comprehensible or publishable apart from the core project” (Morse, 2010, p.340)

of Mixed Methods in Social and Behavioural Research (2010), Morse (2010) describes the central premise of multi-method research:

“Multiple methods design consists of two or more studies using different methods, which address the same research question or different parts of the same research question or programmatic goal. As each research project in a multiple method design is self-contained, complete, and publishable as a stand-alone article, there are no extraordinary methodological conundrums for researchers who are conducting a multiple method design. Often, a researcher conducts the projects and publishes them separately and then publishes a synthesizing article showing the complementary relationship between, or the complementary relationships in, the sets of findings in answering the overall question” (p.340).

4.1.1 Rationale for a multi-method design

In the context of a complex, multi-level health care system with services that extend from acute to palliative care, my desire to explore transitions in care could not be fully met using a single research approach. With an interest in highlighting LTC service use from both a system-level (i.e., using administrative data) and person-level (i.e., experiences of family caregivers), I knew a research design that used both quantitative and qualitative work would best address my research objectives and questions.

Thus far I have presented my thesis as a multi-method project with two distinct components (quantitative and qualitative) that each address specific research questions. However, this approach was not part of my thesis proposal. Initially, I intended to use a sequential mixed-methods research design (Creswell, 2014; Tashakkori & Teddlie, 2003). I had planned to use findings from my quantitative analyses to help structure the eligibility criteria that I would use to recruit family caregivers for the qualitative study. My intentions were to interview family caregivers of individuals who displayed similar characteristics to clients who transitioned from HC to AL or HC to RC, based on trends I saw in the administrative data (e.g., to interview

family caregivers with family members who transitioned from HC-RC, who were female, with a dementia diagnosis, and multiple chronic conditions). However, after reviewing preliminary findings and consulting with my supervisory committee, we decided that my project was better suited to a multi-method design. Using a multi-method design, I was able to first highlight the strengths of each analysis independently and then, bring the quantitative and qualitative work together to generate a more in-depth exploration of care transitions as a whole. Combined, these findings generated meaningful information that will help contribute to exploring how care transitions link to the larger social policy goal of supporting older adults to remain in the community as long as possible.

All methods of data collection have limitations and the use of multiple methods can help alleviate some of the shortcomings of certain methods when used on their own (e.g., detailed qualitative data may provide insight that quantitative data alone may not capture; Bryman, 2006). Quantitative methods can produce reliable and quantifiable data that has the ability to be generalized to a larger population. However, Creswell and Plano-Clark (2007) point out that quantitative research can be “weak in understanding the context or setting in which people talk...the voices of participants are not directly heard” (p.9). On the other hand, qualitative research methods are designed to provide the researcher with an approach to understanding a social phenomenon by both observing and/or interacting with the study participants (Denzin & Lincoln, 2008).

Researchers have suggested several advantages to using different methods in a research project (Creswell, 2014; Morse, 2010; Tashakkori & Teddlie, 2010). Brewer and Hunter (1989) suggest that the multi-method approach allows researchers to “attack a research problem with an arsenal of methods that have non-overlapping weaknesses in addition to their complementary strengths” (p.17). A multi-method design

also has advantages of triangulation, including methodological triangulation (i.e., combining findings from different quantitative and qualitative sources) and theoretical triangulation (e.g., using more than one theoretical framework/perspective to guide the project and interpretation; Denzin, 1978; Patton, 2002). It also allows for the flexibility to explore different dimensions (e.g., individual, social, structural) of a phenomenon which helps provide a more whole picture of the project focus (Tashakkori & Teddlie, 2003).

4.1.2 Applying a multi-method design

As noted, I completed the quantitative component of my project first. This quantitative study developed a unique analysis building on a three year project, the British Columbia Trajectories in Care (BCTIC) project (Penning, Cloutier et al., 2012-2015; CIHR no. 122184, UVIC HREB no. 12-255, FH REB no. 2012-05; described in more detail in section 4.2) funded through the Canadian Institutes for Health Research (CIHR), Partnerships for Health System Improvements Program (PHSI), and the Michael Smith Foundation for Health Research (MSFHR). Applying secondary data analysis techniques to anonymized, linked administrative health data, I explored individual, social, and structural factors (i.e., predisposing, enabling, and need) that influence the transitions from HC to either AL or RC, and how these factors vary by geographic location (urban, suburban, and rural) for older adults. As outlined in Chapter 1, the specific research questions were: 1) what patterns exist in the transitions from HC to AL and HC to RC in urban, suburban, and rural areas of FH? And 2) how do individual, social, and structural factors influence the transition from HC to RC as compared to AL, in urban, suburban, and rural contexts? This quantitative work helped explore transitions in care from the client perspective; illustrating *who* was transitioning out of their home and what their characteristics were (e.g., age, gender, marital status,

health). However, due to the limitations of the assessment tools and data, I was unable to adequately explore a family caregiver's role and level of involvement in the life of the older adult over the course of a key transition (e.g., home to a new LTC environment such as AL or RC). The qualitative study was important to better understand the experiences of a care transition from those who manage and navigate it for a family member; thus contributing to a richer understanding of care transitions.

The qualitative portion of my thesis work used semi-structured interviews and thematic analysis to explore the roles and responsibilities of family caregivers over the course of their family member's transition from home into a new LTC environment. The specific research questions for this qualitative component were: 1) how do family caregivers manage and navigate a key transition in care for a family member and what are their experiences in doing so? And 2) how do family caregivers make sense of the many layers of their caregiving roles and responsibilities?

By combining insights from the quantitative and qualitative analyses, I have developed "a more complete picture by noting trends and generalizations as well as in-depth knowledge of participants' perspectives" (Creswell & Plano-Clark, 2007, p.33). Applying this approach to my project has helped me to explore the multi-dimensional nature of care transitions from both administrative and family perspectives, and contributes further information to address how to best support older adults to remain in the community as long as possible.

4.2 Fit within larger project: British Columbia Trajectories in Care Project

As noted, I am fortunate to have had the opportunity to develop this thesis working within an existing, collaborative project between the University of Victoria and the FH authority (BCTIC). BCTIC's main project objective is to identify and assess the key transitions (movements from one care system to another) and trajectories (sequences of movements and patterns of service use) experienced by older adults using publicly-subsidized LTC (including HC, AL, and RC) in the FH region. This quantitative project uses administrative health data on older adults who received long-term care services between the years of 2008-2011. The following research questions are addressed:

1. What are the most common service trajectories experienced by older adults transitioning between various forms of long-term care (e.g., HC, AL, RC)?
2. How do individual and community level factors (social, psychosocial, health) influence these transitions and trajectories?

To date, the BCTIC project has completed several deliverables including a published book chapter, peer reviewed articles (forthcoming), and multiple conference and related presentations at both national and international events. Guided by a LCP, the priority areas of interest have included: analysis of service use patterns and their sequences alongside the structural, social, and health variables; descriptive analyses of LTC clients using HC, AL, and RC as service entry points into LTC; the relationship between anti-psychotic drug use and social engagement; and service use patterns by geography. To better understand the complex patterns of LTC use over time and the factors that influence service use, the project's current analyses are aimed at using a number of longitudinal methods. This includes exploring transitions between service use groups by their time to transition to RC, time to death, and changes in the intensity of

service use over time. A mix of latent class and latent transition analyses (LCA and LTA), survival analysis, and multi-level modeling techniques are being tested.

The BCTIC project was instrumental in providing both financial and analytical resources to support the completion of this project. With the support of the larger project, I was able to draw on the expertise of an interdisciplinary research team made up of university-based researchers, health care decision-makers, and an Advisory Committee of key client and health authority representatives. Empirically, this project provided me with access to the anonymized data set used for the quantitative study, and with guidance on working with administrative health data.

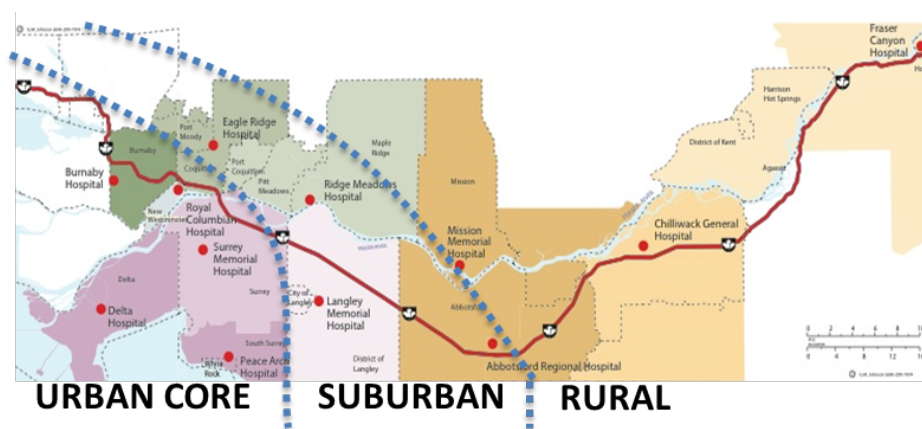
Being nested within the larger BCTIC project has allowed me to explore a different area of the project's existing quantitative analyses of administrative health data. Further, my thesis contributes to the larger project by adding qualitative data on the caregiver journey, thereby providing a unique perspective on transitions and trajectories as older adults and their family caregivers experience them.

4.3 Description of the project area: The Fraser Health Region

Ensuring that communities are equipped with the right information and services requires cooperation between multiple groups and organizations starting with the BCMOH. The BCMOH has the “overall responsibility for ensuring that quality, appropriate, cost effective, and timely health services are available for all residents” (BCMOH, 2016c, p.5), and partners with five regional health authorities to support and fund all public health programs and services. The regional health authorities currently share responsibility for the design, provision, and governance of health services and programming across the province (e.g., hospital care, community-based residential, home health, mental health and public health services).

My project was based in the Fraser Health Region. This health authority has the largest overall population (serving 1.6 million people) and is home to approximately 30 percent of BC's seniors (FH, 2014). Those aged 65 and older comprise 15 percent of the FH population and represent the fastest growing senior population of all the BC health authorities (FH, 2014). FH is highly diverse ethnoculturally, with approximately 38,100 First Nations people and about 60 percent of senior immigrants to BC identifying FH as home in 2012 (FH, 2014). This region is also geographically diverse, with communities ranging in population size from 427,588 in Surrey to 8,095 in Hope (FH, 2014); with 66 percent of the population living in the western part of the region (Hayes & Amram, 2012).

Figure 4.1 Map of the Fraser Health region



Source: Cloutier et al. (2016)

Based on my interest in exploring transitions in care by geography, I used the same geographical designations as the BCTIC project which divided the health authority into three areas (urban, suburban, and rural), starting in the most southwestern corner (more urban) and moving east (more rural; see Figure 4.1). Using a 'rural-urban' index

modified from the work of Allan and Cloutier-Fisher (2006), these three geographic areas reflect diversity across the FH based on census characteristics including population densities, growth rates, and percent foreign born. Moving from West to East, we see decreases in approximate population size with 867,000 persons in the urban area, 567,000 persons in the suburban area, and 190,000 persons in the rural area (see Table 4.1 for selected community characteristics; Statistics Canada, 2011). Several health system variables such as the number of physicians per capita, number of hospitals, number of RC and AL facilities, number of subsidized beds/units, and LTC beds per capita, were used to support this classification.

Table 4.1 Selected Fraser Health community and health system characteristics by geographic area²

	Urban	Suburban	Rural ¹
2006-11 % population change	13.6	9.9	6.0
2011 % population aged 65+	13.4	12.8	17.7
2011 % unemployment	7.3	7.0	7.2
Number of hospitals	5	5	4
Number of RC facilities			
Owned & operated	7	4	3
Contracted	34	24	6
Number of subsidized RC beds	4498	2576	958
Number of AL facilities	17	8	6
Number of subsidized AL units	782	449	162
2013 GP's per 10,000 population	8.5	9.0	7.4
2013 LTC beds per 10,000 population aged 65+	378	309	210

Sources: Cloutier et al., (2016); Fraser Health (2016c), and Statistics Canada (2011).

In addition to exploring local service contexts across FH, it is important to take into consideration the economic activity of each area as well. Economically, all areas in FH have some reliance on agriculture, based on low-density land use (Hayes & Amram, 2012). The role that agriculture plays in FH is particularly evident when moving from

² RC and AL facilities and RC and AL beds/unit numbers reflect 2016 FH reported values and are slightly higher than numbers reported by the Office of the Seniors Advocate (2015).

west to east (i.e., from more urban to more rural areas; Cloutier et al., 2016). In the urban area, technology, manufacturing, services, and industry are the dominant economic activities. The suburban area primarily relies on manufacturing and construction activity, but farming, fishing, mining, quarrying, and forestry also contribute. The rural area's economic activity is more diversified, but tourism, forestry, industrial, mining, and commercial warehousing are the primary economic activities.

For the quantitative component of this project, census characteristics, publicly available boundaries files from Statistics Canada, BC Statistics, and Canada Post were used to designate an individual's location of residence (urban, suburban or rural) based on their forward sortation area (FSA) designated by the first three digits of the postal code, found in the Continuing Care Information Management System (CCIMS) client files. For the qualitative study, I designated family caregivers as urban, suburban or rural based on their location of residence at the time of their interview.

4.4 Ethical considerations

Prior to starting the project, I completed an ethical review through a joint process between the University of Victoria and FH research ethics boards. I obtained a certificate of ethical approval for a minimal risk harmonized project in 2015 (BC15-031).

For the quantitative study, I upheld ethics protocols as outlined in the existing BCTIC ethics approval documents (UVic HREB no. 12-255, FH REB no. 2012-051). For the qualitative study, I obtained informed consent was from all family caregivers prior to formally beginning data collection. I also asked for ongoing consent from each caregiver in the event that I may want to conduct a secondary data analysis, or to allow me to contact a family caregiver in the future. I assigned each caregiver a unique study number and pseudonym to ensure that their identity was kept confidential. I did not

anticipate that participation in this research project would cause any harm, although it was possible that family caregivers could experience unexpected minor emotional discomfort or stress over the course of the interview. If this occurred, I was prepared with a list of FH offices that could be contacted if desired (e.g., FH Patient Care Quality Office a link to the FH Caregivers Handbook). No family caregivers asked for these resources.

All interviews were audio-recorded and transcribed. I used a unique study number for each interview for identification purposes. Once in typed format, all data (i.e., field notes and transcripts) had any identifying markers, such as names and locations, replaced with pseudonyms or removed to protect the anonymity of participants. I only shared anonymized data with my co-supervisors for the purposes of analysis. I stored all consent forms and data in separate locked cabinets accessible only to me.

4.5 Quantitative study – Paper 1 Chapter 5

4.5.1 Data and sample

For the quantitative study, no primary data collection activities were required. As a research team member (research assistant) within the BCTIC project, approval was in place for analysis of the existing anonymized administrative data by all team members. This study drew on administrative data extracted from the Resident Assessment Instrument-Minimum Data Set (RAI-MDS 2.0), the Continuing Care Information Management System (CCIMS), and the Discharge Abstracts Database (DAD). The RAI instruments included both home and community care and residential care assessment tools. FH made these data available for the BCTIC project.

I defined the analytic cohort for the quantitative study using a two-step process. First, I selected all persons aged 65 and over (as of January 1, 2008) whose initial entry point for receiving subsidized LTC services was through FH Home Care (HC) services. These clients had a HC service start date between January 1, 2008 and December 31, 2011. With the objective of exploring two specific transitions in care among LTC clients, step two restricted the group to those clients who subsequently made their first transition out of the home-based community setting into either AL or RC within the 2008-2011 time frame. In total, 3233 clients met the above criteria, including 2,677 (82.8%) clients who transitioned from HC into RC and 556 (17.2%) clients who transitioned from HC into AL. Although subsequent transitions within the LTC environment may have occurred (i.e. AL to RC), these transitions are outside the scope of this project. Chapter 5 captures further detail on the data set and the cohort used for the quantitative analyses.

4.5.2 Measurement and methods of analyses

To draw attention to individual, social, and structural factors (e.g., age, gender, marital status, presence of/relationship to primary caregiver, and health variables) among older adult transitional clients in FH, I used descriptive statistics and bivariate logistic regression procedures to analyze the quantitative data. Descriptive analyses (i.e., frequencies, crosstabs, ANOVA) explored the patterns (prevalence and characteristics) of LTC clients who transitioned from HC to either RC or AL across urban, suburban and rural settings within the FH region. I applied logistic regression analyses to explore individual, social, and structural factors that influence the transition from HC to RC compared to AL, in each of the three regions of FH. I entered my covariates of interest in three blocks representing predisposing, enabling and need

variables as per the health service utilization model (Andersen, 1995; Andersen & Newman, 1973). SPSS software version 21.0 (IBM Corporation, Armonk, NY) was used to facilitate data management and analyses. I report further information on the variables and results in Chapter 5.

4.6 Qualitative study – Paper 2 Chapter 6

4.6.1 Data collection

For the qualitative study, interviews took place with family caregivers who had family members who had transitioned from home into a new LTC environment in FH (i.e., AL or RC). I used a purposeful sampling technique to select these family caregivers to participate in this study. Purposive sampling (i.e., identifying and selecting individuals that are especially knowledgeable about the area of interest [Creswell & Plano-Clark, 2007]) assists in ensuring credibility and rigour by increasing the likelihood that they will be ‘information-rich cases’ rather than a random sampling of participants (Baxter & Eyles, 1997; Patton, 2002). Such information-richness is deemed important in qualitative research in favor of statistical generalizability (Sandelowski, 1995).

4.6.2 Eligibility criteria

As noted, in the beginning stages of this project I had expected the quantitative findings to heavily shape the qualitative work, including defining the eligibility criteria for participant recruitment. Initially I was going to explore the two key transitions (i.e., HC to AL and HC to RC) independently of one another. I was also going to examine these transitions across rural and urban areas. This approach would have generated four sub-groups of participants (HC to AL [5 rural, 5 urban] and HC to RC [5 rural, 5 urban]). The initial eligibility criteria included family caregivers who: 1) had an older adult relative (age 65+) residing in FH who reflected similar characteristics to the trends identified in

the quantitative study (e.g., female, widowed, 3 or more chronic conditions); 2) had managed their relative's transition from receiving publicly-subsidized HC services to publicly-subsidized AL or publicly-subsidized HC to publicly subsidized RC facility in the past 2-6 months; and 3) family caregivers who identified themselves as the person who performs the 'care management activities' (e.g. information seeking, arranging services, paperwork and managing finances) for their family member. However, after reviewing preliminary quantitative findings and consulting with BCTIC research team members who were working in FH at the time, we decided that my recruitment procedure and eligibility criteria needed revision. As advised by these FH team members, recruiting participants who reflected the specific characteristics that we saw from the quantitative work was potentially problematic because it would require heavy involvement on behalf of AL and RC management and staff. Furthermore, at the time of my study, FH was undergoing a significant organizational restructuring and for this reason the FH team members advised me that management and staff at the facilities would not be receptive to the 'extra work' outside their regular duties. Further, a higher level of facility involvement may have jeopardized participant confidentiality and anonymity. The added involvement may have also created 'power-over' relationships between facility staff and family caregivers, who might have felt 'obligated' to participate in the study rather than participating voluntarily.

The main objective of the qualitative study focusses on generating more in-depth knowledge about the experience of managing and navigating a transition in care and is less fixated on drawing a distinction between the type of transition (AL or RC). In order to address these concerns and maximize participant interest, eligibility criteria were broadened to include family caregivers who helped manage and navigate a transition

from home to a new LTC environment in the recent past (specific eligibility criteria used for the qualitative study are captured in Chapter 6).

4.6.3 Recruitment procedure

BCTIC research team members affiliated with FH (at the time) were instrumental in helping me make initial contact with administrators and managers responsible for the care provided within FH owned and operated, as well as contracted, AL and RC facilities. This step was crucial as FH required that I have each facility's approval before displaying participant recruitment materials at their location. I made initial contact by broadcast email to reach as many facilities as possible and to ensure adequate numbers of urban, suburban, and rural facilities knew about the opportunity to participate in my project. I provided my contact information and encouraged directors of care and administrators who were interested in learning more about my project to connect with me. I provided the study information letter (see Appendix A) to all directors of care and administrators who showed interest in participating. This letter outlined the study's purpose and asked permission for participant recruitment to take place at their facility.

The methods of recruitment I used included direct advertising (flyer), and in-person solicitation where possible (i.e., I attended family council meetings to talk about the study and seek participants). I made it clear to administrators and managers that their facility (including all staff) were not to have any other involvement in the project outside of displaying the recruitment poster or having me come speak at one of their family council meetings. This was a joint ethics review requirement to ensure there were no possible "power over" relationships that could influence a family caregiver's decision to participate.

When facilities indicated interest in displaying posters and/or allowing me to attend family council meetings, I mailed them a package containing recruitment posters (Appendix B) and the study information letter (Appendix A). I mailed materials to a total of 22 AL and RC facilities in FH (nine urban, seven suburban, five rural). However, because research team members assisted with the initial contact via a broadcast email, it is likely that more facilities displayed a copy of the recruitment poster (included in the email) instead of contacting me directly for further information and recruitment materials.

I hung posters at facilities that agreed to participate and I attended all family council meetings that I was invited to (a total of three; representing one in each of the three geographic areas [urban, suburban, and rural]). Family caregivers who showed interest in participating contacted me by phone or email, and I responded to their interest using the telephone/email script (see Appendix C). I also provided family caregivers with the participant information letter (Appendix D) and the consent form (Appendix E) to review before their decision to participate. At all points in my communication with potential participants, I emphasized the voluntary nature of participation, that their participation (or not) would have no effect on their health care services or relationships with FH in any way, and that they could withdraw at any point in the study without penalty. If they did not have any questions or concerns, I scheduled individual face-to-face interviews at a time and place of the caregiver's convenience.

4.6.4 In-person interviews

In-person interviews took place at a quiet location that best suited the caregivers' preferences (e.g., at home) and ranged from 45 – 150 minutes in length. Prior to the start of each interview, I gave everyone a chance to ask any remaining questions and to hand in their consent forms. At the start of each interview, I collected relevant socio-

demographic data (e.g., gender, age, education; relationship to family member; see Appendix F). This information provided me with descriptive characteristics of the family caregivers. A semi-structured interview guide, developed prior to entering the field, provided guidance to the conversations (see Appendix G). All interviews were audio recorded with the caregiver's permission. I began by asking caregivers to offer a descriptive introduction to their care receiving family member for the primary researcher. This helped by providing me with some valuable background information and helped with building rapport.

Over the course of the interviews, I asked family caregivers questions in three main areas of interest: the kinds of care activities they had engaged in over the course of their caregiving journeys (including anything they did before their family member transitioned into AL or RC); their specific experiences in managing and navigating the move from home to a new LTC environment (AL or RC); and how they made sense of their roles and responsibilities in caring for their family members, including their thoughts on the 'care management' role. Initial eligibility criteria included a requirement that the family caregivers' family member had received formal HC services prior to their transition into AL or RC. However, after the first few interviews, I stepped away from this prerequisite because most participants were providing a high level of care themselves including direct care and assistance with activities of daily living. Most caregivers did not rely on formal HC services to provide the bulk of the care. Additionally, initial eligibility criteria required family caregivers' family members to have made a transition from home to either AL or RC. However, after the first few interviews, it became clear that when describing their experiences in helping a family member to transition from home to a new care environment, they often assisted with multiple care transitions (e.g., home to

AL to hospital or home to hospital to home to RC). Based on the breadth of information family caregivers were providing about their care transition experiences, including hospitalizations, I chose to keep them in the sample. Again, with the main objective of the project being to explore how care transitions link to the larger social policy goal of supporting older adults to remain in the community as long as possible, this study helped generate more in-depth knowledge about why and how caregivers transitioned a family member from home into a new care environment, which included trips to and from the hospital.

Over the course of the interview, I also captured additional field notes that on the interview guide. At the end of the interview, I gave caregivers a \$15 Tim Horton's gift card as a small honorarium in appreciation for their time. Following each interview, I journaled my reflections in a notebook. A total of 15 interviews were completed (seven urban, three suburban, five rural).

I transcribed all interviews verbatim. Completing this myself (as opposed to hiring a transcriptionist) was both time and labour intensive, but allowed me to gain increased familiarity with my data. To capture the subtleties of the interviews, I recorded hesitations and pauses (as much as possible - Tilley, 2003), marking them with single dashes (-). Sections that were inaudible were marked [inaudible] and time stamped. I used field notes over the course of the transcribing process to ensure I captured emotional expressions (e.g., tearing up, rolling eyes, slamming hand on table) on paper. Words that were emphasized during the conversation were marked with [emphasis] in the transcripts. I took these subtleties into consideration during data analysis, as they were representative of the participant's reactions to and passion about the topic area. Braun & Clark (2012) warn against removing hesitations, pauses, and 'guggles' as

these details can be revealing and offer additional insights that may otherwise go unnoticed (p.60).

4.6.5 Data management and analysis

To facilitate data management and analysis, I entered all transcribed interviews into a qualitative software program (NVivo 8). My first step was to re-read all of the transcripts to ensure familiarity with the content. Following this, I compiled my journal entries, interview notes, and transcripts into interview summary sheets (Miles & Huberman, 1994). I used these as a summary tool to help with the subsequent thematic analysis. These summary sheets served as a way to capture the salient points of each interview and to consider what the main story emerging from the data was. My supervisors also subsequently used the summary sheets as a tool to help familiarize themselves with my data.

After developing the summary sheets, I applied principles of thematic analysis to systematically identify, organize and provide insight into patterns of meaning, allowing for the identification of collective or shared experiences across the data set (Braun & Clarke, 2012). I generated preliminary codes ('open coding') from line-by-line reading of the transcripts and from emerging patterns in the caregivers' experiences in helping care for their family members. First, I categorized each interview according to geographic area (urban, suburban, and rural). Next, I used descriptive coding to capture key events, activities, and experiences (e.g., 'intake process'; 'information gathering'; 'preparedness', 'worrying'). At the same time, I coded events and experiences chronologically to try to capture the influence and importance of the temporal order of events. For example, care-related events, decision making, or emotions that were present before their family member moved into AL or RC, were coded in a chronological

fashion under headings of: 'pre-transition' events; in-between being placed on the waiting list and moving day as 'mid-transition'; and lastly, after their family member moved into the AL or RC as 'post-transition'. Because caregivers were recounting their experiences retrospectively, this helped keep the order of events straight. Field notes also helped with this process.

