TRANSITION EXPERIENCES OF CAREGIVERS OF OLDER ADULTS WITH DEMENTIA AND MULTIPLE CHRONIC CONDITIONS: AN INTERPRETIVE DESCRIPTION
TRANSITION EXPERIENCES OF CAREGIVERS OF OLDER ADULTS WITH DEMENTIA AND MULTIPLE CHRONIC CONDITIONS: AN INTERPRETIVE DESCRIPTION

By

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TITLE: Transition Experiences of Caregivers of Older Adults with Dementia and Multiple Chronic Conditions: An Interpretive Description

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Abstract

Family caregivers of older persons with dementia (PWD) and multiple chronic conditions (MCC) provide high levels of in-home care. Caregiving is complicated by transitions such as changes to one's environment, roles, relationships, and overall health. Although PWD often have MCC, few studies have focused on the influence of MCC on dementia caregiving and transitions. The purpose of this study was to explore the transition experiences of caregivers of PWD and MCC. This study is a sub-study of a larger pragmatic mixed methods randomized controlled trial called MyTools4Care (MT4C). Using interpretive description methodology, semi-structured interviews were conducted across Ontario with a subset of caregivers (n=19) and clinicians working with dementia caregivers (n=7). Purposive theoretical sampling and concurrent data collection and analysis were used. Participants described their transition experiences, factors that influenced these experiences, potential outcomes of transitions, and the influence of MCC on dementia caregiving. Participants identified five key transitions which included: (a) There's no turning off (progressive increase in responsibilities); (b) I'm filling in many roles (changes in roles and relationships); (c) I'm sick, too (changes in overall health and well-being); (d) Dementia defines my social life (changes in social boundaries), and; (e) I know that day will come (changes in preparing for the future). Study findings emphasized how the co-existence of dementia and MCC resulted in added complexity and burden to care management and decision-making for caregivers. Findings suggest that health care professionals (HCP) are an important extension of caregivers' support networks. Thus, HCP need to be comfortable, trained, and knowledgeable in diagnosing and managing dementia and MCCs in order to support caregivers in their transitions. Future research should explore the experience of dementia within the broad context of MCC in order to understand the impact on the dementia caregiving experience.
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Many thanks to the health care professionals who gave up so much of their time to share their experiences with me. You are all to be commended for the difficult work that you do, and for the difference that you make in the lives of your patients.

Last but not least, I would like to thank the caregivers in the study who have been thrust into situations requiring extraordinary strength, courage, faith and resiliency. You are humans of incredible love and patience. Thank you for embracing me and providing me with a window into your lives.
## Abbreviations

<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>PWD</td>
<td>Persons with dementia</td>
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<td>HCP</td>
<td>Health Care Professionals</td>
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<td>MCC</td>
<td>Multiple chronic conditions</td>
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Chapter 1: Introduction

Worldwide there are 47.5 million people living with dementia and there are 7.7 million new cases every year (World Health Organization [WHO], 2015). This number is estimated to increase to 131.5 million cases by the year 2050 (Alzheimer Disease International [ADI], 2015). Dementia primarily affects persons over the age of 65 years, the prevalence doubling with