I then grouped codes into categories that led to the development of a conceptual framework (see Figure 6.1) to illustrate how family caregivers manage and navigate key transitions. The conceptual framework was developed inductively from the data and serves as a visual, organizational tool to help illustrate the roles and responsibilities that family caregivers take on when navigating their family member's care transition. This framework helped me to conceptualize and better understand the caregiver journey and also acted as a guide to structure my findings.

Building from the conceptual framework, I developed three overarching themes (Braun & Clarke, 2012) to address the main objectives of the qualitative study, which were to explore how caregivers make sense of their multi-layered caregiving roles and responsibilities and how these conceptualizations ultimately play out across their caregiving journeys. I labelled these themes with direct quotes (in vivo) from the participants and are: *"I'm just her daughter" / "I'm just his wife"*, *"Just go with the flow"*, and *"There wasn't a door I didn't try to open"*. These themes are discussed in further detail in Chapter 6.

4.7 Role of the researcher

Critical to the process of research, particularly qualitative research, is a researcher's ability to be continuously reflexive over the course of the project, a process wherein the researcher examines both themselves as researcher and the research

relationship (Miles & Huberman, 1994). Being reflexive requires that researchers acknowledge their position (e.g., personal assumptions, values, and biases) in the context of their work, as life experiences and preconceptions may influence the research process (Miles & Huberman, 1994). To practice reflexivity, debriefing meetings with one or both of my co-supervisors helped support methodological decisions and the overall project progress and process in terms of my own values, interests, and personal experiences with transitions across LTC.

4.8 Summary

This chapter has outlined my project's research methods. I introduced a multi-method research design, my rationale for selecting it, and how I applied it to my project. Following this, I described the larger project my thesis work is nested in, as well as the project area where my research is situated. The chapter then outlined ethical considerations, data collection, data management, analytical techniques and strategies, and concluded with a statement on my role as a researcher. Chapter 5 reports on the quantitative study conducted using FH administrative health data to address individual, social, and structural factors (e.g., age, gender, marital status, presence of/relationship to primary caregiver, and health variables) that influence the transition from HC to either AL or RC, and how they vary by geographic location (urban, suburban and rural) for vulnerable older residents. I have structured Chapter 5 as a manuscript that I intend to submit for publication to the Canadian Journal on Aging.

Chapter 5: Paper 1 – Quantitative analysis

Does geography matter in long-term care transitions in British Columbia?

In this chapter, I report on the results obtained from the quantitative component of my thesis project. As noted in Chapter 1, this chapter is written in a manuscript format with this specific work being intended to be submitted to the Canadian Journal on Aging for publication.

For this paper, I performed secondary data analyses on FH administrative health data to draw attention to how individual, social, and structural factors (e.g., age, gender, marital status, presence of/relationship to primary caregiver, and health variables) influence the transition from HC to RC, as compared to HC to AL for vulnerable older adults. I also explored how these factors vary by geographic location (urban, suburban, and rural).

5.1 Abstract

Current aging policy focuses on supporting older adults to remain in their homes in the community for as long as possible. However, as health care needs advance, remaining at home can be challenging. When an older adult's care needs can no longer be met in the community setting, they may need to transition into another care environment that provides a higher level of support such as assisted living (AL) or residential care (RC). This study draws attention to individual and structural factors (e.g., age, gender, marital status, presence of/relationship to primary caregiver, and health variables) that predict these transitions (AL or RC) among a sample of older clients (age 65+) of long-term care in the Fraser Health (FH) region of British Columbia. To address potential variation in local service contexts and explore how geographic location (urban, suburban, and rural) may influence care transitions, logistic regression analyses were completed using administrative health data (2008-2011). Marital status, income, functional disability, and cognitive performance emerged as predictors of the type of transition for both rural and urban clients. Gender, medical frailty, number of chronic conditions, and total hospitalizations were significant among clients in suburban areas. Distinctions in terms of the service context and service users reinforce the importance of taking local service context into account in current aging policy initiatives that address how to best care for older adults in the community.

5.2 Introduction

It is projected that by 2036, one in every four Canadians will be over 65 (Statistics Canada, 2014). 'Aging in place' is at the forefront of current social policy objectives "as well as a strong personal goal for older adults in regards to their autonomy and independence" (Cloutier et al., 2016, p. 89). Helping people stay in a community setting as long as possible also enables older adults to maintain a connection to social support from friends and family (Frank et al., 2002; Wiles et al., 2012). It also represents a cost-efficient alternative to residential care ([RC]; Chappell, 2011). However, as health care needs advance, remaining at home can be challenging due to a number of factors including features of the local service context (e.g., availability and options of supportive services in a community such as home and community care [HC], assisted living [AL] and RC; Cloutier et al., 2016). The availability of supportive community resources is largely based on factors such as population densities, economic productivity, and tax base (Wiles et al., 2012), which as we know, varies by geographic location. Depending on where the individual lives, services are also relied upon differently (Cloutier et al., 2016).

We know that with advancing age, changes in health needs often lead to multiple interactions with health care professionals across a variety of care settings (Andrew & Keefe, 2014; Arbaje, Boonyasai & Dilworth-Anderson, 2011; Coleman & Barenson, 2004; Cummings et al., 2012; Moorhouse & Mallery, 2012). When an individual's care needs exceed what can be offered in their home, a transition into a new LTC environment (e.g., AL or RC) often occurs. Transitions in care (e.g., movements within or between care settings) can occur as a result of a variety of factors, but are particularly significant because it is at these points that older adults are often considered

to be most vulnerable (e.g., older age, living alone, female gender, and being unmarried/widowed; Gaugler et al., 2007).

Existing research draws attention to the relationship between geographic location and health. However, in the context of care transitions, there remains a gap in the literature that assesses the impact of geographic location on factors that may influence the transition out of the HC and into a new LTC environment (i.e., AL or RC).

5.3 The current study

To address these knowledge gaps, our paper compares the characteristics of older (age 65+) publicly subsidized LTC clients in the FH region of British Columbia (BC) whose first transition was from HC services into AL or RC. Our analyses seek to build a better understanding of the interplay between local service context (i.e., urban, suburban, and rural areas) and the attributes of transitional older adult service users. We explore individual, social, and structural factors (i.e., predisposing, enabling, and need factors such as age, gender, marital status, presence of/relationship to primary caregiver, and health variables) that may influence the move out of the home setting (i.e., HC) and into a new LTC environment (i.e., AL or RC), and consider how these factors vary by geographic location. The specific questions this research addresses are:

1. What patterns exist in the transitions from HC to AL and HC to RC in urban, suburban, and rural areas of FH?
2. How do individual, social, and structural factors influence the transition from HC to RC as compared to AL, in urban, suburban, and rural contexts?

Population projections suggest that with our aging population, the demand for LTC services will ultimately exceed supply (Canadian Life and Health Insurance Association Inc., 2012). A chief goal of this work is to generate a more comprehensive understanding of the patterns and predictors of older adults who will move from their home to a new LTC environment and what type of characteristics movers will have. Further, our work fosters knowledge for health care decision-makers about how to improve community based health resources to better meet the needs of older adults to support them in remaining in the community.

5.4 Background

5.4.1 Transitions in care

Transitions in care involve movement within or between healthcare settings (e.g., moving from home to residential care) and are often seen as critical turning points or events in the lives of individuals and their families (Coleman, 2003). Studies looking at care transitions predominantly focus on specific populations (e.g., dementia, cancer, or hip fracture patients); on single transitions to/from acute care settings (e.g., from home to hospital, hospital to AL/RC, AL/RC to hospital or hospital back to home); and on the adverse outcomes and personal experiences (from the perspective of the patient) associated with these moves (e.g., hospital readmission, medication errors; Arbaje et al., 2008; Coleman, 2003; Cummings et al., 2012; Gozalo et al., 2011; Manderson et al., 2012). Other care transition research focuses on movement between LTC services; predominantly exploring the transition from HC to RC (Gaugler et al., 2007; Kemp et al., 2013; Penning & Keating, 2000). More recently, there has been some attention to movements from HC to AL (Rockwood et al., 2014) and AL to RC (Maxwell et al., 2013; McGrail et al., 2012; Rosenberg et al., 2006).

HC services (e.g., support with bathing, dressing, medication administration) help keep older adults in the home (FH, 2016a). They also promote independence and ‘aging in place’, an increasingly desirable alternative to placement in a facility-based care environment (i.e., RC; Kitchen et al., 2011; Sims-Gould & Martin-Matthews, 2010; Wiles, Leibing, Guberman, Reeve & Allen, 2012). McGrail (2011) argues that the use of community-based supports and services and alternative facility arrangements will lessen the need for the most ‘intense’ types of health service (e.g., RC).

With increased care needs, an individual may no longer be able to live safely or independently at home. AL provides housing, hospitality services, and personal care services for individuals who require some support due to physical and functional health challenges, but who can still make decisions on their own behalf (BCMOH, 2016a). In general, AL is described as “a form of housing that combines private units in apartment-style residences with the provision of hospitality and personal care services” (Carter, 2012, p.47). However, they do not offer 24-hour professional nursing care or supervision. AL has been considered a middle option between living at home and living in a RC facility (McGrail et al., 2012); with eligibility criteria that largely favours individuals with less dependence and fewer care needs in addition to the financial means necessary to purchase additional private care if needed (Rockwood et al, 2014).

Compared to RC, the transition from HC to AL is less well-explored. This is in part due to the limited options and availability of AL facilities (variation by geography), but also because of the significant regional and national variation in the definition of AL, eligibility criteria, staffing, and services (McGrail et al., 2012). These differences have raised concern about the quality of care AL clients receive (e.g., poorer detection and

management of health issues [Zimmerman et al., 2005]), which has generated general uncertainty surrounding the impact AL has on the health of individuals (Golant & Hyde, 2008).

Despite these national and regional differences, focusing on AL has gained increasing attention among researchers (Ball, Perkins, Hollingsworth, Whittington, & King, 2009; Golant & Hyde, 2008; Kelsey, Laditka & Laditka, 2010; McGrail et al., 2012; Rockwood et al., 2014; Wolff & Jenkins, 2008). Although there is limited research exploring factors that influence admission to AL, a Canadian study by Rockwood et al. (2014) found that people move from the community into an AL facility largely due to dementia (at least a 'moderate' level), caregiver stress, recent hospitalizations, and problems in balance and mobility. Ball and colleagues (2009) add that transitions into AL are also often are triggered by loss of a spouse and increased social isolation. A comprehensive analysis of six American studies by Golant (2004) explored the extent to which older adults with varying physical, cognitive, and health care needs occupy AL facilities. He found that AL facilities were supporting older residents who required less nursing care and had fewer functional and cognitive limitations/impairments compared to those found in RC facilities.

When an individual's care needs exceed the capacity of supports aimed at enabling them to stay at home as long as possible, often due to substantial changes in cognitive, medical, and functional health, a transition out of the home setting and into a facility-based care environment (i.e., RC) is common. RC facilities provide 24-hour professional nursing care and supervision, in addition to hospitality (e.g., meals, laundry, and housekeeping), personal care services (e.g., medication administration, assistance with ADLs), and recreational activities (FH, 2016a). Similar to HC and AL,

across most jurisdictions there is a mix of public, private, non-profit RC options (FH, 2016a).

Evidence from comprehensive literature reviews suggests that there are a variety of factors that can influence older adults' admission into RC. Most often, researchers report these factors according to the health service utilization framework (Andersen, 1995; Andersen & Newman, 1973). Predisposing factors that have been shown to influence transition into RC often include demographic and social characteristics such as older age (Gaugler et al., 2007; Luppá et al., 2010) and being female (Luppá et al., 2009). Enabling factors often include having low income, being unmarried/widowed, lacking a family caregiver/poor social network, and lack of access to community based services (Gaugler et al., 2007; Luppá et al., 2010; McCusker, Kakuma, & Abrahamowicz, 2002; Wang, Shamliyan, Talley, Ramakrishnan, & Kane, 2013). Researchers regularly report that strongest and most consistent predictors of transition into RC are need factors (often reflecting an individual's functional independence). Specifically, cognitive impairment (e.g., presence of Alzheimer's or other dementia) and greater levels of dependency with basic living and instrumental activities of daily living (ADLs and IADLs) appear most strongly associated with transition into RC (Gaugler et al., 2007; Hajek et al., 2015; Luppá et al., 2010; Tomiak, Berthelot, Guimond, & Mustard, 2000).

5.4.2 Place-based care

Social determinants of health tell us that the environments in which we are born, grow, work, and live influence our health and well-being (World Health Organization, 2012). LTC services occupy a pivotal place in supporting older adults and their families as they cope with changing physical and cognitive abilities. However, communities differ

in terms of the range of services and amenities they offer. To illustrate, compared to urban communities, rural areas have been characterized as having limited formal service options (e.g., hospitals, physicians, specialists, home care and community care) largely based on low population densities, low economic productivity, limited tax bases, reduced government supports, and out-migration (Skinner, Hanlon, & Halseth, 2012; Hodge, 2008; Joseph & Cloutier-Fisher, 2005; Kuluski, Williams, Berta & Laporte, 2012; Skinner & Hanlon, 2016; Skinner & Rosenberg, 2006; Society of Rural Physicians Canada, 2001).

A substantial body of literature addresses differences in rural and urban population characteristics, suggesting rural populations often have lower incomes, less education, and lower life expectancy (Allan, Funk, Reid & Cloutier-Fisher, 2011; DesMeules et al., 2006; Keating, 2008; Kulig, 2010; Pong et al., 2011). Additionally, there is a large focus on illustrating the inverse relationship between health and geographic remoteness (Allan & Cloutier-Fisher, 2006; Dandy & Bollman, 2008; Forbes & Janzen, 2004; Joseph & Cloutier-Fisher, 2005; Keating et al., 2013; Kulig, 2010; Kitchen et al., 2011). Some recent studies have shown that compared to their urban counterparts, rural seniors tend to have poorer mental and physical health status (Crowther, Scogin, & Johnson Norton, 2010). For example, rural areas often have greater proportions of individuals with higher dependencies in ADL and IADL functioning and a higher mean number of chronic conditions (e.g., diabetes and heart failure; Eales et al, 2006; Goeres et al., 2015).

Existing health geography research has tended to focus on home and community care services, physician visits, and hospitalizations in rural and urban areas (Allan,

Funk, Reid & Cloutier-Fisher, 2011; Forbes & Janzen, 2004; Kitchen et al., 2011; McAuley, Spector, Van Nostrand, 2009). Fewer studies specifically address the use of RC or AL by older adults living in different geographic areas (BCMOH, 2015; Cloutier et al., 2016; McCann, Grundy, O'Reilly, 2014). Cloutier et al. (2016) suggest that clients rely upon LTC services differently depending on whether they live in an urban or rural environment, suggesting that rural older adults rely more heavily on HC than RC services compared to their urban counterparts. As such, they note that their results are highly reflective of the limited options and availability of RC services in rural areas. Even fewer studies have explored factors that influence entry into RC facilities in different geographic areas with place of residence most often reported as being non-significant or being discussed as a proxy for other factors such as socio-economic status in the neighbourhood (Bolin, Phillips & Hawes, 2006; Tomiak, Berthelot, Guimond, Mustard, 2000).

More recently, there has been an increase in attention directed towards AL facilities being suitable 'middle options' for older adults facing physical and cognitive challenges (McGrail et al., 2012). However, AL facilities are fewer in number compared with RC locations, particularly in rural communities (Forbes and Janzen, 2004). In a national American study, Hawes et al. (2005) concluded that AL facilities are predominantly an 'urban industry,' with 76 percent of facilities, including the largest facilities, being located in metropolitan areas. Overall, more research is needed in this area.

Research exploring health status and health service utilization in comparative geographical contexts has limitations, as findings are heavily reflective of the local

service context of the research area. Factors such as how to define urban versus rural and the diversity of each type of community (e.g., distance from urban center, nature of the volunteer base, degrees of social engagement, and physical activity opportunities; Jeffery et al., 2013; Keating et al., 2013) all contribute to shaping the study's results which make findings difficult to generalize.

5.5 Health services utilization framework

To generate a better understanding of health service use in geographically diverse areas of FH, the behavioural model of health services use (Andersen, 1995; Andersen & Newman, 1973) guided the analyses. A large body of literature explores elements that influence care transitions and largely use this model to identify factors that affect entry into various care environments (e.g., AL or RC). This model suggests that an individual's use of health services is related to three factors: their 'predisposition' (e.g., demographic and social characteristics) to health service use; factors that may 'enable' or impede health service use (e.g., personal/familial relationships and community resources), and their 'need' for care (e.g., health status; Luppá et al., 2010). Studies have consistently shown that age, functional status (e.g., dependencies in activities of daily living [ADLs] such as eating, bathing, and dressing) and cognitive status (e.g., presence of Alzheimer's or other dementia) are among the most significant predictors of entry into facility-based care (Gaugler, Duval, Anderson, Kane, 2007; Luppá et al., 2010).

As noted, this model suggests that health service utilization is influenced by individual, societal, and contextual factors. Most often, geographic location is included in empirical analyses as an enabling variable. Researchers who do include place of

residence as a predictor of health service use in their analyses tend to limit their focus to the main effects of geographic location. The model combines geographic location with other enabling characteristics such as marital status, income, and presence/relationship to primary caregiver. However by doing so, the model doesn't allow us to see how geographic location may interrelate with other factors. Thus, the role of geographic location in predicting LTC service use may be oversimplified. To our knowledge, few studies, if any, explore the interaction between geographic location and other factors in influencing transitions between LTC services. At the same time, Andersen (1995) suggests that knowing more about the community (e.g., types of health services organizations and providers) would benefit our understanding of health services use.

5.6 Study design

5.6.1 Data and sample

Ethical review was undertaken through a joint process between the University of Victoria and FH human research ethics review boards. A certificate of ethical approval for minimal risk harmonized study (BC15-031) was obtained in 2015.

We conducted the study in the FH region of BC. In BC, five regional health authorities currently share responsibility for the design, delivery, and governing of health services and programming across the province (e.g., hospital care, community-based residential, home health, mental health, and public health services). FH not only has the largest overall population (serving 1.6 million people), but is also home to approximately 30 percent of BC's seniors (FH, 2014). Those aged 65+ comprise 15 percent of the FH population and represent the fastest growing older adult population of all the health

authorities (FH, 2014). Ethnoculturally, approximately 38,100 First Nations people live in FH and about 60 percent of senior immigrants to BC identified FH as home in 2012 (FH, 2014). Most of FH's population (66 percent) lives in the western part of the region. However, communities range in population size from 427,588 in Surrey to 8,095 in Hope (FH, 2014).

The analyses drew on administrative data extracted from the Resident Assessment Instrument-Minimum Data Set (RAI-MDS 2.0), the Continuing Care Information Management System (CCIMS), and the Discharge Abstracts Database (DAD). The RAI instruments included both home and community care and residential care assessment tools. The RAI-MDS 2.0 has undergone reliability and validity testing and been implemented in more than 30 countries including the US, UK, Germany, France, Japan and Australia, as well as Canada (Carpenter & Hirdes, 2013). Seven Canadian provinces/territories, including British Columbia (where it was introduced in 2005), use the RAI-MDS 2.0 to collect information on approximately 300 items related to resident care (Carpenter & Hirdes, 2013). This instrument includes a comprehensive assessment of the clinical and functional characteristics of clients (i.e., cognition, communication, vision, mood and behaviour, psychosocial well-being, physical functioning, continence, disease diagnoses, nutritional status, skin condition, medications, and special treatments and procedures; Carpenter & Hirdes, 2013.) The CCIMS includes LTC client identification information and the hospital discharge abstracts database (DAD) captures administrative, clinical and demographic information on hospital discharges, including deaths, sign-outs and transfers (CIHI, 2015).

The analytic cohort for the quantitative study was defined using a two-step process. The first step involved selecting all persons aged 65 and over (as of January 1, 2008) whose initial entry point for receiving subsidized LTC services was through Fraser Health HC services. These clients had a HC service start date between January 1, 2008 and December 31, 2011. For the purposes of these analyses, long-term HC services included services that kept the client residing at home notably: Home Support (companionship, housekeeping, personal assistance), Direct Care (home nursing, occupational therapy, physical therapy, rehabilitation, social work, nutrition), and 'Other' services (e.g., Adult Day Programs). These clients had to have received HC services for a period of at least 43 days (administrative processing time frame as suggested by FH research team members to capture long-term HC users).

With the objective of exploring two specific transitions in care among LTC clients, step two restricted the group to those whose initial transition was out of the home and into either AL or RC within the 2008-2011 time frame. For the purposes of this study, all clients were receiving publicly subsidized services in either AL facilities (including family care and group homes) or RC facilities. In total, 3233 clients met the above criteria, including 2,677 (82.8%) clients who transitioned from HC into RC and 556 (17.2%) clients who transitioned from HC into AL. Although subsequent transitions within the LTC environment (i.e. AL to RC) may have occurred, these transitions are outside the scope of this project.

5.6.2 Measurement

Our outcome of interest was the type of transition (coded as RC=1 and AL=0). In order to explore the role of geographical context in influencing LTC service transitions,

this study utilized Cloutier et al.'s (2016) designation of FH into three adjacent geographic areas (i.e., urban, suburban, and rural; see Figure 4.1). These areas reflect the geographic diversity of FH based on census characteristics including: population densities, growth rates, and percent foreign-born. Cloutier and colleagues (2016) also used several health system variables such as number of physicians, hospitals, and hospital and residential care beds per capita to support the classification of communities on the modified index from most urban to more rural. Using census characteristics, publicly available boundaries files from Statistics Canada, BC Statistics and Canada Post, an individual's location of residence (urban, suburban, rural) was assigned based on their forward sortation area (FSA) as designated by the first three digits of the postal code recorded in the Continuing Care Information Management System (CCIMS) client files. An urban location of residence was coded as '0', suburban was coded as '2', and rural was coded as '1'.

Guided by the health service utilization framework (Andersen, 1995; Andersen-Newman, 1973), predisposing variables included: gender (male=0, female=1) and age (in years) at the time of transition. Enabling variables included: marital status (not married=0, married=1), low income as assessed by the receipt of the Guaranteed Income Supplement (GIS) (no=0, yes=1), whether the primary caregiver lived with the client (no=0, yes=1) and the primary caregiver's relationship to the client (spouse=0, child/child-in-law=1, other=2, no primary caregiver=3; for the analyses, this variable was treated as a categorical variable with 'spouse' as the reference category). Health-related need variables captured diagnosis, symptoms, and service-related variables (e.g., total hospitalizations) that might influence the transition into AL or RC.

Five of the eight need variables were derived from validated RAI-MDS 2.0 scales. An individual's functional status was assessed using the Activities of Daily Living (ADL) Self-Performance Hierarchy Scale (Morris, Fries, & Morris, 1999). This scale assesses personal hygiene, toilet transfer, locomotion, and eating according to the stage of the disablement process in which they occur (scored from 1 for *Independent* to 6 for *Total Dependence*). Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS) scores (Hirdes, Frijters, & Teare, 2003) were used to identify medical frailty (scored from 1 for *No Instability* to 5 for *High Instability*). The Cognitive Performance Scale ([CPS]; Morris et al., 1994) was used to assess memory impairment, level of consciousness, and executive function combined to identify impairment (scored 1 for *Intact* to 6 for *Very Severe*). The Depression Rating Scale (DRS) indicated the presence of major or minor depressive disorders (scored 1-14, with a cut-off point of 3+ shown to indicate mild/moderate depressive symptoms and coded as no=0 and yes=1 [Burrows, Morris, Simon, Hirdes, & Phillips, 2000]). Higher scores on all scales indicated more severe impairment. The presence of dementia (no=0, yes=1) assessed the presence of Alzheimer's disease and/or other related dementias at the time of assessment and incontinence (no=0, yes=1) measured any evidence of bladder and/or bowel incontinence over the period of assessment. Total number of chronic conditions (i.e., major chronic diseases notably, cardiovascular and musculo-skeletal diseases, cancers, and diabetes; range 0-11) assessed the level of co-morbidity. The remaining need variables included: time to transition which captured the total number of days from the start of HC service use to the start of RC or AL (determined using administrative service start date records); the clients' total number of hospitalizations over the duration of their service use, and their mean length of stay in

hospital (measured in days, across all hospitalizations between 2007/08 and 2011/12 fiscal years).

All covariates were measured from the closest RAI assessment to date of transition, with the exception of two variables: 'primary caregiver lives with client' and 'caregiver relationship to client'. We know informal caregivers play an instrumental role in the lives of older adults, especially at the time of transition. However, their involvement is not well-documented in the administrative assessment tools used in these analyses. The home and community assessment tool captures a limited amount of information on informal caregivers, but such information remains entirely absent from the residential care assessment tool. To acknowledge the role that informal caregivers play in the lives of older adults, 'primary caregiver lives with client' and 'caregiver relationship to client' were extracted from the only available assessment tool that captured these variables (home and community care assessment tool; i.e. pre-transition).

5.6.3 Data analyses

Descriptive analyses (i.e., frequencies, crosstabs, and analyses of variance) were used to explore the prevalence and compare the characteristics of older LTC clients who transitioned from HC into either RC or AL within the FH region (see Tables 5.1 and 5.2). Next, logistic regression analyses were conducted to examine individual, social, and structural factors (e.g., age, gender, marital status, presence of/relationship to primary caregiver, and health variables) that influence the transition from HC to AL or HC to RC. Covariates of interest were entered in three blocks representing predisposing, enabling, and need variables consistent with the health service utilization framework to explore the associations between the predictor variables and service use.

'Location of residence' was initially included in these analyses as an enabling variable. However, this limited our results to the main effects of geographic location and did not allow for exploration of the interaction between geography and the other predictors. Therefore, to address the importance of predisposing, enabling, and need factors in difference contexts, separate logistic regression analyses were also run within each of the three areas: urban, suburban, and rural (see Tables 5.4, 5.5, 5.6). These analyses were conducted using SPSS software version 21.0 (IBM Corporation, Armonk, NY).

5.7 Results

Overall, 556 clients (17.2 percent) transitioned from HC to AL and 2677 (82.2 percent) transitioned from HC to RC.

Table 5.1 compares the characteristics of clients based on transition type (AL and RC). Statistically significant differences were found when comparing the two groups in terms of most predisposing, enabling, and need characteristics. Overall, although both transition groups were less likely to be male (23.4 percent for HC-AL and 40.9 percent for HC-RC) than female, a significantly greater proportion of males transitioned from HC to RC than from HC to AL. Age at the time of transition was also significantly associated with type of transition, with clients transitioning from HC into RC being slightly younger than those transitioning from HC to AL (85.0 for HC to AL and 84.4 for HC to RC).

A comparison of the two groups with regard to enabling characteristics reveals that there was no significant association between location of residence and transition type. Yet, there were significant differences in income, with over half of the clients

transitioning from HC to AL having received the GIS (65.3 percent) compared to 40.8 percent for HC-RC. Overall, both transition groups were less likely to be married (20.5 percent for HC-AL and 40.7 percent for HC-RC) than not married. However, there were significant differences by transition type, with a greater proportion of married clients transitioning from HC to RC. Significantly fewer HC-AL clients had a caregiver who lived with them closest to the time of transition (25.8 percent compared to 54.3 percent for HC-RC). Overall, both transition types were more likely to have a child/child-in-law as their primary caregiver (72.6 percent for HC-AL and 55.1 percent for HC-RC) than a spouse or other person. However, a greater proportion of HC-AL clients had a child/child in law as their primary caregiver whereas significantly more HC-RC clients had a spouse as their primary caregiver (33.6 percent compared to 10.3 percent for HC-AL).

Looking at 'need' characteristics, the analyses revealed that there was no significant difference between transition groups with respect to presence of depression. However, although both transition groups had clients with dementia, this was most evident among clients who transitioned from HC-RC (67.2 percent compared to 24.0 percent for HC-AL). A proportionately larger group of HC-RC clients was also incontinent (52.2 percent compared to 30.0 percent for HC to AL). Other significant differences between transition types included: higher mean ADL for RC clients (0.49 for HC-AL and 2.5 for HC-RC), CHESS (1.1 for HC-AL and 1.6 for HC-RC), and CPS scores (1.2 for HC-AL and 2.8 for HC-RC); total number of chronic conditions (3.4 for HC-AL and 3.0 for HC-RC), mean time to transition (324.5 days for HC-AL and 424.7

days for HC-RC), mean number of hospitalizations (3.9 for HC-AL and 3.4 for HC-RC), and mean length of stay in hospital (12.7 days for HC-AL and 20.0 for HC-RC).

Table 5.1 Descriptive characteristics of transitional clients by type of transition (N=3233)

Variable	Assisted Living (n=556)		Residential Care (n=2677)		SIG
	n	%	n	%	
<i>Predisposing</i>					
Gender (Male)	130	23.4	1092	40.9	.001***
Age at time of transition (mean)	85.0 (84.4-85.5)		84.4 (84.1-84.6)		.046*
<i>Enabling</i>					
Location of residence					.261
Urban	293	52.7	1410	82.8	
Suburban	207	37.2	936	81.9	
Rural	56	10.1	331	85.5	
Receipt of GIS (Yes)	351	63.6	1074	40.8	.001***
Married	113	20.5	1071	40.7	.001***
Primary caregiver lives with client	143	25.8	1434	54.3	.001***
Relationship to primary caregiver					.001***
Spouse	57	10.3	880	33.6	
Child / child-in-law	401	72.6	1442	55.1	
Other	94	17.0	296	11.3	
<i>Need</i>					
Presence of dementia	133	24.0	1778	67.2	.001***
Presence of depression	115	20.8	648	24.5	.062
Incontinent	166	30.0	1381	52.2	.001***
ADL score (mean)	.49 (.41-.57)		2.5 (2.4-2.5)		.001***
CHESS score (mean)	1.1 (1.0-1.2)		1.6 (1.5-1.6)		.001***
CPS (mean)	1.2 (1.1-1.3)		2.8 (2.7-2.8)		.001***
Total number of chronic conditions (mean)	3.4 (3.2-3.5)		3.0 (3.0-3.1)		.001***
Time to transition in days (mean)	324.5 (301.1-348.0)		424.7 (412.1-437.3)		.001***
Total number of hospitalizations (mean)	3.9 (3.6-4.1)		3.4 (3.3-3.5)		.003**
Length of stay in hospital in days (mean)	12.7 (11.4-14.0)		20.0 (19.2-20.8)		.001***

*p < .05. **p < .01. ***p < .001

As noted, Table 5.1 included 'location of residence' as an enabling variable. However, this limited our results to reporting on the main effect of geographic location and did not allow for further exploration of the interaction between geography and the other predictors. To address this, Table 5.2 compares the characteristics of clients based on their location of residence (i.e., geographic area: urban, suburban, and rural).

A descriptive analysis of variability across samples revealed that by and large, clients who made one of the two transitions of interest did not differ by geographic location. However, although no differences emerged with regard to predisposing or enabling factors, differences were found in three of the health and service context (need) variables including: ADL scores, the mean number of days to transition, and the mean length of stay in hospital.

Table 5.2 Descriptive characteristics of transitional clients by geographic area (N=3233)

Variable	Urban (n=1703)		Suburban (n=1143)		Rural (n=387)		SIG
	n	%	n	%	n	%	
<i>Transition type</i>							.261
HC to AL	293	17.2	207	18.1	56	14.5	
HC to RC	1410	82.8	936	81.9	331	85.5	
<i>Predisposing</i>							
Gender (Male)	657	38.6	416	36.4	149	38.6	.471
Age at time of transition (mean)	84.5 (84.2, 84.9)		84.5 (84.1, 84.8)		84.4 (83.7, 85.0)		.878
<i>Enabling</i>							
Receipt of GIS (Yes)	759	44.6	508	44.8	158	41.7	.429
Married (Yes)	599	35.8	430	37.6	155	40.7	.154
Primary caregiver lives with client (Yes)	817	48.6	563	49.6	197	51.6	.569
Relationship to primary caregiver							.058
Spouse	461	27.7	358	31.7	118	31.2	
Child / child-in-law	987	59.3	649	57.5	207	54.8	
Other	216	13.0	121	10.7	53	14.0	
<i>Need</i>							
Presence of dementia	997	59.2	683	60.2	231	60.5	.840
Presence of depression	401	23.8	268	23.6	94	24.6	.925
Incontinence (Yes)	825	49.0	535	47.1	187	49.0	.591
ADL score (mean)	2.2 (2.1, 2.3)		2.0 (1.9, 2.1)		2.2 (2.1, 2.4)		.004**
CHESS score (mean)	1.5 (1.5, 1.6)		1.5 (1.4, 1.5)		1.5 (1.4, 1.6)		.252
CPS score (mean)	2.6 (2.5, 2.6)		2.4 (2.4, 2.5)		2.5 (2.3 2.6)		.112
Total number of chronic conditions (mean)	3.2 (3.1, 3.2)		3.0 (2.9, 3.1)		3.0 (2.8, 3.1)		.063
Time to transition in days (mean)	403.5 (388.2, 418.8)		398.3(379.6, 417.0)		451.9 (417.1, 486.8)		.019*
Total number of hospitalizations (mean)	3.4 (3.3, 3.5)		3.6 (3.4, 3.8)		3.6 (3.2, 3.9)		.276
Length of stay in hospital in days (mean)	19.9 (18.9, 20.9)		17.0 (15.9, 18.1)		18.6 (16.3, 20.9)		.001***

* $p < .05$. ** $p < .01$. *** $p < .001$.

Overall, urban and rural clients had greater levels of ADL dependency, with clients having an average score of 2.2, indicating 'limited dependence.' Post hoc tests revealed that ADL scores were significantly higher among urban clients compared to

suburban clients (2.2 compared to 2.0 for suburban), with no significant difference evident between rural and urban or rural and suburban clients. Rural clients experienced a significantly longer time receiving HC prior to transition compared to urban and suburban clients (451.9 days compared to 403.5 days for urban and 398.3 days for suburban), with no significant difference evident between urban and suburban clients. Lastly, urban clients had significantly longer stays in hospital compared to suburban clients (19.9 days compared to 17.0 days); no significant difference emerged between rural and urban clients or rural and suburban clients.

To address our second research question, binary logistic regression analyses were conducted to explore individual, social, and structural factors associated with the transition from HC to RC as compared to AL. Table 5.3 reports results for all transitional clients (whole sample), with geographic location included as an enabling variable. Overall, the results indicate that men were more likely than women to transition from HC to RC. However, age at time of transition was not a significant predictor. Enabling characteristics that were significantly associated with type of transition in care included receipt of the GIS and having a primary caregiver that lived with the client. Receiving the GIS reduced the likelihood that clients would transition from HC to RC, while having a primary caregiver live with them increased the likelihood that they transitioned from HC to RC rather than to AL. Table 5.3 also suggests that clients whose relationship with their primary caregiver was as a 'child/child in law' or 'other', were less likely to transition from HC to RC. However, looking across models 1 through 3, these covariates lost their strength and significance as predictors when need variables were

included in the model (see model 3), suggesting that such factors serve to mediate the relationship between 'relationship to primary caregiver' and transition type.

Table 5.3 Logistic regression analysis for variables predicting the transition from home and community care services to residential care as compared to assisted living for all clients (N=3233)

Independent Variables	Model 1		Model 2		Model 3	
	B	OR	B	OR	B	OR
<i>Predisposing</i>						
Gender (Female=ref)	0.84***	2.32	0.47***	1.60	0.33*	1.40
Age at time of transition	-0.01	0.99	0.01	1.01	0.01	1.01
<i>Enabling</i>						
Location of residence (Rural=ref)						
Urban			-0.12	0.90	-0.14	0.87
Suburban			-0.21	0.81	-0.03	0.97
Married (No=ref)			-0.18	0.83	0.19	1.20
Receipt of GIS (No=ref)			-0.86***	0.42	-0.57***	0.56
Primary caregiver lives with client (No=ref)			0.96***	2.62	0.50**	1.66
Relationship to primary caregiver (Spouse=ref)						
Child / child-in-law			-0.66**	0.52	-0.17	0.85
Other			-0.65*	0.52	-0.09	0.92
<i>Need</i>						
Dementia (No=ref)					1.20***	3.3
Depression (No=ref)					0.06	1.06
Incontinence (No=ref)					-0.33**	0.72
ADL score					1.02***	2.79
CHESS score					0.25***	1.30
CPS score					0.56***	1.75
Total chronic conditions					-0.08	0.92
Time to transition (30 days)					0.03***	1.03
Total hospitalizations					0.00	1.00
Mean length of stay in hospital					0.02***	1.02
<i>Constant</i>	1.80	5.94	1.18	3.25	-2.23	0.11
R ² (Nagelkerke)	0.04		0.14		0.58	
Model Chi-squared	61.23***		253.04***		1189.83***	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Health-related need characteristics emerged as having the strongest influence on the likelihood of transitioning from HC to RC as compared to AL. In general, transitional clients who had dementia and who had higher levels cognitive impairment, greater ADL dependency, and were more medically frail, were more likely to transition from HC to RC than to AL. Further, clients who spent longer in HC prior to transition and had longer mean lengths of stay in hospital were also more likely to make the HC to RC transition. However, with these factors taken into account, clients with greater likelihood of incontinence were less likely to make the HC to RC transition. Depression, total number

of chronic conditions, and total hospitalizations did not emerge as having a significant influence on the transition type.

Tables 5.4, 5.5, and 5.6 report the results of analyses conducted within each of the three geographic areas. Table 5.4 reveals that among *urban* clients, gender was significantly associated with transitions from HC to RC as compared to AL, with men being more likely to make this transition compared to women. However, looking across models 1 through 3, gender lost its strength and significance as a predictor when enabling and then need variables were included in the model (see model 3), suggesting that such factors serve to mediate the relationship between gender and transition type. Age at time of transition was not a significant predictor of care transition type.

Enabling characteristics that were significantly associated with type of transition in care included having a primary caregiver and the receipt of the GIS. Among urban clients, having a primary caregiver live with them increased the likelihood that they transitioned from HC to RC rather than to AL. However, receiving the GIS reduced the likelihood that they would transition from HC to RC than to AL. Marital status and relationship to primary caregiver did not significantly influence the type of transition among urban clients.

Health-related need characteristics emerged as having the strongest influence on the likelihood of transitioning from HC to RC as compared to AL. In general, urban clients who had dementia, higher levels of cognitive impairment, and greater ADL dependency were more likely to transition from HC to RC than to AL.

Table 5.4 Logistic regression analysis for variables predicting the transition from home and community care services to residential care as compared to assisted living for urban clients (n=1703)

Independent Variables	Model 1		Model 2		Model 3	
	B	OR	B	OR	B	OR
<i>Predisposing</i>						
Gender (Female=0)	0.80***	2.20	0.43**	1.54	0.23	1.25
Age at time of transition	0.00	1.00	0.02	1.02	0.01	1.01
<i>Enabling</i>						
Married (No=0)			-0.02	0.98	0.22	1.24
Receipt of GIS (No=0)			-0.78***	0.46	-0.60**	0.55
Primary caregiver lives with client (No=ref)			1.31***	3.72	0.83***	2.29
Relationship to primary caregiver (Spouse=ref)						
Child / child-in-law			-0.29	0.75	0.09	1.10
Other			0.07	1.07	0.40	1.49
<i>Need</i>						
Dementia (No=0)					0.99***	2.70
Depression (No=0)					-0.14	0.87
Incontinence (No=0)					-0.38	0.68
ADL score					0.94***	2.56
CHESS score					0.00	1.02
CPS score					0.62***	1.86
Total chronic conditions					0.00	1.00
Time to transition (30 days)					0.04***	1.04
Total hospitalizations					0.04	1.04
Mean length of stay in hospital					0.01*	1.01
<i>Constant</i>	1.08	2.94	-0.21	0.81	-3.44*	0.03
R ² (Nagelkerke)	0.03		0.15		0.55	
Model Chi-squared	27.83***		139.0***		586.7***	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Further, urban clients with both a longer time spent in HC prior to transition, and longer lengths of stay in hospital were more likely to make the HC to RC transition. Need variables that did not emerge as significant include: presence of depression, being incontinent, medical frailty, total number of chronic conditions, or their total number of hospitalizations.

Looking at Table 5.5, which reports the results obtained for clients living in *suburban* areas of FH, we see that similar to urban clients, gender was significantly associated with the transition from HC to RC as compared to AL. Suburban men were more likely to make this transition than were suburban women. However, similar to the findings obtained with regard to those living in urban areas, this variable's predictive power lost strength when enabling and then need variables were included in the final

model (see models 2 and 3). In contrast, similar to the findings obtained for urban clients, age at the time of transition did not have a significant influence on the transition from HC to RC as compared to AL.

Among suburban clients, enabling characteristics that were significantly associated with transition type included receipt of the GIS, having a primary caregiver that lived with them prior to transition, and having a child/child-in-law as their primary caregiver. Individuals who received the GIS were less likely to transition from HC to RC as compared to AL. However, these variables become nonsignificant when need variables are included in the final model. Other enabling variables that did not have an influence on transition include marital status and having an 'other' primary caregiver (e.g., other relative or friend/neighbour).

Similar to urban clients, among suburban clients, need variables emerged as having the strongest association with the transition from HC to RC as compared to AL. In general, suburban clients with dementia and higher ADL and CPS scores were more likely to transfer from HC to RC than AL. Those who were identified as being more medically frail (i.e., those with higher CHESS scores) were also more likely to transition to RC than AL. However, with these variables controlled for, clients who had more chronic conditions and higher rates of hospitalization were less likely to transition from HC to RC than to AL, a finding unique to the suburban area. Need variables that did not emerge as being significant include presence of depression, incontinence, time to transition, and length of stay in hospitals.

Table 5.5 Logistic regression analysis for variables predicting the transition from home and community care services to residential care as compared to assisted living for suburban clients (n=1143)

Independent Variables	Model 1		Model 2		Model 3	
	B	OR	B	OR	B	OR
<i>Predisposing</i>						
Gender (Female=0)	1.09***	2.97	0.78***	2.19	0.84**	2.30
Age at time of transition	-0.017	0.98	-0.00	1.00	-0.02	0.99
<i>Enabling</i>						
Married (No=0)			-0.53	0.59	-0.16	0.85
Receipt of GIS (No=0)			-0.75***	0.74	-0.46	0.63
Primary caregiver lives with client (No=ref)			0.52*	1.70	0.24	1.27
Relationship to primary caregiver (Spouse=ref)						
Child / child-in-law			-1.13**	0.32	-0.46	0.63
Other			-1.59	0.20	-0.53	0.59
<i>Need</i>						
Dementia (No=0)					1.64***	5.18
Depression (No=0)					0.49	1.63
Incontinence (No=0)					-0.28	0.76
ADL score					1.31***	3.71
CHES score					0.68***	1.98
CPS score					0.49***	1.62
Total chronic conditions					-0.19*	0.83
Time to transition (30 days)					0.01	1.01
Total hospitalizations					-0.10*	0.91
Mean length of stay in hospital					0.01	1.01
<i>Constant</i>	2.61*	13.62	2.59*	13.30	-0.14	0.87
R ² (Nagelkerke)	0.06		0.15		0.66	
Model Chi-squared	37.58***		95.74***		516.41***	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 5.6 indicates that among *rural* clients, gender was once again significantly associated with the transition from HC to RC as compared to AL. Although again, this variable loses significance when enabling variables (i.e., receipt of the GIS), were included in the model (see model 2). Age at time of transition remained non-significant across all three models.

With regard to enabling factors, rural clients who received the GIS were less likely to transition from HC to RC as compared to AL. This variable loses strength, but remains a significant predictor, when health-related need characteristics were added to the model. Having a primary caregiver that lived with the client was also significant positive predictor of the HC to RC transition. However, it loses significance in the final

model as well. Marital status and the client's relationship to their primary caregiver did not significantly influence transition among rural clients.

Table 5.6 Logistic regression analysis for variables predicting the transition from home and community care services to residential care as compared to assisted living for rural clients (n=387)

Independent Variables	Model 1		Model 2		Model 3	
	B	OR	B	OR	B	OR
<i>Predisposing</i>						
Gender (Female=0)	0.31*	1.37	-0.05	0.96	.031	1.03
Age at time of transition	-0.01	0.99	0.02	1.02	-0.00	1.00
<i>Enabling</i>						
Married (No=0)			-0.02	0.98	0.64	1.90
Receipt of GIS (No=0)			-1.65***	0.19	-1.15*	0.32
Primary caregiver lives with client (No=ref)			0.92*	2.51	0.79	2.20
Relationship to primary caregiver (Spouse=ref)						
Child / child-in-law			-0.77	0.46	-0.70	0.50
Other			-0.82	0.44	-0.33	0.72
<i>Need</i>						
Dementia (No=0)					0.84	2.30
Depression (No=0)					-0.32	0.73
Incontinence (No=0)					0.03	1.03
ADL score					0.99***	2.67
CHESS score					0.29	1.33
CPS score					0.70*	2.01
Total chronic conditions					-0.18	0.83
Time to transition (30 days)					0.03	1.03
Total hospitalizations					0.05	1.05
Mean length of stay in hospital					0.15***	1.16
<i>Constant</i>	2.80	16.34	1.60	4.94	-2.23	0.11
R ² (Nagelkerke)	0.01		0.21		0.66	
Model Chi-squared	1.53***		43.01***		160.24***	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Similar to both urban and suburban clients, need characteristics once again emerged as strong predictors of transition from HC to RC as compared to AL. Rural clients with higher ADL and CPS scores, as well as those with longer lengths of stay in hospital were more likely to transition from HC to RC than to AL. Need variables that were not significantly associated with transition type included presence of dementia, depression, incontinence; medical frailty, their total number of chronic conditions, time to transition, and total number of hospitalizations.

Within all three geographic areas, explanation improved as blocks of variables were added. Full models were tested against preliminary models and were statistically significant, indicating that the predictors included in the overall model distinguished between clients transitioning from HC into RC as compared to those transitioning from HC to AL (urban: $\chi^2=583.434$, suburban: 515.416; rural: $\chi^2=160.235$). Final model Nagelkerke R^2 values ranged from .55 (urban) to .66 (rural) indicating moderate to strong model fit, with successful prediction overall ranging from 90.2% (urban) to 91.3% (rural).

5.8 Discussion

The relationships between people, health and places, have been shown to have an important influence on the lives of older adults (Kitchen et al., 2011; Rosenberg, 2014; Skinner, Cloutier, & Andrews, 2014). This research focused on the importance of local service context to help understand patterns and predictors of older adults' transitions from HC in the community to new LTC environment (i.e., AL or RC).

The first objective of this paper was to explore what patterns exist in the transitions between HC to AL and HC to RC. We found that over the course of the four-year study period, proportionally more clients' first transition in care was from HC to RC than to AL. In addition, statistically significant differences were found in predisposing, enabling, and need characteristics. Clients transitioning from HC into RC were more likely to be male, younger at the time of transition, unmarried, less likely to be receiving the GIS, and tended not to have a caregiver living with them. Clients transitioning from HC into RC also were more likely to have dementia, to be incontinent, and to have higher ADL, CHESS, and CPS scores. Need variables reflecting service use also were

significantly different by transition type, with HC-RC clients having longer transition periods and lengths of stay in hospital. Overall, these findings support both existing research and health policy literature that highlights differences in service users according to service type (Cloutier et al., 2016, Gaugler et al., 2007; Luppá et al., 2010; Rockwood et al., 2014).

These findings appear similar to those of previous studies. For example, a Canadian study by Rockwood and colleagues (2014) found that most participants were involved in a move from the community to a nursing home (synonymous with RC), with the average age for clients transitioning from community to a nursing home being 83.1 and 85.5 for community to AL. Our study reflects similar findings with HC-RC clients being younger than HC-AL clients. Similar to some existing literature, overall, women were more likely to reside in AL or RC facilities compared to men (CIHI, 2011, Freeman, 2015). However, among our transitional client population, proportionally more men made the transition from HC to RC compared to HC to AL. These are similar to the findings reported by Grunier and colleagues' (2013) based on their retrospective cohort study as well as Gaugler and colleagues' (2007) study. However, they contrast those reported by Luppá and colleagues (2010) who found that the influence of gender on institutionalization was not consistent, with most studies finding no significant effect. Rockwood and colleagues (2014) also found that among clients who make the transition from the community into RC, 91 percent were diagnosed with dementia compared to 83 percent of AL clients. Our study found that 67 percent of HC-RC clients had a dementia diagnosis compared to only 24 percent of HC-AL clients. Despite similar findings that suggest larger proportions of clients transitioning into RC with dementia, their study did

not require participants to have been receiving HC services prior to transition.

Furthermore, the considerable difference in the percentages between our study and Rockwood et al. (2014) are likely due to significant variation between provinces in the definition of dementia and when diagnosis took place, admission/discharge criteria, and services of AL facilities (Maxwell et al., 2013). For example, in BC, AL units are most often subsidized and viewed as intermediate settings between home and RC; not primarily designed or resourced for individuals with significant physical or cognitive impairment (McGrail et al., 2012). Alternatively, in Nova Scotia, where Rockwood et al.'s study took place, AL facilities are privately owned and targeted at older adults who are largely independent but who can bring in more supportive services if required (e.g., dementia support). Having the financial means to pay for additional support to keep them in AL, despite cognitive decline over time, may account for the considerable differences between our results and theirs

Despite expectations, our preliminary analyses also revealed that geographic location was not significantly associated with type of transition at the bivariate level. However, significant differences by geographic area (see Table 5.2) were evident in terms of clients' ADL scores, mean number of days to transition, and mean length of stay in hospital. In particular, suburban clients had significantly lower ADL scores, shorter lengths of stay in hospital, and shorter time to transition following HC use compared to rural clients. This raises the possibility that although older adult LTC clients look more similar than not in terms of predisposing, enabling, and need characteristics, factors beyond individuals operate differently in influencing care transitions within the

different areas (i.e., geographic area as a proxy for service availability may interact with predisposing, enabling and need factors).

The suburban area emerged with some unique findings that may be explained by the local service context (i.e., options and availability of HC services and/or AL and RC facilities). For example, in a study exploring the clinical and health profiles of RC clients in BC's Northern Health Authority, Freeman (2015) found that 24 percent of individuals living in RC facilities had lower health needs that did not meet the provincial eligibility criteria for care. The study found that this group had lower levels of need including being "likely to exhibit 'no' to 'moderate' functional impairment, 'no' to 'mild' cognitive impairment, and stable health" (p. iv). Freeman suggests that this may be a result of "large gaps in availability of community supports" (p.43) and case managers having limited options outside of placing individuals on waiting lists for RC.

Our findings may also be explained by inappropriate placement into RC facilities in the suburban region, as highlighted by lower levels of ADL dependency and shorter time spent in HC services before the transition. The shorter time to transition period reflects a greater availability of LTC beds per 10,000 people aged 65+ in the suburban area compared to the rural area (309 beds versus 201 in rural; as cited in Cloutier et al., 2016); which suggests that unlike rural areas, waiting for an available RC bed in the suburban area may not be an issue. Shorter hospital stays for individuals may also reflect the range and nature of community support services that are available in the suburban area, or the amount of help family members provide. Based on the combination of lower levels of care dependencies and adequate HC options, suburban

clients may be being discharged from hospital in a timely manner, ultimately spending less time in the hospital compared to their rural counterparts.

On the other hand, urban clients' longer hospital stays may be a result of spending longer as 'Alternative Level of Care' (ALC) patients. ALC patients "no longer require acute care services but wait in acute care beds for placement in a more appropriate setting such as home or residential care" (CIHI, 2012, p.1). CIHI (2012) reports that more than half (54%) of ALC older adult Canadians transitioned into a RC facility. Thus, urban clients may be relying on the hospitals for care needs that could be met instead in the community with appropriate supports.

Our second research objective was to explore how individual, social, and structural factors influence the transition from HC to RC as compared to AL, in urban, suburban, and rural areas of FH. Our initial findings revealed that geographic location was not significantly associated with type of transition when other predisposing, enabling, and need factors were controlled for. On the one hand, this suggests that location of residence may not be relevant to transitions from HC to AL or RC. However, separate analyses conducted within each geographic area revealed differences in individual, social, and structural factors associated with the type of transition.

Overall, ADL and CPS scores emerged as significant predictors of HC to RC transition as compared to HC to AL within all geographic areas. However, income emerged as a significant predictor of type of transition in rural and urban, but not suburban areas. In contrast, the suburban area had a unique set of predictors including:

gender, medical frailty, total number of chronic conditions, and number of hospitalizations.

Consistent with the literature, this study illustrates that overall, cognitive impairment and greater dependency in activities of daily living have strong influence on the transition from HC to RC (Gaugler et al., 2007; Hajek et al., 2015; Luppá et al., 2010; Rockwood et al., 2014). Our findings reflect current eligibility criteria indicating that an individual's access to long-term RC is based on clinically determined need for that level of care (BCMOH, 2016b). In our logistic regression analyses, entering the covariates of interest in blocks allowed us to see the effects of one type of variable (i.e., predisposing, enabling, need) when the other types of variables were added to the model. Within all three regions, adding the need variables (Model 3) resulted in the largest improvement in model strength; reinforcing the significance that health-related variables have in influencing transitions in LTC (Gaugler et al., 2007; Luppá et al., 2010).

As noted, the suburban area revealed unique findings. In terms of individuals, this area reflected client complexity and had the greatest number of need variables emerge as predictive of transition type including: presence of dementia, medical frailty, ADL and CPS scores, and total hospitalizations. No enabling factors emerged as being significant predictors of care transition. Unique to this area and to the HC to RC transition, suburban clients were more likely to be male and more medically frail (i.e., having higher CHESS scores). Furthermore, compared to suburban clients with 'no dementia', those with dementia were 5.2 times more likely to move into RC as compared to AL; denoting the single strongest predictor of the transition into RC within

all three geographic areas. These results are similar to the findings of previous studies exploring the predictors of RC admissions (Eska et al., 2013; Rockwood et al., 2014). Our findings are consistent with the existing literature that suggests that the movement into RC is often characterized by a progressive decline in cognitive and physical functioning (i.e., increased frailty; Andrew & Keefe 2014; Moorhouse & Mallery 2012; Wu et al., 2014).

Logistic regression results also suggest that suburban clients with more chronic conditions and a greater number of hospitalizations were less likely to transition from HC to RC than to AL; which also reflects the characteristics of our the client group who transitioned from HC-AL (i.e., HC-AL clients had lower ADL scores). We know that admission to AL or RC is primarily determined by an assessment of the client's needs and service availability. This is consistent with existing literature that suggests that individuals with lower levels of dependence and fewer care needs are more likely to reside in AL facilities (Rockwood et al, 2014). AL facilities provide assistance with personal care (e.g., medication management, bathing, and dressing) as well as housekeeping, which may be 'enough' to maintain a greater level of independence. Existing literature and policy documents suggest that those in AL can usually 'cope' longer by bringing in additional services (i.e., companion services) to help supplement their care needs (FH, 2015; McGrail et al., 2012; Rockwood et al., 2014). Our findings suggest that AL facilities in suburban areas may be sufficiently equipped to monitor an individual's chronic conditions, keeping them out of RC for longer.

Although the suburban area revealed some unique findings, the rural area also warrants discussion. Logistic regression results revealed higher ADL and CPS scores as having significant influence on the transition from HC to RC compared to AL among

rural clients. Combined, these findings reflect existing literature suggesting that rural clients have some higher dependencies (functional and cognitive) compared to their more urban counterparts (Kitchen et al., 2011; Pong et al., 2011). Rural clients exhibited longer times to transition which appears consistent with existing literature that suggests rural communities may be doing a better job than 'more urban' areas at providing supports to help older adults age in place through the use of a more established network of informal and community supports (Cloutier et al., 2016; Davenport, Rathwell & Rosenberg, 2005). On the other hand, the high proportion of HC to RC transitions (and conversely the low number of HC to AL transitions) combined with longer time to transition periods may reflect rural areas having fewer formal service options (i.e., AL facilities). In turn, this results in clients not having the option of entering a lower level of care facility first, but having to enter RC because of there being 'no other choice'. Further, this suggests that for some rural LTC clients, entry into a RC facility may not be solely based on need for the services provided by that facility, but also may reflect the facility becoming a 'default option' due to lack of other community level supports (Freeman, 2015; Kuluski et al., 2012).

Our results also suggest that rural clients with longer mean lengths of stay in hospital were more likely to transition from HC to RC than to AL. This could highlight limited health service availability given that there are fewer RC beds and community supports in those areas (see Table 4.1; Cloutier et al., 2016). Rural clients are spending longer in hospital waiting for RC placement as a result of having no other available options.

Looking across the geographic areas, the impact of enabling and health-related need factors on transitions from HC to RC versus AL is evident. Within all geographic

areas, gender became less important when enabling and then health need variables were entered into the model. These findings suggest that gender differences in LTC transitions may reflect gender differences in enabling characteristics (e.g., relationship with primary caregiver or receipt of the GIS), health status, and/or other health service use. Similarly, enabling variables (i.e., receipt of the GIS, whether the primary client lives with the caregiver, and the relationship to primary caregiver) also became less important or had diminished significance when health-related need variables were included in the model (see Tables 5.4, 5.5, and 5.6). These findings suggest that among our sample of clients, differences in those factors that influence the type of care transition are strongly related to health status and/or health needs. Overall, the findings regarding these enabling variables suggests that care transitions for older, GIS recipients, and those who live with a caregiver (for example) are heavily impacted by their health-related need characteristics.

5.9 Limitations

The findings presented in this paper focus on two specific transitions made by older populations when they are no longer able to remain at home. Although a more full consideration of these key transitions generates valuable knowledge for LTC policy and programming initiatives in FH, there are limitations to this research. First, this study defined HC, AL and RC broadly to capture the breadth of services that either supported the client to remain living at home and receiving supportive care (HC services), receiving minimal support in a monitored environment (AL) or being provided with full, 24-hour nursing care and other forms of facility support (RC). However in reality, the nature and quality of each of these forms of service can vary broadly by geography. In addition, there are other transitions that may further complicate a client's transition from

home into a new care environment. For example, we know that with advancing age, there is an increased risk of hospitalizations; often influenced by transitions in care (Coleman & Boult, 2003; Manderson et al., 2012). Findings from the larger project from within which this study is set (BCTIC) indicate that multiple hospitalizations often occur between HC and admission to either RC or AL. However, in this paper, number of hospitalizations was summed across the four-year period and not explored in greater depth (e.g., timing and frequency within the overall care trajectory). Integrating hospitalizations as a specific part of the care trajectory (e.g., moving from HC to hospital to HC to RC) would contribute to research in this area.

Also, it is important to bring attention to the way these geographic regions were delineated. Labelling the geographic areas as urban, suburban, and rural and considering them as a continuum provided a way to highlight variation in contiguous local service contexts across FH. Administratively, FH is divided into three health service delivery areas (HSDAs): Fraser North, Fraser South and Fraser East that look quite different from our regions; with resource allocation decisions are more likely to parallel these boundaries. Our project's geographical boundaries (concentric rings ranging from urban to rural) did not seamlessly align with these HSDA boundaries, which may pose additional challenges to interpreting findings and implementing change at the health authority level.

As noted earlier, FH is a health authority with a large population and is home to a diverse range of cultures and ethnicities. To help generate more in-depth information on transitional older adults who moved from their homes in the community to a new care environment, there is a need to better address service users in their local service

context. Exploring the population makeup in the suburban area may help to explain some of our findings (i.e., shorter time to transitions and the role primary caregivers play in supporting older adults outside the formal care system). Transitions in care have been shown to reflect multiple characteristics from the individual to the health care system (Dilworth-Anderson, Hilliard, Williams, & Palmer, 2011; Forbes et al., 2008; Hayes & Amram, 2012). However, these important contextual pieces remain uncaptured on RAI-MDS 2.0 assessment instruments, making it challenging to fully interpret our findings. Similarly, family caregivers have a widely known presence in the life of the older individual moving through the health care system and play an instrumental role in maintaining the well-being, functional independence, and quality of life for older adults (Chappell & Hollander, 2013; Kemp et al., 2013; Naylor & Keating, 2008); key elements to supporting an older adult to remain in the community as long as possible. Specifically, information about their level of involvement is not adequately captured administratively (e.g., RAI-MDS 2.0 assessment instruments). Moving forwards, a qualitative component is viewed as helping to develop a more complete understanding of movement across the LTC system. Bringing together insights from the quantitative and qualitative analyses, offers a richer and fuller picture that explores the complex, intersecting nature of transitions in care across the LTC system from both administrative and family perspectives.

Finally, as noted, this study primarily reported within area effects and on comparing coefficients across groups, and did not include interaction terms in each of the models. This would be a step for future analysis.

5.10 Conclusion

Overall, our findings highlight the importance of exploring transitions in care in relation to the service user and local service context and illustrate the impact of predisposing, enabling, and need factors and how their differences by geography. We found that in general, transitional clients (HC-RC and HC-AL) do differ significantly by geography in terms of three main characteristics: ADL scores, the mean number of days to transition, and the mean length of stay in hospital. Logistic regression analyses revealed that higher ADL and CPS scores were the most consistent predictors for clients making the HC to RC transition across all geographic areas. In addition, the suburban area revealed unique predictors of the type transition including gender, total number of chronic conditions, and total hospitalizations.

Our findings have generated information that can meaningfully influence social policy efforts aimed at enabling older adults to remain at home in the community for as long as possible. We have demonstrated that health-related needs have the strongest influence on transition type. However, to provide quality care support for older adults, local service provision must also reflect the care needs of individuals living in that area. As noted earlier, suburban clients had lower ADL dependencies than their rural counterparts, but had longer lengths of stay in hospital and experienced shorter time periods between HC and RC. With older adults being generally less dependent in the more suburban areas, improved availability and access to community supports post discharge will help reduce their length of stay hospital. Improved community services will also limit the use of RC among those whose needs could be adequately supported in the community. To conclude, this study has generated a more comprehensive understanding of individual, social, and structural factors that influence older adults'

transition from their home in the community to a new LTC environment and reinforces the importance of service users and local service context.

Chapter 6: Paper 2 – Qualitative analysis

Transitions and trajectories: Family caregiver journeys

In this chapter, I report on the findings from the qualitative component of my thesis. As indicated in Chapter 1, this chapter is written in a manuscript format and is intended to be submitted to the journal of *Ageing & Society*.

For this qualitative study, I focus on the unique time period in a family caregiver's caregiving journey when they help a family member to transition from home into a new LTC environment. For this chapter, I developed a conceptual framework to help illustrate how family caregivers manage and make sense of their roles and responsibilities around care transitions (Giosa et al., 2014). Reflecting on the experiences captured by the conceptual framework, this chapter concludes with a discussion of three overarching themes that emerged from the data (Braun & Clarke, 2012). Labelled with direct, *in vivo* quotes, these include: "*I'm just her daughter*" / "*I'm just his wife*", "*Just go with the flow*", and "*There wasn't a door I didn't try to open*".

6.1 Abstract

Family caregivers play an instrumental role in supporting the functional independence and quality of life of older adults; helping them to remain in the community as long as possible (Chappell & Hollander, 2013; Kemp et al., 2013). However, transitions in care (movement between or within health care services) often occur when care needs exceed community supports and family caregiving capacities. Existing literature highlights a range of care activities families perform over the course of their caregiving journey (Gaugler & Kane, 2015), yet little attention focuses on the 'care management' activities, such as the care-related dialogue about the arrangements for formal care, information seeking, finances, and paperwork (Rosenthal, Martin-Matthews & Keefe, 2007). Furthermore, few studies, if any, focus on these activities in the context of care transitions. This provides an important rationale for this qualitative study which explores how family caregivers manage and navigate a key transition in care for a family member. In this research, the focus is on the kinds of activities involved, decisions needing to be made, and the joys and challenges in doing so. Finally, we seek to better understand how family caregivers make sense of the many layers of their caregiving roles and responsibilities.

This paper is based on the qualitative data from 15 semi-structured interviews with family caregivers located in the Fraser Health region of British Columbia. Data were analyzed using thematic analysis (Braun & Clarke, 2012), from which a conceptual framework emerged that elaborates on the caregiver journey; highlighting the key activities that caregivers engage in before, during, and after their family member's transition into a new care environment. This framework was used as a mechanism to organize and develop the findings from this study. In addition to presenting the

framework and discussing the findings accordingly, the analysis reflects three overarching themes that capture and describe how family caregivers make sense of their roles and responsibilities. Our findings provide valuable insights into family caregiving roles and responsibilities and serve to illustrate some of the ways that family caregivers can be better supported to make their family member's care transition more seamless.

6.2 Introduction

Formal long-term care (LTC) services are fundamental elements in the care continuum (Havens, 1995). However, they are often criticized as being fragmented, poorly coordinated, and difficult to navigate (Chappell & Hollander, 2013). Movements between different care settings or levels of care within the same setting (i.e., care transitions; Coleman & Berenson, 2004) have been recognized as significant, often complex, events in the lives of older adults, as they are usually urgent and can occur unexpectedly. Older adults are often most vulnerable at times of transition because of declines in health and functional status, as well as changes in other life circumstances (e.g., loss of spouse, increased dependence, reduced income, change in home; Dilworth-Anderson & Palmer, 2011). Existing research suggests that poorly orchestrated care transitions can leave older adults experiencing discontinuities in care as well as breakdowns in information and communication (Coleman, 2003). Further, declines in functional health and adverse reactions to medications may occur that can cause increased stress, anxiety, and heighten the risk of re-hospitalization (Cummings et al., 2012; Jeffs et al., 2013; Manderson et al. 2012).

With the increasing likelihood of physical, mental, and cognitive decline with age, older adults often rely on support from family members to help cope with their changing care needs. According to the 2012 Statistics Canada General Social Survey, approximately 8 million Canadian caregivers provided informal support to a friend or family member in a given year (Sinha, 2013). Almost half (48 percent) are adult children providing care to a parent or parent-in-law, with most between the ages of 45 and 65. Consistent with existing caregiver literature, approximately 54 percent of Canadian caregivers are also female (Sinha, 2013).

Family caregivers play an important role in supporting and maintaining the well-being, functional independence and quality of life of older adults (Ashbourne, 2015; Chappell & Hollander, 2013; Giosa, Stolee, Dupuis, Mock, Santi, 2014). The majority of caregivers have provided help to a family member for one year or longer, with approximately half reported to have provided care to a family member for four or more years (Sinha, 2013). They often provide support with personal and/or instrumental 'activities of daily living' (ADLs and IADLs such as, bathing, eating, toileting, meal preparation, cleaning, laundry, banking, and transportation) in addition to providing emotional support and companionship (Brody, 2004; Cranswick & Dosman, 2008; Gitlin & Wolff, 2011; Sinha, 2013). They also seek, obtain, and coordinate formal care services for their family members. Sinha (2013) found that 31 percent of Canadian caregivers engaged in scheduling and coordinating appointments for their family member and 27 percent managed their finances.

Over the course of their caregiving journeys, a considerable amount of time, energy, and resources are spent providing support. Sinha (2013) found that family caregivers spend an average of 3 hours a week caring for a family member or friend. However, this increased to 10 hours a week for caregivers caring for a spouse. Caregivers provide a high level of care for a family member, but often at the expense of their own health and well-being (Chappell, Dujela & Smith, 2014; Gitlin & Wolff, 2011). Sinha (2013) found that when asked specific questions about their health symptoms, over half (55 percent) of caregivers reported feeling anxious about their caregiving responsibilities while 35 percent reported feeling overwhelmed. Despite these negative health symptoms, most caregivers (92 percent) felt that providing care was in fact a rewarding experience (Sinha, 2013).

Existing caregiving literature highlights the wide range of care activities families perform over the course of their caregiving journeys. However, to date, there has been little direct attention to the 'care management' activities of family caregiving, which include tasks and activities other than direct 'hands-on' care (Rosenthal et al., 2007). Care management activities include care-related dialogue with other family members or the care recipient about the arrangements for formal care services and financial matters, doing relevant paperwork, and help with information seeking (see Rosenthal et al., 2007). Rosenthal et al. (2007) found that among caregiving men and women, the number of hours spent providing care varied by the type of care they were providing. Those providing only managerial care engaged in the fewest hours of care per week, while those providing both managerial care and direct care (i.e., assistance with ADLs and IADLs) engaged in the greatest number of hours of support per week.

While many researchers have explored the characteristics of caregivers, there is little research focusing on the characteristics of those performing care management activities. Within the research that has focused on care management activities, some studies suggest that gender is a strong predictor of involvement (Horowitz, 1985). However, not all literature reports similar findings. Lawrence, Goodnow, Woods and Karantzas (2002), Campbell and Martin-Matthews (2003), and Williams (2006) found that organizing formal care services (including financials and paperwork) tends to be done by caregiving sons. However, Keating et al. (1999) found that similar proportions of men and women helped with financial matters (e.g., banking and bill paying) when caring for an older adult with long-term health problems. Other research suggests that caregivers who have no siblings may be more likely to provide managerial care, since they have no other siblings to share care activities with (Lawrence et al., 2002).

Archbold's (1983) study remains the most detailed examination of managerial care. She found socio-economic status influenced whether a woman was a 'care-provider' or a 'care-manager', noting that income was the major determinant of whether formal care services were sought to help support the family member. She also found that care managers reported financial constraints, career interruptions, and tension/conflict with siblings (Archbold, 1983). Largely based on different ways of identifying and defining the kinds of activities caregivers engage in, Chappell & Hollander (2013) note that making generalizations about the care management role is difficult. Further, no known research has explored how family caregivers perceive or relate to the 'care management' role.

We know that when an older adult's care needs reach a point where they can no longer live safely or independently at home, family caregivers often take on distinct caregiving responsibilities to help navigate the transition from home into a new LTC environment (Gitlin & Wolff, 2011). While transitions in care mark changes in the life of the older adult involved, they also can have significant impact on the lives of family caregivers. At specific points across the transitional care timeline (Giosa et al., 2014) caregivers often experience distress, anxiety, and confusion (Ashbourne, 2015; Afram et al., 2014; Duggleby et al., 2010; Giosa et al., 2014). For example, family caregivers are often forced to work within the boundaries of 'system-constraints' (e.g., eligibility criteria, financing, and mandatory policies³). These can contribute to the stress of helping a family member to transition into a new care environment. In a systematic review examining informal caregiver needs and challenges when caring for people with

³ In BC, for example, access to RC facilities is governed by the provincial government's Ministry of Health's Residential Care Access Policy. In practice, this policy sets in place a process where seniors who are eligible for subsidized RC must accept the first appropriate bed they are offered and occupy that bed within 48 hours of when it was offered (BCMOH, 2016b).

dementia pre/post a LTC transition, Afram and colleagues (2014) found that 'emotional concerns' (e.g., grief and shame about the decision to move a family member into care), needing more 'knowledge/information' to understand the transition process, and the need for more 'support' (e.g., caregiver counselling) were the most frequently reported experiences related to care transitions. Bramble et al. (2009) found that when the decision to move a family member into a new care environment occurred in a crisis scenario, caregivers often felt unprepared and that the transition "*happened rather quickly*". Afram and colleagues (2014) also report that post-transition, some caregivers expressed the need to be reassured that they had made the right decision to move their family members. Further, Givens and colleagues (2012) found that after admission into a RC facility, caregivers still expressed a need to be involved in their family members' care. This finding also reflects the dynamic, non-static nature of the caregiving role.

While transitions in care are often reported as being physically and emotionally challenging for family caregivers, the transition experience can also have positive aspects. Studies by Levine, Halper, Peist & Gould (2010) and Giosa et al. (2014) found those caregivers who received adequate support and information promoted positive caregiver self-esteem, self-worth, and confidence in their care abilities; all factors that can contribute to a more positive care transition experience. Further, Ashbourne (2015) found that when caregivers felt the health care system made the effort to accommodate or work with them (e.g., provide prompt diagnosis information pre-transition and quality interactions with staff), they felt more supported over the course of their caregiving journeys.

In summary, although there is a growing body of literature broadly focusing on caregiver needs across their caregiving journey (Ashbourne, 2015; Giosa et al., 2014),

there is less attention to how family caregivers managed the care transition including their roles, responsibilities, and experiences (e.g., the kinds of activities involved, decisions made, challenges faced, and/or joys experienced). In particular, there is a need to explore the complex array of care management activities that family caregivers engage in before, during, and after a family member's transition between care environments and to develop an understanding of how family caregivers perceive and relate to the care management role. This study will generate meaningful information about the family caregiving role and the conceptualization of care management in the context of a care transition.

6.3 Research objective and questions

The objective of this research is to explore the unique time in a family caregiver's caregiving journey when they help a family member to transition from home into a new LTC environment. Specifically, this study seeks to generate in-depth information about family caregivers' roles, responsibilities, and experiences in managing their family members' care transitions before, during, and after the transition takes place. Based on gaps in the existing literature, and our current understanding of family caregiving, our main research questions are:

1. How do family caregivers manage a key transition in care for a family member and what are their experiences (e.g., the kinds of activities involved, decisions needed to be made, challenges faced, and/or joys) in doing so?
2. How do family caregivers make sense of the many layers of their caregiving roles and responsibilities?

6.3.1 Life course theoretical framework

This study was guided by a life course perspective (Elder, Johnson, & Crosnoe,

2003; Hutchison, 2011; Marshall, 2009) to better understand family caregivers' involvement in managing a family member's care transition. This perspective brings attention to the broad social contexts within which older adults and family caregivers are situated and helps provide a better understanding of the "continuities as well as the twists and turns in the paths of individual lives" (Hutchison, 2011). The life course perspective is a particularly valuable guiding framework in the context of family caregiving and transitional care because it draws attention to multiple trajectories (e.g., health and care) and the fact that it is at these junctures when there are not only changes in physical environment, but also changes in responsibilities and relationships (Levine & Feinberg, 2012).

This perspective is consistent with existing research that suggests that family caregiving is a dynamic activity and reflective of a "career" (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995), meaning that it "consists of a variety of stages around which a discernible career is organized" such as the onset of care related tasks through to "the relinquishing of at-home/community care responsibilities to residential long-term care" (Montgomery & Kosloski, 2001, p.142). It has been proposed that a family member's care transition evokes a simultaneous shift in the family caregiver's 'career' rather than an abrupt end to their caregiving role (Ball, Perkins, Whittington, Hollingsworth, & King, 2004; Kemp, 2012; Williams, Zimmerman & Williams, 2012; Wolff & Jenkins, 2008). Focused primarily in the dementia caregiving literature, family caregivers are identified as having caregiving careers comprised of three main phases: (1) a beginning (e.g., the initial start of providing care for a family member); (2) a series of events/activities that characterize their caregiving journey (e.g., transitions between care environments, significant declines in health); and (3) an end or resolution (e.g., recovery, death, or

nursing home placement; Montgomery & Kosloski, 2001). Although existing literature generally focuses on the caregiver's care journey over a longer period of time, the notion of their changing role is highly relevant to exploring family caregivers roles and responsibilities when transitioning a family member into a new care environment.

6.4 Research design

Prior to conducting the qualitative interviews, an ethical review was undertaken through a joint process between the University of Victoria and FH human research ethics boards. A certificate of ethical approval for minimal risk harmonized study (BC15-031) was obtained in 2015.

A qualitative research design was chosen as being ideally suited to the objectives of this study. This approach is often used for exploring the way individuals attribute meaning to a social or human experience. Thematic analysis was undertaken to develop the study findings. These findings were developed inductively from multiple passes through the data to build understanding from specific data fragments or bits into a general theme structure (Creswell, 2014).

6.5 Study area

This study was conducted in the FH region of British Columbia (BC). The province is divided into five regional health authorities that share responsibility for the development, delivery and monitoring of health services and programming (e.g., hospital care, community-based residential, home health, mental health and public health services). Serving 1.6 million people, FH not only has the largest overall population across all health authorities, but is also home to approximately 30 percent of the province's seniors. With fifteen per cent of the population being 65+, FH represents the fastest growing senior population of all the health authorities (FH, 2014). FH is also

ethnoculturally diverse (e.g., approximately 38,100 First Nations people, and about 60 percent of senior immigrants to BC identified FH as home in 2012 [FH, 2014]).

Following Cloutier et al. (2016), the study area was stratified into three adjacent geographic regions (i.e., urban, suburban or rural) in order to explore possible variations in experiences based on residence. FH is divided into 13 local health areas with communities ranging in population size from 427,588 in Surrey to 8,095 in Hope (FH, 2014). However, 66 percent of the population resides west of the Langley/Maple Ridge areas (Hayes & Amram, 2012). Starting in the most southwestern corner and moving east (see Figure 4.1), the geographic areas reflect diversity based on census characteristics (e.g., population densities, growth rates, and per cent foreign born), and on the basis of health system variables (e.g., physicians per capita, number of hospitals, and hospital and residential care beds per capita).

6.6 Methods

6.6.1 Sampling and data collection

A purposeful sampling technique (Patton, 2002) was used to select family caregivers (Davis et al., 2014; Sims-Gould & Martin-Matthews, 2010). Purposeful sampling allows for understanding the experiences associated with managing and navigating key transitions in care by those who are most intimately engaged with them; ensuring credibility and rigour by increasing the likelihood that they will be ‘information-rich cases’ rather than a random sampling of participants (Baxter & Eyles, 1997).

In exploratory qualitative research, the overarching goal is not statistical generalizability, but rather to develop an in-depth understanding and appreciation for the complexity of the data. Thus, there are no precise rules for determining an appropriate sample size. According to Morse (2000), qualitative sample size is said to

be best determined by a number of factors including: the scope/objectives of the study, the amount of time allotted, and the availability of resources. Morse (2000) also noted that studies that are narrower in focus may require fewer participants compared to a study looking at a much broad research topic. Two recent and topic-relevant studies (Ashbourne, 2015 & Giosa et al., 2014) used a grounded theory approach to examine family caregiver experiences in supporting care transitions for family members, with sample sizes of 29 and 12 respectively. Since this study also aimed to explore commonalities in caregiver experiences of managing a care transition for a family member, a similar number of interviews (between 15-25) was projected.

Recruitment started with research team members contacting Directors of Care and Site Administrators of all FH owned and operated/contracted AL and RC facilities to provide the project information letter (providing an introduction to the project and outlining its overall objectives) and to obtain permission for study recruitment at their facility. Methods of caregiver recruitment included direct advertising (i.e., posters displayed on public information boards and inserted into family communication packages where applicable) and in-person contacts by the primary author (Hainstock) who attended Family Council meetings to introduce the project.

Caregivers were eligible to participate if they self-identified as being the primary person who managed/helped navigate a family member's recent move from home into either AL or RC. Family caregivers were directed to contact the primary author by phone or email and were then provided with a study information letter and consent form to review prior to agreeing to participate. After allowing them time to review this material, the primary author followed up with interested individuals to address any outstanding questions or concerns. At this point, individual face-to-face interviews were scheduled at

the caregiver's convenience. These interviews took place at a quiet location that best suited the caregiver's preference and ranged from 45 – 150 minutes in length. Prior to the start of the interview, caregivers were given the opportunity to ask any remaining questions and to hand in their consent form. Background information was also collected (e.g., caregiver gender, age, occupation, relationship to the care recipient, etc.).

All interviews were recorded with the caregiver's permission and began by asking caregivers to offer a descriptive introduction of the care recipient. This helped provide background context for the researcher and provided an added level of comfort to the interview. Using a semi-structured interview guide, family caregivers were then asked questions in three areas of specific interest: the kinds of care activities they had engaged in over the course of their caregiving journey (including the support they provided before their family member transitioned); their specific experiences in managing and navigating the move from home to a new care environment; and how they made sense of the roles and responsibilities encompassed in caring for their family member, including their thoughts on the 'care management' role.

Following each interview, the researcher developed an archive of field notes focused on reflections about the interview experience. Pseudonyms were given to every caregiver to protect their anonymity and confidentiality.

6.6.2 Interpretive analysis

Audio recordings were transcribed verbatim following each interview by the first author. Initial analysis began with summary sheets (Miles & Huberman, 1994) that were developed from each interview using field notes and journal entries to capture the main ideas emerging from the interview and thoughts about the overall experience. Then, principles of thematic analysis were used to systematically identify, organize and

provide insight into patterns of meaning; allowing for the identification of collective or shared experiences across the data set (Braun & Clarke, 2012). Transcripts were read multiple times and 'open coding' was undertaken until the entire data set was reviewed. Research team members helped to collapse data into a smaller number of categories to identify areas of similarity and overlap, as well as difference or uniqueness, and to reflect coherent and meaningful patterns in the data (Braun & Clarke, 2012).

Information-richness is deemed important in qualitative research in favor of statistical generalizability (Sandelowski, 1995). Lincoln and Guba (1985) suggest that the trustworthiness of a study is an important measure of its worth. Criteria to establish trustworthiness include confirmability (i.e., the degree to which the findings of a study are moulded by the respondents and not by researcher bias). This study used the triangulation of data from multiple sources (i.e., interviews, observations, literature, and field notes), memoing/journaling, and peer debriefing with research team members to guarantee this. Other strategies used to ensure trustworthiness included capturing 'thick descriptions' of caregiver experiences (e.g., rich and salient details, including gestures and body language) were noted during interviews (Lincoln & Guba 1985). Qualitative data software (NVivo v.8) was used to organize and facilitate the thematic analysis.

6.7 Findings

6.7.1 Caregiver characteristics

Fifteen interviews were conducted in FH between July 2015 and November 2015. Seven were completed with urban participants, three with suburban and five with rural family caregivers. Despite an initial intention to explore differences by type of transition (i.e., home to AL versus home to RC), only one caregiver managed their family member's transition into an AL setting. Thus, the major focus in this research is

on transitions from home to RC. Nine interviews were conducted with daughters caring for an older parent, and five were conducted with a spouse or common-law partner. One of the 15 interviews took place jointly with a husband and wife who both provided care to the wife's sister. The husband and wife dyad were counted as a single interview, as they were both present at the same time and given equal opportunity to respond/contribute to the questions. However, caregiver characteristics were collected from both the husband and the wife, which resulted in a sample size of 16 caregivers.

Caregiver characteristics are captured in Table 6.1. Their ages ranged from 46 to 87, with an average age of 67. Most caregivers were married (n=9); while four were single, two were divorced and one was in a common-law relationship. Most had some level of post-secondary education, with only two caregivers indicating high school as their highest education. Only two women were employed at the time of the interview, while thirteen were retired, and one was unemployed. Family caregivers lived between 1.4 km and 34.8 km from their family member's care facility, at an average distance of 8.36 km.

Table 6.1 Characteristics of family caregivers

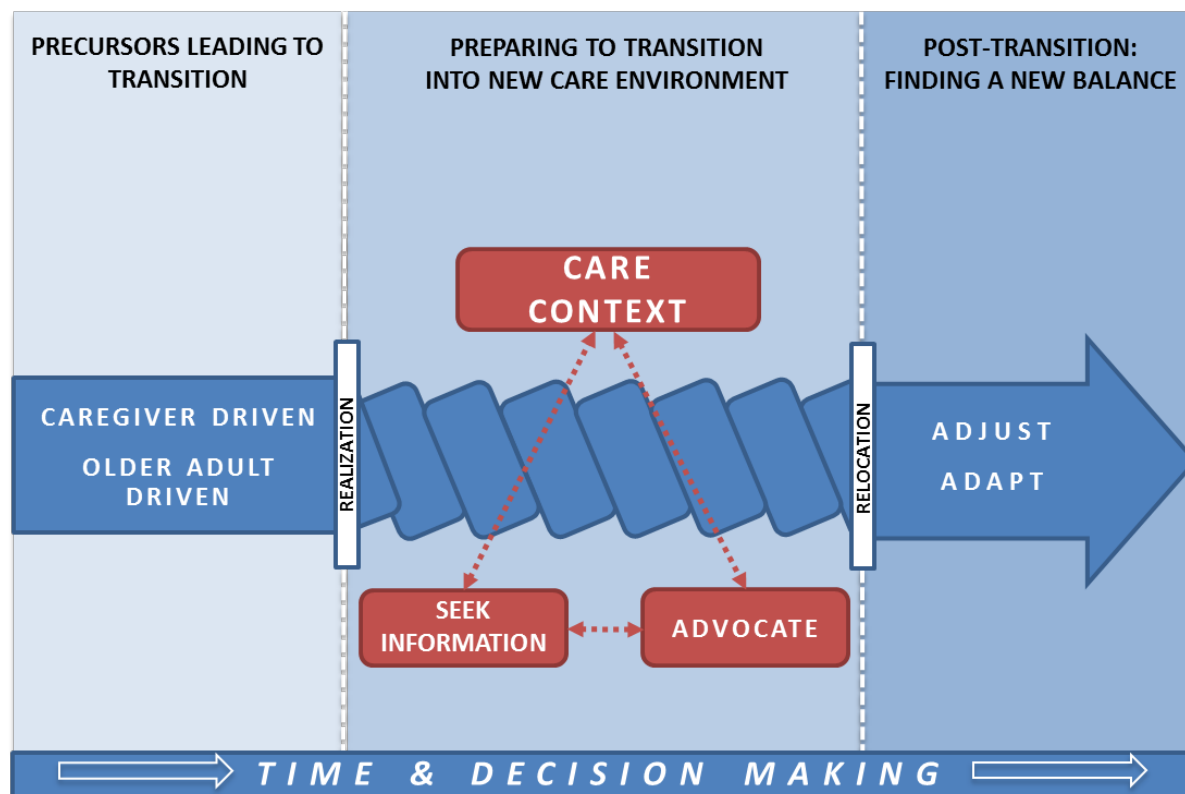
Characteristics	N
Gender	
Female	15
Male	1
Relationship to transitional client	
Wife/common law	5
Daughter	9
Sister/brother-in-law	2
Mean age	67 (46-87)
Marital status	
Married	9
Single	4
Common Law	1
Divorced	2
Education	
High school	2
Some college	2
Some university	4
Undergraduate degree	4
College diploma	1
Graduate degree	2
Occupation	
Retired	13
Baker	1
Realtor	1
Not applicable	1
Geographic Area	
Urban	8
Suburban	3
Rural	5
Distance to LTC facility (Avg. Km)	8.36 (1.4-34.8)

6.7.2 Understanding how family members manage care transitions in long-term care

Using thematic analysis, a conceptual framework (see Figure 6.1) was developed inductively to help to illustrate family member experiences with managing key transitions in care on behalf of a family member. Caregivers provided and managed their family member's care for anywhere from thirteen months to five or more years. This framework acts as a visual, organizational tool for understanding care transitions; a particularly unique period in the caregiver journey. The framework helps illustrate the roles and responsibilities family caregivers take on over time and acts as a guide for structuring

the discussion of the findings. Although the sample was stratified to explore possible variations in experiences based on urban, suburban, and rural residency, geography was found not to be as meaningful as other factors in differentiating experiences. In some cases, caregivers directly addressed their location of residence as having an impact on aspects of the care transition. However, experiences were more similar than dissimilar and geographic representation of the sample was preserved as it was one of the early objectives. Caregivers are identified using their assigned pseudonyms and location of residence throughout this paper (see Appendix H).

Figure 6.1 A conceptual framework for understanding how family members manage care transitions in long-term care⁴



⁴ Informed by work from Byrne, Orange, & Ward-Griffin, 2001 & Giosa et al., 2014

Reflective of the caregiver career literature, this framework echoes three 'phases' across the caregiving trajectory: Phase I: '*Precursors leading to transition*' (i.e., those circumstances such as caregiver burnout and declining health of their family member that are precursors to the transition); Phase II: '*Preparing to transition into new care environment*' (i.e., the various activities, navigational pieces, and roles that family caregivers take on to prepare for the care transition including paperwork, finances, advocacy); and Phase III: '*Post-transition: Finding a new balance*' (i.e., where the family caregiver adjusts, adapts, and seeks a new balance between their caregiving role and new found time for other activities now that their family members' care is the primary responsibility of the new LTC environment).

Consistent with existing literature, our findings support the concept that family caregiving is not a static activity (Aneshensel et al., 1995; Barelo, Savarese & Graffigna, 2015; Gaugler & Teaster, 2006; Gitlin & Wolff, 2011; Montgomery & Kosloski, 2001; Nolan et al., 2003). 'Time' is an important component of the framework and reinforces the longitudinal nature of a transition in care (e.g., activities leading up to/beyond the move). However, family caregivers spend different amounts of time in each phase of the transition depending on their family member's specific needs and availability of services. An important caveat to including time in the framework is that caregivers described their experiences retrospectively, which may impact their recall accuracy with regard to the order of events, decisions made, and overall timing of the transition. To address these limitations, the primary researcher developed a transitional care timeline for each participant to understand their care trajectory in the context of

their telling the story of the journey. Clarification was sought often and when needed over the course of the interviews.

Over the course of the care transition, family caregivers experienced constant changes that required shifts in their roles and responsibilities. Although caregivers cared for their family member in different capacities (e.g., personal care, banking/bill paying, and seeking formal home support), all caregivers became their family member's primary decision-maker. Caregivers engaged in decision making across all phases of their family member's transition; a role captured across the bottom of the framework.

6.7.3 Phase I: Precursors leading to transition

Phase I focuses on the circumstances that led up to the care transition. Sub-themes discussed in this phase include: the need to relocate being driven by a growing awareness for the family caregivers (i.e., caregivers experiencing burnout) and/or as a result of the declining health of their family member.

The first phase in managing a LTC transition for a family member begins with the caregiver identifying or realizing the need to make a move. Caregivers appeared to arrive at this 'realization' in different ways: either by a change in their family member's care needs (i.e., older adult driven) or based on their own needs as a result of caregiver 'burn-out' (i.e., caregiver driven).

Caregivers who arrived at the realization based on factors directly driven by the older adult, identified the need to relocate either because of a specific event (ranging from falls to violent outbursts) or because a decline in their family member's health had progressed to a point where they felt that more help was needed. Marge (rural) spoke about her experience with her husband:

And then he had his second stroke in 2008 and that really took the stuffing from out of him. His speech got slurred. His memory- he's got dementia- developed dementia and his memory started to be shot and uh, then he became incontinent, then he developed diabetes- the whole [thing] just sort of mushroomed out. He physically became weaker and weaker and that's eventually why we had to institutionalize him because he couldn't walk anymore and stuff like that.

Other caregivers, like Amelia (urban) referenced personal challenges such as fatigue, stress and burden that instigated the need to relocate their family member to a new care environment, noting: *"I think I was getting depressed and you know- I'm not that type of person really. I'm pretty positive."* Caregivers who expressed personal challenges as being heavily influential in their family member's relocation indicated that they had reached a point where they could no longer maintain the level of support they had been providing and knew something had to change. As Mary (rural) noted, *"I was at the end of my rope. I had tied the knot and I was hanging on with my teeth."*

With age, an individual's health often becomes more complex (e.g., multiple chronic conditions and decreased cognitive functioning). These changes can result in multiple interactions with health professionals across a variety of settings before they transition into a new LTC environment. Almost all caregivers had to navigate their family members' care in a hospital setting at some point in time over the course of their experience. In 14 of the 15 cases, the ultimate decision to relocate was made while the care recipients were in a hospital setting. Although there were different reasons for their family members' hospital admission (e.g., falls, urinary tract infections, aggressive outbursts, etc.), preparing for discharge was when caregivers were first faced with deciding their family members' next steps. Preparing for discharge was when most

caregivers were directly asked by the doctor or social worker what the next steps for their family member were going to be. Rebecca (suburban) was juggling personal health issues at the same time as managing her husband's care and recalls the interaction at the hospital:

They said 'he should be at home or he should be in a home. So make a decision.' Well, I couldn't handle it. I was miserable and just waiting for my operation and yeah. So we decided a home, right and uh, that was it.

Feeling 'naïve' and unfamiliar with how 'the system works', caregivers found themselves asking "what's the next step?" and "what should we do next?"; noting "it takes time to work through it." Most caregivers wanted to be able to bring their family members back home, but first had to assess if they were prepared, both physically and financially, to provide the required level of care. Like most of the caregivers, Tina (rural) had to take time to process the decision:

I had to sit down for a few days to tell myself- weigh the pros and cons and whether I honestly felt I could do it and I thought you know, I can't. It took me a while and I- I felt guilty about it, you know? But I was- once I made that decision, I still felt guilty, but it was a decision I knew I had to make.

For some caregivers, the decision to relocate was easier than for others, but most identified discussing the need to move with their family member as a specific challenge. Caregivers with family members who faced physical/functional declines, as opposed to dementia related declines, often found it difficult to persuade their family members about the need to move. As Mary (rural) noted, "*I think one of the hardest things is- can be, convincing the ill person that they need to go into the care home or assisted living.*"

Family caregivers often wanted to involve their family member in the transition process as much as possible, but sometimes cognitive impairments and dementia

status prevented this. Rosanne (urban) took note of her role change: *“Well I had to become the boss. I had to become my mother’s boss because she doesn’t listen...And uh- which is difficult because you’ve gotta take on the role.”*

As conveyed in the excerpts above, this difficult relocation/decision making juncture was an overwhelming time of distress and confusion and left caregivers riddled with feelings of guilt or ‘giving in’. Amelia (urban) noted, *“...they hand you the pamphlet and you are distressed, but you don’t really read it, but you read what you want to hear, you read what you believe is right for your mother.”* Sharon (rural) reiterated similar feelings, *“...that was really tough- for me to accept the fact that I had done all I had done for so long and then had to give in to taking her up there.”*

6.7.4 Phase II: Preparing to transition into a new LTC environment

Phase II focuses on the complexity of the specific events and activities that take place once the decision to relocate has been made. The sub-themes discussed in this phase include the rigorous process of seeking information, advocating for their family member, and navigating the formal LTC care system. In this phase, caregivers are heavily focused on ensuring coordination and continuity of care for their family members.

Information seeking

Across all interviews, caregivers addressed the need for more information and resources to be made available to support making informed decisions over the course of the transitional care timeline. Mona (urban) addressed the need for more information:

...it would have helped us a lot I think had there been more information available as to how to deal with this sort of- this sort of process. Just, you know, the steps involved in getting there and what to look for.

Only one caregiver specifically referred to being handed reference material to prepare for the transition:

When I was in the hospital, the social worker, she actually gave me one book on like how to prepare myself for her- transitioning from hospital to this kind of place. Even prepared me for later-. [Annie, urban]

Caregivers emphasized their efforts in actively “scout[ing] out” and “search[ing]” for as much information as possible, from both formal (e.g. social workers, case managers and other health professionals) and informal (e.g., friends and family) network members to help them make decisions. As Marge (rural) noted, “...*get as much information as you can. You know, ask everybody everything- anything.*”

Only two caregivers (one retired nurse and one dental worker) had healthcare backgrounds. Those who had an understanding of the healthcare system and experience working within it noted their backgrounds assisted in the information gathering process. However, those without such expertise found gathering and understanding information challenging, thereby adding an additional layer of complexity to this unique period in their caregiving journey. Sharon (rural) noted her experience in gathering information was primarily self-taught:

Um, you know I've just shopped- I've just gone around and figured out things but I don't know if, um, yeah, how I've learned the system [laughs]. I don't think anyone's really taught me what the system is, I just sort of figured it all out.

While caregivers also relied on multiple sources to help make informed decisions about their family members' relocation, the social worker stood out as being a particularly valuable information source for most. Marge (rural) highlighted the diverse

roles social workers have, noting:

They seem to have a broader perspective. They know the legal requirements. They know the physical requirements and they also are involved in emotional situations, so I think the social worker. I know nothing really about their jobs, but they seem to be a little more involved than some of the other bureaucrats in health services.

Annie (urban) further emphasized the importance their support, *“Without the social worker, I wouldn’t know where to go.”* Rural caregivers were the only individuals to indicate that their relationships with health care professionals and care staff were linked to their geographic location. Most rural caregivers noted that because of the smaller nature of the town and care facility, they felt more tightly connected to the care transition process. With this ‘tight-knit’ nature of their communities evoking a higher overall level of satisfaction with their family members’ care:

Oh yeah, I wouldn’t want him anywhere else. I did look in Kelowna where my daughter was- she thought maybe, you know, he could go there, but my daughter said ‘Mom, there’s no place like here. They- they’re so good to dad. Everybody’s just wonderful’ you know? [Moira, rural]

Most family caregivers also identified other members of their informal networks (e.g., children, spouses or friends) as being equally as important. Marge (rural) emphasized the role her children played in helping her manage her husband’s care transition, *“I’ve got four bright, bright kids and uh, they gave me all kinds of legal advice, medical advice, um, almost too much advice [laughs].”* Pieta (urban) also found her friends to be a key resource in helping gather information, *“I have a lot of friends in healthcare, so I got a lot of really good information sort of under the- [gesture; hand under table] you know?”*

Recognizing that no two care journeys are the same, seeking information was highly dependent on their family members’ health needs. Caregivers who had mixed

experiences in gathering information largely attributed it to there being insufficient communication between care environments (e.g., transfers between hospitals) or a disconnect in communication between themselves and healthcare staff. One caregiver, Tina (rural) went to visit her partner at the local hospital, who had been admitted the night before due to a fall, and found out that he had been relocated to a hospital out of town. She received no notice of the move and found the lack of information to be particularly challenging: *“No information, not even about him being transferred. Nothing. Um, that was the key. There was absolutely no information.”*

The excerpts above illustrate the wide range of information sources family caregivers used to help them make key decisions when managing a care transition. Some caregivers had more positive experiences than others. Paul (urban) reflected on the overall process of gathering information, *“It was rather a puzzle, wasn’t it?”* In many ways, Paul’s concluding thoughts are reflective of all the caregivers’ information gathering experiences.

Advocacy

A second responsibility that family caregivers appeared to take on was the role of advocate. Caregivers worked hard to support and maintain their family members’ well-being and quality of life when making decisions related to their care preferences and needs in preparation for a move. Joanne (urban) highlighted her efforts in enduring that her mother’s preferences be upheld *“...she would have been snuffed out of all that if I hadn’t been an advocate for her and spoke up.”*

In their advocacy role, despite all their hard work, family caregivers often felt that they lost their ‘final say’ in the face of system rules and restrictions. Sometimes things did not

go as anticipated, causing caregivers to react strongly (e.g., “becoming belligerent”, issuing formal complaints, and writing letters). Some caregivers felt ‘the system’ didn’t take into account the contextual realities of their situation (i.e., unsafe home, no other family to help provide care) or that system-level decisions were being made that didn’t reflect what they believed were in their family members’ needs and best interests. On these occasions, caregivers sometimes became more forceful in their advocacy role. Amy (suburban) recounted a particular experience she had when her mother was in the hospital:

...and then they said, um, ‘but we can’t keep her here.’ And I said, ‘no, listen to me.’ I said, ‘you have to keep her here until I can make arrangements and I can do that, I can make arrangements, but you have to keep her here.’ And he said, ‘we can’t.’ And I said, ‘no you have to listen to me. She can’t go back as she is.’ I said, ‘there’s no body able to care for her there. She’d be unsafe in my house. I have stairs and she’s blind in one eye. She’s so unsteady and she’s so sick and she has Alzheimer’s- she’d be unsafe.’

In two cases, caregivers became particularly forceful and threatened to take their concerns public. Nicole (suburban) described one specific experience in the hospital, “*I said ‘I’m not packing her up. If you guys wanna move my mom, you come and pack her up. You move her and I’ll have the press here to watch you do it.’”* Pieta (urban) also threatened going public with her concerns, “*I said ‘well there’s been some incidents in the newspaper lately, maybe this would be of interest to them as well?’”*

Such actions speak volumes about caregivers’ dedication to advocating on behalf of their family member, but sometimes caregivers felt like they were being forced to act in ways that weren’t like themselves. Although Pieta (urban) had threatened to bring her concerns to the newspaper, she wasn’t comfortable with how forceful she needed to become, “*I don’t ever like to be- you know, out of harmony with other people,*

but you know, certainly if I am being protective of someone I love then, you know?"

Navigating the system: Care context

A third aspect of preparing to transition into a new environment involved the family caregivers' ongoing navigational challenges in what was, for most, a complex and foreign landscape. In a care system that was inundated with ongoing organizational restructuring, caregivers routinely dealt with different health care professionals, administrators and care staff. All caregivers experienced changes in caseworkers, case managers, social workers, as well as nurse practitioners and doctors over the course of their family member's transition. These discontinuities added even more complexity to navigating their family member's care. While waiting for her mom to be placed in her new care environment, Annie (urban), experienced multiple social workers within a single hospital stay, *"Lots of changing. I think she had three social workers [laughing] it was really something. Like two or three months only and she had three."*

Although discontinuity in health care professionals was a common experience across caregivers in all three geographic regions, only rural caregivers specifically attributed this experience to their location of residence. Most rural caregivers identified challenges in the availability of health specialists (i.e. only one AL and one RC facility) and a routine discontinuity in health professionals/care staff, as being related to their "more rural" location. Some participants also mentioned that the high turnover among health care professionals may be related to the student placement opportunities that FH offers in those areas; however this idea wasn't confirmed.

Managing a family member's transition from home into a new care environment often involved a number of activities such as arranging eligibility assessments, selecting

the “top three” facility choices, and paying unexpected hospital fees associated with their family member’s stay. Caregivers found these aspects of the relocating their family member particularly restrictive and challenging to navigate. The three most talked about challenges of this phase included: eligibility and needs assessments, the unexpected “short stay” user fee, and the bed ‘waitlist’ itself.

LTC services have general eligibility criteria (based on citizenship, age, health condition, etc.) as well as service-specific criteria (based on assessed needs). As discussed in Phase I, relocating to a new care environment was a decision that was most often made in the hospital setting, which meant that family members’ needs assessments were typically performed there as well. The nature and timing of these assessments was often expressed as an additional source of frustration for caregivers:

Yeah, why does your assessment take so bloody long? He's in the hospital anyways. You're not doing an assessment of his condition particularly- physically- you're doing an assessment of God only knows what. But, I don't know why it takes two weeks. [Sally, urban]

Another challenge caregivers experienced in managing/navigating their family member’s transition was the unexpected “short stay” user fees⁵ that they were charged for staying in the hospital while waiting to be transferred into a RC facility. Not knowing what facility their family member was going to move to, and often having no other choice but to keep their family member in the hospital, caregivers were caught by surprise when the fee was demanded from them. Amelia (urban) recounts her experience with the hospital fee:

⁵ Individuals are billed a daily ward rate if they are waiting to transfer into a RC facility. This fee starts after a 30 day grace period (from the start of the wait) and continues until the individual has transferred (FH, 2016b).

...all of a sudden I've got this social worker coming to me saying 'your mom can't stay here anymore and we're going to have to start charging her rent.' I was like 'what? I didn't know this.' ... I was so, like so not knowing.

RC facilities are in high demand and waiting to be placed into one is not uncommon.

Family caregivers understood the basic concept of the waitlist (e.g., the prioritization of higher-need clients and bed availability), but identified it as being a source of stress:

At some point you gotta move. Now, you might not know when you're going to move, or where, because it's all a matter of when the bed is open...it was a case of when beds became available, but that was so stressful for people. So stressful. [Amy, suburban]

Caregivers' emotions were provoked through interactions with health authority staff when they inquired about their status on the list. Nicole (suburban) noted, *"They wouldn't tell me if the wait list was four years, two years- and they wouldn't tell me how it correlated with coming in from the hospital and I just wanted some kind of a picture."*

Being denied details about how the waitlist is structured, some caregivers resorted to 'playing the game' to make sure they got their family member into their preferred home:

I got the system- see you have to waitlist until you are given a bed. If it isn't the place where you want to be, you have to turn it down. You have to come off the waiting list for 30 days, then you go back on it. I played that game and I have kept turning down these places. Each time they gave me a choice, it seemed even worse than the last place. [Nicole, suburban]

In their efforts to get the best care possible for their family member, organizational and administrative constraints were cited as key sources of frustration for caregivers. Over the course of the interviews, caregivers routinely used the words "business" and "the system" when describing their experiences with the health authority. Most often, caregivers noted a lack of "empathy", "effort", and "compassion" from health

professionals. Amelia (urban) discussed the routine-like nature the health care professionals took to their jobs noting “...*this is what they do every single day. They're wheelin' them in and their wheelin' them out, they pass away...*” Rebecca (suburban) also thought there was general lack of ‘care’ by the health professionals she interacted with: “*They don't care. They really don't at all. I don't want to say it, but...*”

Overall, these excerpts from the data illustrate that preparing to transition into a new care environment is a period in a caregiver's journey when they put forward immense effort to gather information, advocate, and navigate the system on behalf of their family member.

6.7.5 Relocation

Referring to Figure 6.1, ‘*Relocation*’ represents the juncture between Phase II: *Preparing to transition into a new care environment* and Phase III: *Post-transition: Finding a new balance*. This time period is of particular importance in the context of care transitions because it captures the events and activities directly associated with receiving the notice that a LTC bed has become available and the physical move. Because LTC beds are in high demand, individuals moving into RC are given 48 hours to accept or decline the first appropriate and available bed⁶. Unlike other decisions caregivers had to make on behalf of their family members, having to decide where their family member was going to call home from then on was considered “*overwhelming*”. Caregivers emphasized the “*panic mode*” effect that the 48-hour time frame had on their ability to make a final decision for their family member. Rosanne (urban) described her reaction when she found out a bed became available for her mother:

⁶ See footnote 3.

... you know because you're doing the transition when they said a bed became available, I thought- you're in panic mode. You can't think straight when you've got 48 hours to do everything. You can't. You cannot make a sound decision- I don't care who you are- when it comes to that, unless you don't care about your loved one at all. 'Let's get rid of them', I know people like that too unfortunately, but uh, I don't want that for my mother.

The physical act of moving their family member into the facility was also challenging both logistically and emotionally. With regards to logistics, some caregivers specifically discussed the challenges of getting their family member from the hospital to the facility, as they were left to their own devices. Most caregivers had to hire community transportation services to help with the move or had to get other family members to help:

They don't give you one day or two or whatever notice. I phoned my daughter and said "come and have a look". And anyway, we had to make a decision right away and I um- and transportation. The transportation you have to talk to the bus that's coming-which you have to pay for, which I think was \$1000 something.
[Rebecca, suburban]

Sally (urban) also spoke about the challenges of moving her husband into the care facility, focusing on emotional challenges she knew she may face if she did it herself:

I hired an ambulance company. I said, "I can't do this". You know? I- I was always concerned that if I took him out in the car he'd think he was going home and I didn't know how to deal with that.

In addition to organizing transportation, most caregivers spoke about the emotional challenges of moving day. Amy (suburban) discussed deciding which belongings to take and which to leave behind as particularly difficult, "So then I had to start talking about what- what we can't take. This was probably one of the hardest things I ever had to do."

6.7.6 Phase III: Post-transition: Finding a new balance

When the family member arrives in their new care environment, the support caregivers provide does not stop. Instead, it shifts, with the next phase in their on their transitional care timeline being a period of finding new balance. Phase III focuses on caregivers' efforts to adjust and adapt to their family members' moves and to the new care environments including: the change in the kind of care they were now providing, the emotional factors associated with the move, and the importance of preserving their own personal health and well-being.

Changes in care provided post-transition

Post-transition, family caregivers were clear that they were still committed to providing care for their family members. However, the kind of care that they provided often changed following the transition. For example, caregivers reported that they performed fewer personal care activities for their family members. Amy (suburban) noted, *"Can I [give] the basic caregiving up? Absolutely. Absolutely."* Instead, they focused their attention on providing emotional support, advocacy, and assistance with various activities that were not part of regular facility care (e.g., banking, driving to specialist appointments, going out for lunch and coffee, doing laundry, visiting, providing comfort, keeping up their wardrobe, "overseeing" and "tweak[ing]" things):

Now of course the care home people are doing all the care. I'm just sort of the emotional- a bulwark of his existence now. I'm the familiarity of the past. But as far as physical care- I think I'm a lot of mental care, but no, no, there's no physical care going on. [Marge, rural]

As a result of the change in the kind of care activities performed, two caregivers reported feeling that they were no longer as "helpful" as they were in other care environments (e.g., hospital). Annie (urban) described some of the changes she

experienced in her caregiving role after her mom moved into RC:

After being here I have been feeling like so helpless. Like not- not as helpful as I was in the hospital. When I was in the hospital, of course I got to help with feeding my mom.

Post-transition, family caregivers provided a different kind of care, but findings revealed that that didn't necessarily mean that they were providing "less" care. All caregivers mentioned their continued involvement in maintaining their family members' finances (including completing their income tax returns), paying bills, and scheduling appointments (i.e., doctor, optometrist, and specialists). Alongside these activities, some caregivers emphasized the importance of making sure there was always money in their family member's comfort fund to cover the costs of things like outings and haircuts. However, most caregivers mentioned doing other small tasks for their family members like putting cream on their arms, cleaning their dentures, helping them get dressed, painting their nails, and maintaining their wardrobes. On the other hand, some caregivers continued to provide a high-level of care to their family members. One caregiver mentioned sleeping at the facility twice a week to allow the personal companion helper (who they paid for out of pocket) some time off. Rebecca (suburban) expressed a unique post-transition burden; noting the level of care she was providing to her husband as being particularly burdensome:

7 days a week. 7 days a week I have a job. I'm 87 years old and I have a job to come here... You know, it takes more than a half hour to get here and um, being here, you know, helping with his food, you know, and I try to stay to the end.

All caregivers maintained a visible presence at the facility, with their number of visits per week ranging from three to seven. Caregivers caring for a spouse report visiting more

frequently than those caring for their mothers. Marge (rural) noted her daily visits were primarily to ‘maintain’ their relationship and often included a meal:

So yeah, I go every day. Not for any sort of um- because he needs somebody to keep an eye on him, that's not it at all. It's just- it's a nice little routine. It's like getting up and brushing your teeth in the morning, you know. And it's a good- a healthy thing for both of us I think.

Some caregivers felt that their constant presence in the facility resulted in “better care” for their family members, but it also sometimes meant they ended up helping other residents as well. Amelia (urban) described her presence at her mother’s care home noting:

I'll do stuff for the other residents... because they know me and I'm just that type of person...I'll walk down the hall and they'll say 'oh Amelia, can you get me some water dear?' And I just respond with 'yep, okay, I'll get you some.'

Post-transition emotions

Helping a family member transition from home to a new care environment is often an emotional rollercoaster for caregivers. The following excerpts are a sample of the post-transition emotions caregivers experienced including: relief, guilt, loneliness, and frustration.

So once he was here, I was more relieved and I [knew] he was feeling more comfortable and because I could see him all day and every day and you know ... I wasn't strained or tired- [Tina, rural]

And you know, [my] little heart would go 'oh my God' [gesture; pulling at heart motion] almost like you were leaving your kid at school. Do you know what I mean? And I thought, oh my God [gesture; looks down]. [Amelia, urban]

I'm a gregarious person. I like to be out and about and I find loneliness is the thing that's bothering me the most about this business with my husband being away. [Marge, rural]

Some caregivers specifically noted the first few weeks of their spouse being away as being the most difficult. Moira (rural) mentioned she would often find herself in tears, *“Well, like I told you, in the very beginning, I'd spend my time like I still do and I'd come home and the minute I'd come home I'd start crying.”*

Family caregivers also acknowledged a change in their relationship with their family members now that they were in a new care environment. Those caring for a parent or sibling most often identified their relationship as having improved. Mona (urban) described the changes she in her relationship with her mother:

I think the main thing is that we became closer and more understanding of each other. She's not so prickly about [laughing] you know, being- that I would be saying critical things to her-and I certainly, um, tried to be more loving and show her that um, we just wanted the best for her. (Mona, urban)

However, caregivers caring for a spouse had different perceptions of how their relationship had changed; often focusing on the change in the closeness they felt between themselves and their family member. Tina (rural) spoke about the difficulty in living away from her partner and the pressure it has put on their relationship: *“It's hard for him to- he thinks I'm moving on without him, I'm sure. And I'm thinking- sometimes I feel stuck, you know? But, I know I'm not. I ma[de] my bed; I'm going to lie in it.*

Other caregivers saw the move as just a “glitch in [their] whole life experience”; a life event that they felt actually brought them closer. In particular, Marge (rural) shed a uniquely positive view on the changes in her and her husband's relationship:

No. I think our relationship is probably stronger to be quite honest. I- see poor old T, I have no idea because he has dementia and he can't tell me. But, I think- I think that he is- he feels as strongly about me as I feel about him. I am sure he does. I'm absolutely positive he does, even if he can't articulate. You know, you pick up those vibes.

Frustration was another emotion that some caregivers experienced after their family members' relocation. This was often a result of witnessing a more rapid degenerative process involving their family member's mental (i.e., Alzheimer's disease and other dementias) and physical state than during the pre-transition phase. Caregivers experiencing these emotional challenges indicated that they also didn't understand the dementia trajectory and the "stages" their family member was going through:

It's hard because she's in a wheelchair and can't do anything. She can't walk and it sucks. It sucks. I hate it. I hate that she has gone from this amazing, strong, independent woman to this lump kind of, you know? ... So you know, it's just this- and then frustration with her lack of understanding- I didn't understand the dementia and I didn't understand the Alzheimer's, but then I started to read about it. (Amelia, urban)

Acknowledging their periodic moments of frustration, caregivers emphasized the importance of being more patient, kind and loving. Rosanne (urban) indicated that her main goal post-transition was to keep her mom happy: *"You know, because you're really not realizing what's going on with her. Now I do and we just kind of play along and just, yeah. We know where she's at. We try to keep her happy. That's the main goal."*

Personal health and well-being

Caregivers adjusted to the relocation of their family members in different ways, with some taking longer to 'accept' the relocation than others. Over the course of the transition, family caregivers often directed all of their attention and efforts to ensuring their family member was adequately cared for. Despite speaking to the importance of maintaining good health, caregivers often neglected to pay equal attention to their own

health and well-being at the same time. Moira (rural) spoke about the differences in her personal health before and after her husband moved.

...even my nurse provider, um, it just seemed like a few months after Jack went in, they said 'well, you know, you're really looking great.' So that was nice to hear, you know. I didn't realize how dragged out I was, you know?

All caregivers spoke of the importance of 'supports' for family caregivers, including: caregiver groups (e.g., family councils) run through the health authority or care home; family members, friends, church congregation, choir, and bowling. However, not all family caregivers used these supportive networks equally. Some caregivers didn't think any caregiver supports or resources even existed in their area. Moreover, it seemed that caregivers' personalities were a driving force in dictating how or if the resources were used:

I've never thought I ever needed it, I was very- I've always been strong and mouthy and- 'I don't need any of these kinds of things.' Independent. Ran- you know, just did it all type thing. But then all of a sudden you- you're not as tough as you think you are. Yeah, it's a bit of an eye opener. Which is a good thing, you know, bring you down a notch, yeah. [Marge, rural]

Those who did use these resources were most frequently involved in the 'family council' or 'caregiver support' groups at RC facilities. Often lead by the social worker or through the hospice society, these support groups were seen as invaluable resources:

...that was a major thing that helped me. Absolutely, once mom was in the care home. Because I wouldn't have been able to go when she was still here because I wouldn't have had time [laughs]. But really, that helped a lot and I attended their sessions for one cycle- two- two and a half cycles of it. So yeah just to keep going, but then finally you get to the point where your need for it is less for it than the need to do the other things in your life and you go 'okay, well' and they're always open to you going back if you have another bad time- well, then go back. [Mary, rural]

Marge (rural) was unique in praising the efforts of the health authority in making sure that her health and well-being were looked after in addition to her husbands:

So, that's where Fraser Health went over and above. They certainly didn't have to introduce me, they had to look after my husband- but they were also a little concerned about me falling apart at the seams. This is where they introduced me to [the family council] and I found them very supportive too.

Despite their recognizable value, caregivers also noted the challenges in making sure family caregivers used them. Mary (rural) highlighted the problem: *"Trying to get all the caregivers to realize they need to go there is one of the challenges."* Caregivers who didn't use the available resources at the facility often pursued alternative means of support, including the Alzheimer's Society, private counselling and on-line forums.

In the continued effort to find new balance in their lives post-transition, family caregivers shifted some of their focus to pursuing activities related to their own interests and personal growth; to keep them busy (e.g., making jewellery or volunteering) or because they didn't have time before. Pieta (urban) spoke highly of her newly found free time: *"I'm really lucky because I have a lot of friends and you know, I do a lot of really great things and now- now I can because I have the time and- you know?"* While Moira (rural) embraced the personal time she now had: *"Well, I think it's just finding myself and who I am ... you know, I don't know what it's like to be alone. I need to challenge myself."*

Although most family caregivers enjoyed having more free time, some caregivers still found it difficult to adjust to the shift in their caregiving responsibilities. Marge (rural) found it difficult to have so much free time alone, noting *"...being here by myself- I mean it's beautiful, but you get bored with your own company."* Amelia (urban), described the feelings she had when trying plan a vacation with her husband: *"Our whole plan was that we were going to travel. So you know, he wanted to go to Italy for a month and go to Hawaii and you know- but I'm like 'oh, no. I can't go that long.'"*

Finally, “appreciating what you have in the moment” and maintaining a positive outlook was a focus for most family caregivers post-transition:

Life, you won't believe it, but life is short [laughs]. So you know, you've got to, you know, celebrate the day you're in and um, make it work ... cherish your health and live as positively as you possibly can... [Marge, rural]

These last excerpts reveal how the last phase in navigating a family members' care transition was a time of rebalancing for the caregiver, as they adjusted and adapted to their new responsibilities in managing their family members' care. Reflective of the fluid nature of the caregiving role, the support that caregivers provided to a family member post-transition did not terminate but instead shifted.

6.8 Discussion

Caregiving activities are particularly important to examine in the context of transitions from home into a new care environment since it is at these junctures that crucial care decisions have to be made (Gitlin & Wolff, 2011). As illustrated by the conceptual framework (Figure 6.1), transitions in care not only mark changes in the lives of older adults, but they also have significant impacts on the lives of family caregivers. As we see from the excerpts above, family caregivers are instrumental in managing and navigating such moves.

To address our second research question, three overarching themes were developed (Braun & Clarke, 2012). Here, we explore how caregivers make sense of their multi-layered caregiving roles and responsibilities and how these conceptualizations ultimately play out across their caregiving journey. The three themes, labelled with direct quotes are: “*I'm just her daughter*” / “*I'm just his wife*”, where caregivers linked the care they were providing to their role in the family (i.e.,

mother/daughter or husband/wife); *“Just go with the flow”*, which focuses on caregivers ‘not knowing’ and having their ‘sense of control’ challenged and/or lost after acquiring formal LTC services; and *“There wasn’t a door I didn’t try to open”*, denoting the lengths and determination family caregivers’ put forth to promote, protect and enhance their family members’ well-being.

6.8.1 Theme I: “I’m just her daughter” / “I’m just his wife”

As suggested by the existing caregiver literature, our findings revealed that family caregivers took on a wide range of tasks over the course of their caregiving journeys, including personal care, ‘care management’, and emotional support activities for their family members (Ashbourne, 2015; Giosa et al., 2014; Sinha & Bleakney, 2014). In making sense of their caregiving roles and responsibilities, when family caregivers were asked if they saw a difference between “caregiving” and “care management,” some caregivers could describe a distinction between these two roles:

I guess a caregiver is somebody who is working with the individual. A care manager might be somebody who is doing more of the financial grunt work, that kind of stuff. [Sally, urban]

To me, it's different. To my girlfriend, they're the same, but to me, they're different. Like, caregiving was like, helping her to get dressed, putting her to bed, giving her a shower, um, you know, making her meals, all that kind of stuff. Um, care management, relatively speaking, I find a lot easier. [Mary, rural]

However, as suggested in earlier studies, caregivers generally maintained that the kind of care they provided for their family members was in fact a combination of a wide range of care-related activities including both hands-on and care management (Funk, 2012; Gitlin & Wolff, 2011; James, 1992). Mona (urban) described the assortment of activities she helped her sister with over the years:

“I mean, you have to do every little thing for that person like you would do

for your [own] life, right? There's so much. Like, when she needs new clothes, she has to have her taxes done, you know? Her activities and her outings- just to get out, if I hadn't taken her, she never would have gone anywhere. I mean, there's so, so much. I could, you know, write a long list of all the things [laughing]."

Although caregivers agreed that they performed all the care management activities (as defined by Rosenthal et al., 2007), the care management label did not resonate with caregivers. They felt that “there was some baggage around the word manager”, noting that it sounded too “business-like,” thereby taking away the personal connection of caring for a family member.

While, it is important to highlight the intricate nature of navigating a care transition; it is equally important to understand how caregivers conceptualize their roles and responsibilities. Most notably, when asked to summarize the overall support they provided, caregivers seemed to ‘downplay’ their caregiving roles. The following excerpts highlight how some of the caregivers linked the care they were providing to their role in the family (i.e., as a daughter or as a spouse/partner):

I'm not her manager ... I am her daughter who has to manage some things for her. [Amy, suburban]

I would just say that I'm the wife of a fellow who has dementia... [Sally, urban]

I don't even think I thought of myself as a caregiver until I took this dementia course back in December. I just thought of myself as a daughter. Because that's something that- daughter, family, to me that's just a given. [Nicole, suburban]

These excerpts support existing caregiving literature suggesting that family caregivers’ conceptualizations of their roles and responsibilities primarily emerge from their relationships with their family members (Dupuis & Norris, 2001; Funk, 2012; Haynes, 2008; Montgomery & Kosloski, 2013). Building on a life course perspective,

Aneshensel and colleagues (2004) discuss the seemingly natural relationship that caregivers and family members have to one another, that is, their interconnections long before the need for care begins (i.e., parent and child or husband and wife). They maintain that when a spouse or parent requires care, familial relationships are 'transformed' and family caregivers' roles and responsibilities become characterized by the new and changing circumstances (Aneshensel et al. 2004, p. 423).

A recent study by Gill and Morgan (2012) explored the ways that caregiving daughters and their parents make sense of the older adult's aging and one another's changing roles when deciding on a parent's move into a care facility. They found that "daughters engaged in avoidance, rushing to decisions, and other paternalistic behaviours" (p.19) that limited their parents' involvement in the decision making process. Similarly, all caregivers in our study made note of a shift in their relationship with their parent. Specifically, daughters who helped their mother's transition into RC identified a 'reversal' in their family roles with the onset of care provision. Mary (rural) provided the most detailed description of how her role as daughter reversed over time:

...for the first four or five years, it was definitely mother-daughter. Then, as her health went down, it was more mother-servant- well, mother-servant-daughter, you know? Then when she went in to the home, it was more like mother-daughter, but this way [gesture; one hand on top the other] and I know we're gradually going into mother-child [gesture; reverse stacked hands]."

A recent study by Byrne, Orange and Ward-Griffin (2011) found similar experiences with caregivers caring for a spouse. They found that caregivers repositioned their relationships from "husband and wife" to "parent and child". Rebecca (suburban) was particularly clear that her relationship with her husband had transformed post-transition noting, "Oh I'm the caregiver. No, no. I mean it's like a child. Like a 5 year old I have to

look after.” Later adding, “*No. It’s- it’s a challenge. A 5 year old can be very, very challenging, you know?*” Although the role reversal was apparent, Rebecca’s position was somewhat unique to the other caregivers, as her husband had experienced significant cognitive decline in a very short period of time and she was finding it difficult to adjust.

6.8.2 Theme II: “Just go with the flow”

The theme “*Just go with the flow*” addresses two common experiences of family caregivers: being in a perpetual state of ‘not knowing’ and having their ‘sense of control’ challenged, or lost, once they engage with the formal care system.

Due to the technical nature of eligibility assessments, finances, and waitlists, caregivers were often charged with negotiating their family members’ care in largely unfamiliar landscapes including acute, AL, and RC environments. Barello, Savarese and Graffigna (2015) characterized caregivers’ experiences with the formal care system as being similar to a “complex and intimidating maze [that] they are forced to navigate without the benefit of a map or a guide to help” (p.112). Family caregivers in this study were caught in a perpetual state of “not knowing” what the next care step was going to be. This left most caregivers having to “just go with the flow.” Similarly, Duggleby et al. (2011) found that when family caregivers were asked how they dealt with the changes in their caregiving roles, one of the main themes was “taking one day at a time” and “as you go...in bits and pieces” (Duggleby et al., 2011; Funk, 2012).

Family caregivers also discussed being largely bound by the restrictive nature of the system, indicating that they could make decisions up to a certain point before ‘system constraints’ took over (e.g., the ‘First Appropriate and Available Bed’ policy).

Ashbourne (2015) also found that strict system-related timelines caused family caregivers to feel rushed when making decisions about transitioning their family member into a LTC facility, noting that “rather than accommodating or negotiating with caregiver goals, the health care system forced it’s reality on caregivers” (p.55). Davies and Nolan (2003) found that there were limited opportunities for family caregivers and service providers to work collectively, which fostered a sense of ‘losing control’ over the situation among family caregivers.

Caregivers were also aware of the fact that their family member’s health would progressively decline, but they were unsure of when and how fast everything would happen. Those who had family members with Alzheimer’s disease or other dementias found that not having sufficient information about the disease to better understand the condition’s trajectory was particularly challenging. Not having enough information about the trajectory is a commonly reported finding in existing literature (Afram et al., 2014; Ashbourne, 2015; Dugglebey et al., 2011; Giosa et al., 2014). Being flexible in their roles and responsibilities, caregivers had to figure out what to expect with their family members’ changing needs and what the best approach was to help them to manage over the course of the care transition. Rosanne (urban) described a simple and honest approach noting, “*You know, you take one day at a time. Whatever comes, comes.*”

Caring for a family member is a dynamic and complex role that involves continuous adaptation by the caregiver (Bruhn & Rebach, 2014). Constantly moving from one activity to the next, caregivers’ roles do not start and stop over the course of the transition. The theme “just go with the flow” highlights the non-static nature of the roles and responsibilities in managing a family member’s care transition (Bastawrous,

Gignac, Kapral, Cameron, 2015; Montgomery & Kosloski, 2001; Talley & Montgomery, 2013). Amy (suburban) summarized her caregiving role by emphasizing the importance of doing what's best for her mom:

...at the end of the day- that person's functional ability is going to leave them and their physical abilities are going to decline, no matter what the diagnosis is. So, you have to figure out what's the easiest transition for that person to make and it's how to you help manage that.

6.8.3 Theme III: “There wasn’t a door I didn’t try to open”

Navigating a transition in care required caregivers to work exceptionally hard to support their family members’ preferences and needs. The interviews revealed unmistakable determination to ensure their family members received the best possible care, which strongly influenced many aspects of their care efforts:

I will do everything in my power to ensure that she receives a maximum degree of care and compassion and that she is allowed to function at her highest level of ability and maintain her dignity. [Amy, suburban]

The advocacy role caregivers assume was a particularly important (Ashbourne, 2015; Funk, 2012). Byrne and colleagues (2011) found that family caregivers engaged in ‘safekeeping’ when there was a risk or perceived threat to their family member’s physical, emotional, or social health and well-being. This notion is reflective of the continual efforts family caregivers’ put forth to promote, protect and enhance their family members’ well-being. Caregivers did everything in their ability to ensure that their family member received the best possible care. This recognition and corresponding motivation appeared most notably when seeking out information. Nicole (suburban) described her far-reaching efforts to get help for her mom, noting that she

...turned to everybody for help. There wasn't a door I didn't try to open and

you know, the sad part is that there [are] probably other people who are in the same position as my mother where their kids weren't as tenacious as I am...

The above excerpt reflects Funk (2012)'s study that found that caregivers felt they needed to be vocal and persistent in order to best advocate for their family member. Wiles (2003) also found that caregivers had to be "assertive, persistent, and well organized to get effective help" (p.194).

Knowing that every caregiver's journey is different and that different decisions need to be made at different times, for different reasons and in different contexts, the drive for family caregivers to do everything in their power to care for their family member was clear. Ultimately, however, caregivers had to come to terms with the reality of their family member's changing needs. Amy (suburban) reflected on the trajectory of her mother's care and her involvement over the journey:

This is my mom's journey, you know, and I can't change it. Would I? Oh God, in a heartbeat- um, there's nothing I wouldn't do to protect my mom. There's nothing I wouldn't do to take this away from her, but I can't alter her path. I can't- I can't do anything to change this. The only thing that I can do- I just take her hand and I just walk down the path with her and I'll do that, to whatever length that I can do that.

The above excerpt reflects similar findings (Ashbourne, 2015) highlighting caregivers' gradual acceptance of the future and the need to maintain a positive outlook.

6.9 Strengths and limitations

The most notable strength of this qualitative study is the important contribution it makes to the literature on care transitions. This study broadens our understanding of LTC transitions from the perspective of family caregivers; those who are often most intimately engaged with navigating them. Through qualitative interviews, this paper highlights family caregivers' experiences of a specific time frame in their caregiving

journeys around managing a care transition. It also explores how family caregivers make sense of their multi-layered caregiving roles and responsibilities. The framework for managing a family member's LTC trajectory (Figure 6.1) was developed as a visual aid for understanding how family caregivers manage their family member's care transition, while also emphasizing the complexity often involved.

Despite the richness of the data and the insights emerging from this study, the authors also recognize several limitations. First, purposive sampling allowed for a focus on the transition from home into a new LTC environment; however, older adults often experience a greater number of transitions in care over time (e.g., home to hospital, hospital to independent living, AL to RC). Although equal efforts were undertaken to recruit persons from both AL and RC facilities in FH, the sample included an overrepresentation of caregivers who helped a family member move into RC as opposed to AL. Although this is partly due to a smaller number of AL facilities, this contributed to us being unable to compare experiences involving the two care environments. This overrepresentation does however illustrate the availability and more frequent use of RC facilities compared to AL.

Another limitation to the study was that all caregivers were female, with the exception of the one husband-wife dyad. Although historically females are more likely to be caregivers (Cranswick & Dosman, 2008) and assist with more personal and direct forms of care than males (Sinha, 2013), similar percentages of male and female caregivers have been shown to provide managerial care (Rosenthal et al., 2007). Further exploration of care management activities from male perspectives could provide valuable insights to the overall conceptualization of managerial care. The sample also

consisted of caregivers who were all retired when they started caring for their family members, which resulted in fewer caregivers reporting having to balance caregiving and job-related activities; a common burden experienced by family caregivers (Funk, 2012; Rosenthal et al., 2007). Lastly, all interviews took place after their family members had transitioned into a new LTC environment, which meant that all transition experiences were recounted retrospectively. In describing experiences that happened several years before (for some), the chronological order of events were often muddled. This made it challenging for the researchers to establish a clear, definitive timeline to each transition.

6.10 Conclusion

Transitions in care are undeniably complex. This study generated a more in-depth understanding of a caregiver's roles and responsibilities at a time when a family members' care needs exceeds their caregiving capacities and the available community supports. This paper focused on generating an improved understanding of the activities involved in managing a family member's transition in care including: decision making, information seeking, and advocating. Our study brings attention to the fact that over the course of the caregiving journey, there are times when caregivers require more information and guidance. Largely, this entails a need for greater help with system navigation, such as having a better understanding of how clients move through the system, improved understanding of the range of care options that are available, and help determining at what points decisions have to be made. Our findings reinforce the necessity to ensure family caregivers are meaningfully integrated and well-informed over the course of the care transition process to ensure a smoother care transition for their family member.

Chapter 7: Discussion

Chapter 7 is the culminating chapter of my thesis. The objective of this chapter is first to briefly summarize the key findings from the quantitative study (Chapter 5) and the qualitative study (Chapter 6). To avoid repeating what was presented in discussion sections of Chapters 5 and 6, the focus of this chapter is to integrate and discuss both studies together highlighting the contributions of this project to research, theory, and policy. This is followed by a consideration of the overall project limitations, and a conclusion that details opportunities for future research.

7.1 Summary of Key Findings

I employed a multi-method research design to better understand the multi-dimensional nature of care transitions, and to explore relationships between service users and their local social and service contexts. Using this approach, I was able to explore transitions in care from a quantitative, client level perspective and then qualitative work was undertaken to better understand experiences of care transitions from the perspective of those whose voices are often missing in the quantitative work - family caregivers. In this study, the use of both quantitative and qualitative methods fostered a richer exploration of care transitions and contributed valuable information for helping family caregivers to make a family member's care transition more seamless when they are unable to live safely or independently in their own home.

7.1.1 Quantitative study

Key findings from Chapter 5 address the research questions I proposed for the quantitative component of my project: 1) what patterns exist in the transitions from HC

to AL and HC to RC in urban, suburban, and rural areas of FH? And 2) how do individual, social, and structural factors influence the transition from HC to RC as compared to AL, in urban, suburban, and rural contexts? Overall, I found that there are some meaningful differences by geography both in terms of the clients served and the individual, social, and structural factors that influence the transition from HC to RC, as compared to AL. However, ultimately, geography did not emerge as a significant predictor of a LTC transition (HC-RC or HC-AL) as expected.

Among my total client population making the transition from home care to another care environment (N=3233), 556 individuals (17.2 percent) experienced their first care transition from HC to AL, while 2677 (82.8 percent) transitioned from HC to RC over the four-year study period (see Table 5.1). Statistically significant differences ($p < .05$) were found when comparing the two transition groups (HC to AL and HC to RC) in terms of most of the predisposing, enabling, and need characteristics from the health service utilization framework (Andersen, 1995; Andersen-Newman, 1973). In particular, greater numbers of HC to RC clients had dementia, symptoms of depression, higher ADL dependencies, were more medically frail, and had lower levels of cognitive performance compared to HC-AL transitional clients. These findings reflect the existing literature that reports RC residents as being more vulnerable, with more complex care needs, as compared to AL residents. However, location of residence did not emerge as having a significant influence on the type of transition.

Exploring the overall client group who made the transition from home to either AL or RC by geographic location, I found significant differences in health-related need characteristics including ADL scores, mean length of time between HC start and the

transition, and mean length of stay in hospital (see Table 5.2). ADL scores were significantly higher among urban clients compared to suburban clients, with no significant difference evident between rural and urban or rural and suburban clients. Urban clients had significantly longer stays in hospital compared to suburban clients, while no significant difference emerged between rural and urban clients or rural and suburban clients. Lastly, rural clients experienced a significantly longer time receiving HC prior to transition compared to urban and suburban clients, with no significant difference evident between urban and suburban clients. There were no significant differences in predisposing and enabling factors by geographic location.

Binary logistic regression analyses were conducted to address the factors influence the transition from HC to RC as compared to HC to AL, in urban, suburban, and rural areas of FH (Tables 5.4, 5.5, and 5.6). Overall, health-related need characteristics emerged as the strongest predictors of the likelihood of transitioning from HC to RC as compared to AL across all three geographic areas. In particular, greater ADL dependency and higher levels of cognitive impairment were found to have the most significant influence on transition type. I also found that geographical areas across FH exhibit meaningful differences in the predictors of the type of transition. Marital status, income, functional disability, and cognitive performance emerged as predictors of type of transition for both rural and urban clients. While gender, medical frailty, number of chronic conditions, and total hospitalizations emerged as significant among clients in suburban areas only. Interestingly, among suburban clients, there were no enabling factors that emerged as significant in the final model. Within all geographic areas, the suburban area had the greatest number of significant need variables (i.e., presence of

dementia and ADL, CHESS, and CPS scores) emerged as predictive of the HC to RC transition.

7.1.2 Qualitative study

Findings from Chapter 6 helped me to address the research questions for the qualitative study: 1) *how do family caregivers manage and navigate a key transition in care for a family member and what are their experiences in doing so?* and 2) *how do family caregivers make sense of the many layers of their caregiving roles and responsibilities?* This project drew on a sample of 15 semi-structured interviews with family caregivers who had helped a loved one transition from home into a new care environment in FH. Using thematic analysis, a conceptual framework was developed inductively to illustrate how family caregivers manage and experience their family member's care transition, including the activities they engaged in before, during, and after their family member's relocation from home to a new LTC environment (see Figure 6.1). The framework highlights three key phases in the caregiver's experience of managing care transitions. In Phase I, *'Precursors leading to transition'*, family caregivers described the circumstances that precipitated the need for their family member to transition from home to a new care environment. Most often, these included caregiver burnout and their family members' increased care needs as a result of declining physical and functional health. Phase II, *'Preparing to transition into a new care environment'*, was identified as the most complex phase in the transitional care timeline as family caregivers worked rigorously to gather information, advocate for their family members, and navigate the formal care system. In this phase, caregivers were heavily focused on ensuring coordination and continuity of care for their family members. In Phase III, *'Post-transition: Finding a new balance'*, caregivers tried to

adjust and adapt to their family members' move and to the new care environment. Their post-transition experiences focused on three aspects including: the change in the kind of care they were now providing, the emotional factors associated with the move, and the importance of maintaining their own personal health and well-being.

Building on these findings, I identified three overarching themes to address my second qualitative research question: *how family caregivers make sense of the many layers of their caregiving roles and responsibilities?* These themes, labelled with direct quotes, include: *"I'm just her daughter" / "I'm just his wife"*, *"Just go with the flow"*, and *"There wasn't a door I didn't try to open"*. The first theme speaks to the wide range of tasks family caregivers take on over the course of their caregiving journeys (i.e., personal care, 'care management', and emotional support) and highlights how caregivers conceptualized their caregiving role not as 'care managers', but as an assumed responsibility based on their familial relationship with their family member (i.e., daughter, wife, or sister). In this manner, this theme also reflects a gendered lens on caregiving, as historically, and in my study, more women engage in caregiving activities than men (Sinha, 2013). The theme *"Just go with the flow"* addresses two common experiences of family caregivers: being in a continuous state of 'not knowing' and having their 'sense of control' challenged, and/or lost once they engage with the formal care system. The final phase in their transitional caregiving timeline is *"There wasn't a door I didn't try to open"*. This theme highlights the exceptional efforts family caregivers put forward to support their family members' care preferences and needs. Caregivers displayed extreme determination to ensure their family members received the best

possible care, which strongly influenced many aspects of their care efforts including threatening to take their complaints 'public'.

7.2 Integration and implication of findings

7.2.1 Research

As a graduate student new to research, finding a way to meaningfully contribute to a highly relevant and rapidly expanding field can be both inspiring and challenging. With current social policy efforts aimed at enabling older adults to 'age in place', I chose to focus my research on an event that frequently happens when an individual's health-related needs exceeds both support that can be provided in the community and their family's caregiving capacities. Thus, my qualitative research explored the precarious period in time when individuals must transition out of their homes into a new care environment (i.e., AL or RC).

By employing a multi-method approach, my project provides a unique set of data and findings that have relevance for understanding characteristics of service users, of the local service context, and of the information necessary to better support family caregivers in making their family member's care transition more seamless. My quantitative research supports existing research that acknowledges health-related needs as the strongest predictors of transition type. This study also reflects existing literature that highlights the importance of considering local service context and its impact on the provision, and subsequent use, of health services. By dividing the health authority into three contiguous geographic areas that differed from the administrative boundaries, this project used a novel approach to illustrate differences in service users and care transitions across FH. Employing this approach generated unique findings

that would not have otherwise been captured if my project followed the pre-defined health service delivery areas (HSDA) within FH (i.e., Fraser South, Fraser North, and Fraser East). For example, the unique findings emerging from a consideration of suburban areas might have gone unnoticed if I followed FH's HSDA boundaries.

My project also attempted to draw insights on family caregiving from the quantitative study. However, as previously noted, my efforts were restricted to a limited number of variables. The urban area was the only geographic location where 'primary caregiver lives with client' emerged as having a significant influence on transition, suggesting clients with a primary caregiver that lived with them before their transition were more likely to transition into RC as compared to AL. To meet the shortcomings of family caregiving information from the quantitative study, my qualitative study added a complementary perspective to care transitions. Shifting from client focused analyses, I focused on the individual who managed their family members' transitions in care. This was done in order to capture their experiences in doing so, in addition to the multiple roles and responsibilities they took on over the course of their transitional care period. There is limited existing literature that focuses on the care management activities of caregiving with even less literature exploring caregivers' experiences in the context of care transitions. Although my findings do reflect some of the existing caregiver literature (e.g., caregiver burden, stress, system navigation and communication challenges), my qualitative project generated innovative and meaningful ways to conceptualize the caregivers' journey, including the roles and responsibilities they engage in both over time and over the common transition from HC to RC. I learned that in real life caregivers do not see themselves as 'care managers' despite engaging in a wide range

of care management activities. The conceptual framework that I developed from the qualitative findings helps to illustrate key dimensions of a caregiver's experiences in managing a care transition, noting the complex array of decisions, challenges/joys, and activities that reflect the caregiving journey.

Transitions in care are often explored from a quantitative approach, which requires a transition to be pinpointed to a very specific point in time. However, findings from my qualitative study suggest that any given transition in care is not experienced within a family in the same way. For families, the transition starts months or sometimes years earlier depending on the family member's health needs and the level of care the family caregiver is able to provide. Taken together, the quantitative and qualitative findings expand on definitions and conceptualizations of care transitions and incorporate the voices of caregivers whom the literature suggests are crucially important in the lives of older adults.

7.2.2 Theory

Two theoretical perspectives, used heuristically, informed my study: the life course perspective (LCP; Elder, 1998; Hutchison, 2011; Marshall, 2009) and the health service utilization framework (Andersen, 1995; Andersen & Newman, 1973). Principles of a LCP and health service utilization framework are reflected in both the quantitative and qualitative components of this project. The use of these two theoretical frameworks reinforces the strength of this project's findings by tying empirical results to relevant theories that illuminate health service use and life course experiences, as well as contributing to research in health geography, sociology, and gerontology.

From the quantitative study, predisposing, enabling, and need variables from the health service utilization framework were significantly related to the type of transition older adults experienced. Consistent with existing research that has applied this framework, in my study, health-related need variables were also the strongest predictors of the transition from HC to RC (Gaugler et al., 2007, Luppia et al., 2010; Rockwood et al., 2014). For all geographic locations, predisposing variables (specifically gender) were less important compared with selected enabling (i.e., receipt of the GIS), and health-related need variables that were included in the final models. Similar conclusions can be drawn about the loss of predictive power of enabling variables when health-related need variables were included to the final model. This not only reinforces findings from previous studies, but also speaks to the underlying reality that social factors (e.g., gender and economic resources) influence health and health needs over the life course, which ultimately influence care transitions. I suggest that future theorizing and iterations of this model need to consider how to integrate factors that predict future/subsequent service utilization, when the client is already using health services (i.e., movement between LTC services). In addition, it would be worthwhile to consider how individuals currently access the system and whether those 'current use' factors reflect enabling or need characteristics. For example, I included time to transition as a 'health-related' need variable in my quantitative analyses, yet it could be argued that this is an enabling variable (e.g., a client may have received services for a long period of time that supporting them in remaining at home and thus ultimately delaying their transition). Further exploration of the direction of influence of variables in this model, and of the model itself in the context of LTC transitions is needed.

As mentioned, geographic location is often included as an enabling variable; however a limitation of this framework exists in exploring how these factors interact with one another. To my knowledge, no other studies have explored predictors of care transition types by geographic location. Though results were not significant, my project has contributed to expanding the use of this model and its ability to better understanding the role geographic location has on individual, social, and structural factors that influence care transition. The findings suggest the possibility that factors beyond individual characteristics operate differently in influencing care transitions within the different areas (i.e., geographic location acts as a proxy for factors such as degree of service availability, density of networks of physicians/nurses, etc. that may interact with predisposing, enabling and need factors). These differences may highlight the reality that 'geographic location' as a label by itself does not capture some of the diversity that exists in service environments (e.g., type and nature of services available). Health authorities and decision-makers need to focus efforts on exploring the local service context in different ways (e.g., through multi-level models) order to best understand the full influence of geography and to continue to meet the care needs of LTC clients and families.

In the literature, the LCP approach draws attention to chronological age, nature of relationships (e.g., family and friends), common life transitions (e.g., education, marriage, entering the workforce, retirement), and social/historical change (e.g., wars, economic recession, globalization, declining labor market opportunities, etc.) that contribute to shaping individuals' lives (Hutchison, 2011). Researchers who use a LCP often apply similar concepts to their work speaking about: cohorts, transitions,

trajectories, life events, and 'turning points' (Hutchison, 2011). Over the course of the project, from an LCP, it became clear that the quantitative and qualitative studies have different ways of addressing similar principles. Although they both reinforce some LCP core themes (i.e., that biological changes take place over time), the themes of 'turning points' and 'linked lives' between family members were not addressed the same way in both the quantitative and qualitative studies.

From a quantitative perspective, transitions were studied according to concrete dates captured in the administrative data. We could see when service use started and when the transition occurred. In other words, the 'turning points' (i.e. moves from home to new care environments) were clear and precise. Alternatively, from the stories of individuals speaking about their caregiving journeys reflected in the qualitative study, these 'turning points' in their family member's care were not as clear. Most caregivers described the care transition as having taken place over a long period of time and were largely unable to link the transition to a specific 'turning point' date⁷. Drawing on their personal experiences, this resulted in the conceptualization of a 'transition' as encompassing a more extended period of time as well as capturing a multitude of activities. Yet, at a more broad level, caregivers identified the whole transition experience as a 'turning point' in their family member's life.

A LCP also draws attention to the interconnected nature of individuals' lives. Although the two caregiver variables did not consistently emerge as having a significant influence on the transition type within each of the geographic areas in the quantitative

⁷ Some caregivers referred to binders and journals where they kept a detailed account of events. Those who did refer back to these tools were able to provide a more clear idea of their family member's care journey.

study, the qualitative study reinforced the integral role family caregivers play in the lives of older adults as they transition from home to a new care environment. On the other hand, although some differences emerged by geographic location in the quantitative study, geography was not as meaningful in differentiating experiences in the qualitative study. In some cases caregivers directly addressed their location of residence as having an impact on aspects of the care transition. Overall, although the findings for both studies ended up being more similar than dissimilar for urban, suburban, and rural areas, a LCP acted as a valuable lens to explore the relationship between person, environment, and time.

7.2.3 Policy

In general, older Canadian adults are living longer and in better health than ever before. This can largely be attributed to changes in individual lifestyles, in conjunction with the growing number of targeted public health initiatives. These efforts focus on helping older adults maintain healthy and active lifestyles; ensuring they are aware of the supports and services available to them; and facilitating them to remain in their own home as long as possible (Office of the Minister of State – Seniors, 2014).

As we know, aging is not a uniform process. However, Muscedere (2016) reports that the most rapidly increasing segment of the population is comprised of those over the age of 80, with up to 80% of these older adults having at least one chronic condition. Although recent data show that the aging population is not a major health care cost driver in Canada on its own (CIHI, 2014), the increased longevity of older adults, coupled with the rapidly growing proportion of individuals over the age 65 with greater numbers of chronic conditions, has (and will continue to) put immense pressure on our

health care system; a system that has been described as “poorly equipped to respond to chronic care needs” as it is presently configured and much less so into the future (Williams et al., 2016). Further contributing to these pressures is the declining availability of family caregivers as a result of societal shifts in the structure of the nuclear family, women’s strong presence in the labour force, and particularly in more rural areas, the out migration of youth (who are potential future caregivers) should be observed (Fast, 2015). As family caregivers contribute the bulk of day-to-day care for family members there is general agreement that there will be even greater demand on the system in the coming years (Chappell & Hollander, 2013; Williams et al., 2016).

In light of these changes and growing pressures, health care and social policy makers are not only faced with addressing the complexities of meeting the current needs of older adults and their families, but also planning ways to best ensure efficient, quality care in the future. However, differences in funding models, service provision, and eligibility criteria make this process complex, with differences in environmental (e.g., urban, suburban, rural) and social (e.g., population profiles) factors further muddying the waters.

The notion that an “improved system of home and community care for seniors can help seniors live healthy, independent lives, and reduce pressure on hospitals” (McGrail, 2011, p.5) is not a new or revolutionary recommendation. However, my findings support the need to continue to invest in efforts aimed at supporting older adults to age-in-place in the community for as long as possible, as well as ensuring that appropriate forms of AL and RC facilities are available to a small proportion of older persons who will need them. As health-related care needs emerged as having the most

significant influence on older adults moving *out* of the community, reflected in both the qualitative and quantitative studies, it is clear that these are factors that health and social policy decision makers should be addressing to support older adults to remain *in* the community as long as possible. In particular, a focus needs to be placed on mental health initiatives (i.e., Alzheimer's, other dementias), as well as supporting functional independence (i.e., assistance with daily activities of living such as bathing, dressing, and eating).

There is a need for health and social policy action to include both the individual requiring support as well as the family caregivers providing support. Over the course of the qualitative study, caregivers were clear in articulating their desires to have a better understanding of their family member's mental and physical health trajectory wherever possible. They wanted more information and better communication about the changes that were to come and not feel belittled in the process. Having a better understanding their family member's health/disease trajectory, may help reduce factors that this study has shown as influence care transition. Caregivers also identified wanting better information on the health care system as a whole, including where to start looking for supportive services and how the care transition process worked (i.e., eligibility criteria, fees, and waitlists). Ultimately, the care management activities of transitioning their family member from home into a new care environment were fundamental challenges and sources of stress and frustration.

Supported by the findings that emerged from my project, I agree with the need for health and social policy efforts to focus on home and community based services; particularly addressing the physical and cognitive factors that may reduce subsequent

care needs. However, even before we concentrate all our efforts on the care needs of the individual, I suggest that we place a substantial emphasis on ensuring the caregivers' needs are met first. Again, although this suggestion is not novel (Horowitz, 1985; FH, 2011; Lilly et al., 2012), caregivers play a dominant role in supporting older adults at home and if they are not adequately prepared, then the health of both individuals becomes compromised (e.g., caregivers may become stressed which impacts how they provide care, which subsequently impacts the well-being of the care receiver). I suggest that health and social policy makers focus their efforts on educating caregivers before their caregiving capacities are exceeded by their family members' needs. Further, beyond developing initiatives to solely deliver information to caregivers, there is also a need to ensure caregivers are in fact aware of the care support services available to them. From the qualitative study, most caregivers recognized the importance of caregiver supports, but didn't use them themselves because: they didn't think they existed in their area, they didn't qualify for them, or 'support groups' weren't their 'thing'. Although in many cases, a care transition may be unavoidable, educating and preparing caregivers on how to best navigate the care system (including having a better idea of the resources, supports, and possible outcomes particularly when relocating from home into a LTC environment), opens up possibilities for both theirs and the family members' transition experience to be improved.

Although providing adequate supports to meet the needs of caregivers is a fundamental component in helping older adults age in place, decision makers can't take a 'one-size-fits-all' approach. With the appointment of Canada's first ever Seniors Advocate in 2014, whose role is to monitor and analyze seniors services, address

system level issues, and make recommendations to the government (OSA, 2016a), BC has initiatives that are largely underway to gather feedback and advice from the perspective of older adults and their families. In 2015/16 the Seniors Advocate attended 13 town hall forums, visited 22 facilities, did 62 community presentations, had 99 stakeholder meetings, and visited 45 communities across BC (OSA, 2016b). This is the exact approach that needs to be taken. Listening to service users, their families, and service providers in their local context is essential as we collectively work towards reshaping the LTC sector as an effective and more seamless continuum of care. McGrail (2011) argues that community-based supports and services, in addition to alternative facility arrangements such as AL, “will lessen the need for the most intense types of service [i.e. RC]” (p. 42). McGrail further suggests that “it is quite possible to organize a system of care that includes a continuum from home-based care to supportive housing, assisted living, and residential care that de-emphasizes this last step” (McGrail, 2011, p.42). My research complements current provincial initiatives with findings that echo work done by the OSA (see the first Senior’s Advocate report: *The Journey Begins: Together We Can Do Better*, 2014).

Overall, bringing together the different types of data in this multi-method project helps to inform and support efforts aimed at ensuring individuals are adequately cared for in environments that are best suited to their care needs.

7.3 Limitations

Specific limitations with respect to each of the quantitative and qualitative studies were addressed in Chapter 5 and 6.

Overall, this project focused on publicly-subsidized LTC services which do not capture clients using privately sourced LTC services; therefore, the experiences depicted in the results may not be relevant to all residents in the FH catchment area using LTC services. Further, the concentric rings used to delineate the vision of more contiguous areas of urban, suburban, and rural influences and do not align with regional health service delivery areas, which might pose challenges for FH decision-makers to interpret and integrate the findings.

The quantitative component of my project used assessment instruments that can produce high-quality data for policy makers (Carpenter & Hirdes, 2013). However, despite their clinical strengths, these instruments do not collect adequate information on the role of family caregivers. Without a comprehensive understanding of caregiver roles and responsibilities, needs assessments only capture a part of the whole picture. Understanding the needs of caregivers, which are tied to changes in the health of family members, is crucial to being able to provide appropriate supports (HCC, 2012). Although family members are involved in many other ways alongside and across the health care system, without an administrative presence, their role remains largely peripheral.

7.4 Opportunities for future research

Overall, I believe that my project speaks to the strengths of a multi-methods approach that health and social policy initiatives, health authority decision-makers, and other health researchers should consider for within their research programs.

Future research exploring the way that care is provided in LTC needs to focus on generating a better understanding of the local health and social contexts of individuals

and how to better integrate the findings into policy and programming. For example, a unique finding was that suburban individuals spent a shorter amount of time in HC before transitioning to RC compared to rural clients. If we were to further explore the kind of HC support or the number of hours of HC they were receiving we may be able to further explain the some of the trends that emerged.

More research is also needed on the role of ethnicity and culture in the context of health service use and transitions in care. These factors aren't adequately captured on the needs assessment instruments that were used in the quantitative study, but may have an important and unique impact on some of the projects' findings. With 60 percent of older adults who immigrated to BC in 2012 calling FH their 'home' (FH, 2014), a qualitative component exploring ethnocultural diversity in LTC service use would also bring valuable new insights to the care transition literature.

Although a large focus of my project explored the impact of geography on care transitions, further research is needed in this area. This is particularly so given the changing face of family structures and their impact on the availability of caregivers (e.g., outmigration of youth who are potential future caregivers). Although caregivers in the qualitative study lived an average of 8.36km from their family member, caregiver/family member proximity is not always the reality. Exploring experiences in managing a family member's care transition for those caregivers who provide support from a distance may also generate valuable insights for care transition and caregiving literature. In a field that is constantly growing, opportunities to further explore transitions in care and informal caregiving are endless.

7.5 Knowledge dissemination

Initial results of the quantitative study were presented at the Canadian Association on Gerontology 2015 conference and the University of Victoria's annual IdeaFest. The entirety of my thesis project was presented in the annual Three Minute Thesis (3MT) competition, as well as at the Embrace Aging Event hosted by the Institute on Aging and Lifelong Health (March 2016). Further presentations are anticipated at various academic and public events. As noted, results from both studies will be submitted to a peer-reviewed journal for publication. Participants from the qualitative study, as well as the Fraser Health staff (including the Research and Evaluation department and Directors/managers) will be provided an executive summary of the project's findings following final thesis submission.

7.6 Conclusions

With care transitions being recognized as critical junctures both in the lives of the older adult experiencing the relocation as well as the family caregiver, this project focused on generating a more complete picture of the care transition experience. The findings offer new insights on long term care service users, family caregivers, and the importance of considering local service context. Overall, this project has generated meaningful information to improve our understanding of how local service and social contexts relate to policy efforts to support older adults to age in place.

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Appendix A: Study information letter



Study Information Letter

Mapping 'care management': Exploring family caregivers' experiences in managing a loved one's transition in long-term care

Hello, my name is Taylor Hainstock and I am a graduate student in the Social Dimensions of Health Program at the University of Victoria. To fulfill the requirements of my degree, I am conducting a research project entitled *Mapping care management: Exploring family caregivers' experiences in managing a loved one's transition in long-term care*.

This research is a unique study that is emerging from an existing research project (BC Transitions in Care Project [BC-TIC] Penning-Cloutier, 2012-2015, CIHR no. 122184, UVIC HREB no. 12-255, FH REB no. 2012-051) based at the University of Victoria and reflects a strong, existing partnership with the Fraser Health Authority (FH).

Purpose and Objectives

The purpose of this research project is to understand how family caregivers think about, navigate and manage key transitions between long-term care services for their family members. Specifically, my research will explore family caregivers' experiences in managing a loved one's transition between publicly-subsidized home and community care services to either an assisted living or residential care service within Fraser Health.

Your Role

With your permission, I would like to post my participant recruitment flyer at your establishment. This will help me recruit family caregivers to participate in 60-90 minute interviews. Existing research suggests that it is often a family member who navigates these transitions on behalf of their loved one and understanding these experiences is the focus of my project. Your involvement in the project does not extend beyond the posting/distributing of the recruitment flyer at your location.

Importance of this Research

'Care management activities' (e.g. managing finances, paperwork, information gathering) are important to examine at times of transition since this is when many care decisions must be made. It is also at these transition points where often multiple complexities arise. This research will strengthen and support current and future health care planning and will encourage efforts to develop more well-informed and relevant resources to most appropriately support patients and families during transitional care.

If you have any questions or concerns, feel free to contact me, Taylor Hainstock, by email (thainsto@uvic.ca) or by phone (---). You may also contact Dr. Denise Cloutier at () ___-___ or Dr. Margaret Penning at () ___-___ to seek further information and/or clarification about the study and/or your role in it. Deanne Taylor (now located at Island Health) may also

help answer any questions you may have by email (----). Lastly, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) or by contacting the Fraser Health Research Ethics Board at 604-587-4436.

Thank you in advance,

Taylor Hainstock

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Taylor Hainstock, BHSc
MA Student, Social Dimensions of Health
Research Assistant, BC Trajectories in Care Project
University of Victoria
thainsto@uvic.ca |

Appendix B: Recruitment poster

Managing Transitions in Long-term Care



Are you helping care for a loved one?

A research project at the University of Victoria, partnered with Fraser Health, is looking to understand how family caregivers think about, navigate and manage key transitions between long-term care services for an older adult relative.



Importance?

At times of transition, many care decisions must be made. It is also at these transition points where multiple complexities often arise. Existing research suggests that it is often a family member who navigates these transitions and understanding these experiences is why I am looking to speak with **you!**

Who can participate?

- ✓ Family caregivers who have an older adult relative (age 65+) residing in Fraser Health
- ✓ Managed their relative's transition from receiving publicly-subsidized **home and community care services** to either a publicly-subsidized **assisted living** or **residential care facility** in the recent past
- ✓ Family caregivers who identify as the person who performs the '**care management activities**' (e.g. information seeking, arranging services, paperwork and managing finances) for their loved one

What is required?

- ✓ One in-person interview (approximately 60-90 minutes) scheduled at your convenience

Benefits:

- ✓ The chance to share your experience and provide important information for developing better health care and community support systems that will help caregivers navigate between long-term care services in the future!

In appreciation of your time, you will receive a \$15 Tim Hortons gift card!

- * Your participation in this study must be entirely voluntary and will have **no effect** on the health care services or relationships with Fraser Health in any way. You can withdraw at any point over the course of the study and your confidentiality and anonymity will be protected throughout the study.

For more information on eligibility and to discuss your potential participation, please contact:

Taylor Hainstock
 Email: thainsto@uvic.ca
 Phone:



**University
of Victoria**

This research project is being conducted as part of a Masters of Arts degree in the Social Dimensions of Health Program at the University of Victoria and has been approved by both UVIC and Fraser Health Human Research Ethics Boards



Appendix C: Telephone/email script



Mapping 'care management': Exploring family caregivers' experiences in managing a loved one's transition in long-term care

Hello,

Thank you for contacting me. I am very pleased to hear that you are interested in discussing your potential participation in my research project! This letter is intended to give you a little more information about me, my project and your participation.

My name is Taylor Hainstock and I am a graduate student in the Social Dimensions of Health Program at the University of Victoria. I am conducting a research project on how family caregivers think about, navigate and manage key transitions between long-term care services for a loved one. Specifically, I am exploring caregivers' experiences in managing a family member's transition between publicly-subsidized home and community care services to either assisted living or residential care, with a focus on how these experiences vary by geographic location (more urban compared to more rural areas). Attached in this email I have provided you with a "Participant Information Letter" and the "Participant Consent Form" for you to review.

I was hoping to speak with someone who was the primary person involved with managing the care of your loved one when they moved from receiving home and community care services to living at an assisted living (or residential care) location. I am looking to speak with someone who most often engages in activities like having conversations with other family members or the care recipient about arranging to move from the home to an assisted living or residential care facility, dealing with financial matters; doing relevant paperwork; and looking for other supportive information. I want to make sure that that is you?

If this is **not** you, I appreciate you taking the time to contact me, but because of my research objectives, I am looking to speak with someone who takes on these 'care management' tasks. I wonder if you could pass the "Participant Information Letter", "Participant Consent Form" and my contact information on to the relative/person who does take on these kinds of tasks for your family member? Please ask them to contact me via email and/or telephone so that we can discuss their potential participation.

If you **are** the person who takes on the 'care management' tasks for your loved one, please take time to review the "Participant Information Letter" and "Participant Consent Form". Do you have any questions or concerns about the study? ***Please reply to this email with any questions or concerns prior to deciding to participate or not in the study.***

If you **do not** have any questions or concerns and are interested in participating in this research project, please indicate below your preferred form of contact for the interview, either in-person

or by telephone. I am asking that in-person interviews take place either in your home or in another quiet location as they will be audio-recorded.

A. ***In-Person Interview*** (please reply to this email providing **2** available dates before July 1st, 2015)

- Date: _____
- Time: _____
- Location Address: _____

*Please have the signed "Participant Consent Form" at the time of the interview. Before we begin, we will review the consent form to ensure any questions have been answered.

B. ***Telephone Interview***: Please reply to this email providing **2** available dates before July 1st, 2015.

- Date: _____
- Time: _____
- Phone Number: _____

* Please ensure that you review the "Participant Consent Form". Before the telephone interview begins, I will give you time to ask any additional questions, then I will ask for your verbal consent to participate in the study over the telephone. Your consent will be audio-recorded for my records.

Your participation in this study is confidential and your contact information will not be shared with anyone. If you decide to participate, your name will not be used in the research. *Please refer to the "Participant Consent Form" for further details on confidentiality.*

If you have any concerns or complaints about your rights as a research subject and/or your experiences while participating in this study, contact the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) or the Fraser Health Research Ethics Board (604-587-4681) where you may discuss these rights with one of the co-chairmen of the Fraser Health REB.

I will be in contact with you shortly to confirm the date and time of the interview, but if you think of any questions between now and then, please do not hesitate to contact me by phone or email (----- / thainsto@uvic.ca).

Thank you for taking the time to participate and I will be in contact with you in the upcoming weeks.

Best,

Taylor Hainstock

Taylor Hainstock, BHSc
 MA Student, Social Dimensions of Health
 Research Assistant, BC Trajectories in Care Project
 University of Victoria
thainsto@uvic.ca

Appendix D: Participant information letter



Participant Information Letter

Mapping 'care management': Exploring family caregivers' experiences in managing a loved one's transition in long-term care

I am very pleased to see that you are interested in discussing your potential participation in my research project!

My name is Taylor Hainstock and I am a graduate student in the Social Dimensions of Health Program at the University of Victoria. To fulfill the requirements of my degree, I am conducting a research project entitled *Mapping care management: Exploring family caregivers' experiences in managing a loved one's transition in long-term care*.

This research is a unique study that stems from an existing research project (BC Transitions in Care Project [BCTIC] Penning-Cloutier, 2012-2015, CIHR no. 122184, UVIC HREB no. 12-255, FH REB no. 2012-051) based at the University of Victoria and reflects a strong, existing partnership with Fraser Health (FH).

Purpose and Objectives

The purpose of this research project is to understand how family caregivers think about, navigate and manage key transitions between long-term care services for their family members. Specifically, am exploring family caregivers' experiences in managing a loved one's transition between publicly-subsidized **home and community care** (HCC) services to publicly-subsidized **assisted living** (AL) or **residential care** (RC), with a focus on how these experiences vary by geographic location (i.e., more urban compared to more rural areas).

For the second phase of my study, I am looking to complete interviews with family caregivers who have managed the transition from publicly-subsidized HCC to AL or RC for their loved one. Existing research suggests that family members are involved in helping older adults to navigate these transitions. Understanding the experiences of a primary caregiver is the focus of my project which is why I am interested in speaking with you!

Importance of this Research

'Care management activities' (e.g. managing finances, paperwork, information gathering) are important to examine at times of transition since this is when many care decisions must be made. It is also at these transition points where often multiple complexities arise. This research will strengthen and support current and future health care planning and will encourage efforts to develop more well-informed and relevant resources to most appropriately support patients and families during transitional care.

Your Role

You are the primary caregiver for a family member who has transitioned from home and community care services to either publicly-subsidized **assisted living** or **residential care** in the

past **two-twelve** months and identify as the person who takes on the 'care management activities' mentioned above. I am interested in hearing about your experience in managing this transition in care and would love to have the chance to interview you. ***(*If you are not the caregiver who performs the 'care management' tasks, please forward my contact information, this information letter and the "Participant Consent Form" to a family member who assumes this role).***

Along with this letter, you have been given the "Participant Consent Form" to review. It is important to note that Fraser Health staff are not involved in the research project and will not know if you decide to participate or not. Your decision to participate in this study (or not) must be completely voluntary and will have **no effect** on the health care services or relationships with Fraser Health in any way.

In appreciation of your participation and time, you will receive a \$15.00 Tim Hortons gift card at the end of the interview.

If you have any concerns or complaints about your rights as a research subject and/or your experiences while participating in this study, contact the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) or the Fraser Health Research Ethics Board (604-587-4681) where you may discuss these rights with one of the co-chairmen of the Fraser Health REB.

If this is an opportunity that you are interested in being a part of, I encourage you to contact me at your **earliest** convenience. I can be reached by telephone at () ____ - ____ or by email at **thainsto@uvic.ca**.

I truly look forward to connecting with you in the upcoming week where we can discuss the study and your participation more thoroughly.

Thank you for taking the time to consider participating!

Regards,
Taylor

Taylor Hainstock, BHSc
MA Student, Social Dimensions of Health
Research Assistant, BC Trajectories in Care Project
University of Victoria
thainsto@uvic.ca

Appendix E: Participant consent form



Mapping 'care management': Exploring family caregivers' experiences in managing a loved one's transition in long-term care

Principal Investigator: Dr. Margaret Penning

Primary Researcher: Taylor Hainstock

Affiliation: University of Victoria

Funding Agency: CIHR & MSFHR (no.122184)

You are invited to participate in a study entitled *Mapping care management: Exploring family caregivers' experiences in managing a loved one's transition in long-term care* that is being conducted by Taylor Hainstock, a graduate student in the Social Dimensions of Health program at the University of Victoria.

As a graduate student, I am required to conduct research as part of the requirements for a Masters of Arts degree in Social Dimensions of Health program. It is being conducted under the co-supervision of Dr. Denise Cloutier and Dr. Margaret Penning. This research is a unique study that is emerging from an existing research project (BC Transitions in Care Project [BC-TIC], Penning-Cloutier, 2012-2015, CIHR no. 122184, UVIC HREB no. 12-255, FH REB no. 2012-051) based at the University of Victoria and reflects a strong, existing partnership with Fraser Health (FH).

Purpose and Objectives

The purpose of this research project is to understand how family caregivers think about, navigate and manage key transitions between long-term care services for their family members. Specifically, this research will explore your experience in managing a family member's transition between publicly-subsidized home and community care services to publicly-subsidized assisted living or residential care, with a focus on how these experiences vary by geographic location (urban and rural) within the Fraser Health region.

This research aims to build a deeper understanding of family caregivers' experiences of the 'care management' role caregivers assume when a loved one transitions between long-term care services. These types of activities include: conversations with other family members or the care recipient about arranging to move from home to a facility and the associated financial matters; doing relevant paperwork; and looking for other supportive information.

Importance of this Research

Care management activities are important to examine at times of transition since this is when many care decisions must be made. It is also at these transition points where often multiple complexities arise. The proposed study aims to contribute to the fields of caregiving and health geography by developing a deeper understanding of 'care management' as a notable component of caregiving. This research will strengthen and support current and future health care planning and will support efforts to develop more well-informed and relevant resources to most appropriately support patients and families during transitional care.

Participation

You are being asked to participate in this study because you are the primary 'care manager' for a family member who has transitioned from publicly-subsidized home and community care services to either publicly-subsidized assisted living or residential care in the past two-twelve months.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. Any data collected up to the point of your withdrawal from the study will be kept for data analysis purposes under strict provisions of confidentiality.

If you consent to partake in this research, your participation will include an interview that will last approximately 60-90 minutes and will be tape recorded and transcribed. A time and place for the interview will be set up that is convenient for you. In the event that an in-person interview cannot be arranged, a telephone interview will take place at your convenience. At the completion of the study, you will be sent a summary of the results if you would like them.

Participation in this study should not inconvenience you other than taking up a few hours of your time.

Risks

Participation in this research is not anticipated to cause any harm. Although unlikely, it is possible that you may experience unexpected, minor emotional discomfort or stress over the course of the interview as we discuss your experiences in managing your loved one's transition in care. Research does suggest that transitions in care are times in which caregivers often experience anxiety and stress and it is possible these feelings may reemerge during the interview.

There is a chance you may also experience fatigue or stress when arranging a time to partake in the interview (i.e. arranging a time outside of work and family obligations), however, it is not expected that the interview itself will trigger either of these emotions.

The interviews are not intended or designed to evoke discomfort, fatigue or stress, however in the event that you do experience one of these feelings, the researcher conducting the interview will offer you a break, the chance to stop and reschedule the interview; and/or the chance to stop the interview/research activity altogether. The researcher will also be able to direct you to a list of contacts should you wish to speak with someone at Fraser Health about your experiences.

Potential Benefits

You may benefit from being able to share your personal experiences, but are not likely to receive any other major benefits from participating in this study. However, it is anticipated that the results may provide important information for developing better health care and community support systems that will help caregivers navigate between long-term care services in the future.

Incentive

In appreciation of your participation and time, you will receive a \$15.00 gift card to Tim Hortons. If you choose to withdraw before the completion of the study, you will still be given the gift card. If you agree to participate in this study, this incentive must not be seen as coercive.

Confidentiality

Any personal information you chose to provide is voluntary and your confidentiality will be respected. However, research records or other source records identifying you may be inspected in the presence of the primary researcher or her designate by representatives of CIHR, Fraser Health Research Ethics Board and University of Victoria Human Research Ethics

Board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law.

You will be assigned a unique study number as a subject in this study. Only this number will be used on any research-related information collected about you during the course of this study, so that your identity [i.e. your name or any other information that could identify you] as a subject in this study will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without your consent unless required by law.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the researcher and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request.

Consent forms and data will be secured in a secured filing cabinet and on a password protected flash drive.

Fraser Health staff are not involved in the research project and will not know if you decide to participate or not. Your decision to participate in this study (or not) will have **no effect** on the health care services or relationships with Fraser Health in any way.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways: an executive summary for the Fraser Health Authority and participants (if interested), conference presentations (both oral and posters in local and national venues) and related academic journal publications.

Disposal of Data

The typed transcripts, with identifying information removed, will be retained by the research team for additional educational and research purposes. After seven years, the original audio-tapes and electronic transcribed interviews will be destroyed seven years following study completion. Any paper copies will be shredded.

Contacts

If you have any questions or concerns over the course of this study, you may contact Taylor Hainstock by email (thainsto@uvic.ca) or by phone (----) You may also contact Dr. Denise Cloutier at () ___- ___ or Dr. Margaret Penning at () ___- ___ to seek further information and/or clarification about the study and/or your role in it. If you have any concerns or complaints about your rights as a research subject and/or your experiences while participating in this study, contact the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) or the Fraser Health Research Ethics Board (604-587-4681) where you may discuss these rights with one of the co-chairmen of the Fraser Health REB.

Participant Consent Form

Mapping 'care management': Exploring family caregivers' experiences in managing a loved one's transition in long-term care

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project. Your participation in this study does not give up any legal rights by signing this consent form.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
<i>Name of Primary Researcher</i>	<i>Signature</i>	<i>Date</i>

PLEASE SELECT A STATEMENT REGARDING FUTURE USE OF DATA BY RESEARCH TEAM MEMBERS:

**Future use of data will not contain any identifiers.*

It is possible that future data analysis will occur in the event the primary researcher decides to do her PhD or if the other research team members wish to work with this project data. The potential future use of this project data would not extend beyond the current research team members. In the event that new research interests arise over the course of the study, research teams might be interested in contacting you to discuss participating in a new study. Please initial a statement below related to the future use of your data:

I consent to the use of my data in future analysis: _____ (Participant to provide initials)

I **do not** consent to the use of my data in future analysis: _____ (Participant to provide initials)

I consent to be contacted by research team members for future research participation should new research interests arise over the course of the study: _____ (Participant to provide initials)

I **do not** consent to be contacted by research team members for future research participation should new research interests arise over the course of the study: _____ (Participant to provide initials)

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix F: Participant socio-demographic information sheet



Participant Demographics

Mapping 'care management': Exploring family caregivers' experiences in managing a loved one's transition in long-term care

DATE: _____

PARTICIPANT ID #: _____

Age: _____

Gender: _____

Relationship to individual being cared for (e.g., father/mother, brother/sister): _____

Marital Status: _____

Education Level: _____

Occupation: _____

Location of residence (town/city): _____

Location of family member (Assisted Living/Residential Care site): _____

Appendix G: Interview guide

Mapping ‘care management’: Exploring family caregivers’ experiences in managing a loved one’s transition in long-term care

DATE:

START TIME:

PARTICIPANT ID #:

My name is Taylor Hainstock and I am a graduate student in the Social Dimensions of Health Program at the University of Victoria. To fulfill the requirements of my degree, I am conducting a research project entitled *Mapping care management: Exploring family caregivers’ experiences in managing a loved one’s transition in long-term care*.

The purpose of this research project is to understand how family caregivers think about, navigate and manage key transitions between long-term care (LTC) services for their family members. Specifically, I am exploring family caregivers’ experiences in managing a loved one’s transition between publicly-subsidized **home and community care** (HCC) services and either **assisted living** (AL) or **residential care** (RC) services with a focus on how these experiences vary by geographic location (i.e., more urban compared to more rural areas). Existing research suggests that family members are involved in helping older adults to navigate these transitions. Understanding the experiences of a primary caregiver is the focus of my project.

Over the course of the interview I’d like to talk about your overall caregiving experiences, the specific experiences of the transition from home to AL/RC and finally your thoughts on the management of care role.

Care Recipient Context

1. To start off, I was hoping you could tell me a little about (introduce me) to your mom/dad/husband?

I appreciate learning a little more about your loved one. Now, I would like to move on to talking about your overall experiences as a caregiver.

Overall Caregiver Role – Thinking more broadly about your role as a caregiver...

1. How would you describe your level of involvement in caring for _____.

(Probe: What kind of care do you provide for your loved one? How often? About how many hours per week (on average)?

2. Is this a shared or family responsibility?

a. Could you elaborate on the range of roles and duties your family takes on and the reasons?

b. How do you see your role the same or different from your family members?

3. How long have you, and/or your family, been involved in caring for _____?
 - a. What prompted the need to take on this role?
(Probe: Declining health? Loss of Spouse?)
 - b. When you first started caring for _____, did you feel prepared?
 - c. Did you do anything different to prepare?

4. How has your role in their care changed over time?
(Probe: level of care? type of care?)

Is there anything in your life that makes it easier or harder to provide the level of care that you'd like to provide for your mom/dad/husband?

Thank you for giving me a better idea of both yours and your families' caregiving experiences. Your answers have been very informative. Now, I would like to ask you some questions about your family member's transition specifically from home and community care services to assisted living (or residential care). I'm going to be using the term 'move' as I ask you questions, but I don't want you to think about this word in its most literal sense (i.e. moving day), rather more broadly to refer to the overall transition process from home to RC or AL.

Transition from HCC to AL or RC

1. I'd like to hear a little more about your involvement in their transition specifically from home to AL or RC.
 - a. What specific circumstances led to the move?
 - b. Were there hospitalizations at any point?
 - i. If so, how many and for what reasons was your family member hospitalized at these points?
 - c. How was the decision made to move? (Joint/family or individual?)

2. What kinds of activities /decisions were involved over the course of the move and who was involved? (Probe: Can you tell me about each person's involvement at each stage of the transition, before during and after?)

3. Did the transition involve relocating from one community to another?
 - a. How did factors like distance and location impact the move?
 - b. How does your location (relative to their location) facilitate or act as a barrier?
 - c. Was relocation a necessity based on service availability? Convenience? Preference?

- d.** How would you describe the availability of services in your community?
- 4.** Thinking about the whole transition, from the time you started looking for information on AL/RC, were there any main events that stood out as far as you were concerned?
- 5.** What sorts of challenges stood out for you at the start of the transition? (Probe: emotional, stress, environmental, financial)
- a.** What were the challenges during?
 - b.** Are there challenges still? (after the relocation?)
- 6.** How did you try to meet these challenges?
(Probe: Formal or informal services? Respite? Community? Family support?)
- a.** Which services did you find most helpful or supportive over the course of the transition?
 - b.** What kinds of information did you receive?
- 7.** *Pre-amble...Our aim is not to paint a picture of everything being difficult when you helped ___ transition into AL/RC.....*
- a.** Are there any things that you could point to that went well or that were more positive experiences within your role?
 - b.** What joys did you experience before, during and after the transition?
(Probe: Sense of satisfaction? Ease? Fulfillment? Knowing they were safe?)
- 8.** Overall, how long was the process of the transition?
- 9.** Over the course of the transition, did your relationship with your loved one change at all?
- 10.** Reflecting on the transition from beginning to now, how did your level of care change? (Probe: did the hours/number of activities increase?)
- 11.** Overall, would you consider the transition 'successful'? Why or why not?
- 12.** What one piece of advice would you give another caregiver who was preparing to help with a move?
- 13.** What one piece of advice would you give to the health system to promote better care transition experiences for families?

Thank you for giving me a better idea of the caregiver experience over the course of _____'s transition from home to AL or RC. Now, I would like to ask you some questions about the 'managing' activities involved in caring for _____ over the course of the move, ask for any other final thoughts and then we're done!

Conceptualization of Care Management Role

Earlier on, you mentioned that you did a lot of the organizational care activities like looking into service options, making arrangements for services, taking care of financial and/or legal issues, involved in your _____'s transition.

14. How do you see the roles of caregiver and manager of care (the one doing the organizational tasks) as being different or the same?
 - a. Would you consider yourself a 'care manager'? How does this 'title' sit with you?
 - b. How did your role as care manager change over the course of the transition?
 - c. If you were to give yourself a title that summarized your caregiving role, what would that be?
15. Is there anything else you would like to say about your role in helping to manage your loved one's care/transitions?
16. Is there anything else I should have asked you or anything else you would like to comment on?

Thank you once again for taking the time to speak with me. In appreciation of your time, I have a Tim Hortons gift card for you. Your interview today has contributed meaningfully to the completion of my Masters of Arts degree. It is anticipated that the final results of my study will also be shared with Fraser Health (in the form of an Executive Summary), for conference presentations (both oral and posters in local and national venues), related academic journal publications, and of course, shared with you should you be interested.

Would like to receive the results:

- Yes
 No

Preferred method:

- Email
 Mail

Appendix H: Caregiver pseudonym table

ID #	Pseudonym	Age	Education	Relationship	Family member's transition
URBAN					
U1	Sally	72	Some University	Husband	H - H+ - RC(temp) - RC
U2	Pieta	57	BBA	Mother & Father	H - IL - RC(temp) - H+ - H+ - RC (dad)
U3	Rosanne	66	Some College	Mother	H - H+ - H - H+ - AL- H+ - RC - RC(waiting to relocate)
U4	Amelia	55	Post Graduate	Mother	H - H+ - H+ - H+ - RC - H+ - RC
U5	Joanne	61	College	Mother	H - IL - H+ - RC(temp) - RC
U6	Mona	75	Some University	Sister	H - RC
	Paul				
U7	Annie	46	BA	Mother	H - H+ - H - H+ - RC(temp)- H+ - RC
SUBURBAN					
S1	Amy	68	Nursing	Mother	H - IL - H+ - IL - H+ - IL - H+ - RC - RC(relocated due to facility closure)
S2	Nicole	69	Some University	Mother	H - H+ - IL - H+ - IL - H+ - RC
S3	Rebecca	87	Grade 12	Wife	H - H+ - RC - RC(waiting to relocate)
RURAL					
R1	Moira	75	Grade 11	Husband	H - H+ - RC(temp/rehab) - H - RC
R2	Mary	68	BA	Mother	H - H(new house) - H+ - H - H+ - RC(first as respite, then full)
R3	Sharon	63	University	Mother	H - H+ - H - RC (w/compassionate care)
R4	Marge	80	Masters Education	Husband	H - H+ - H - H+ - RC
R5	Tina	63	Some College	Spouse	H - H+ - H+ - RC(temp/rehab) - H+ - RC

H = home
 H+ = hospitalization
 IL = Independent living
 RC = residential care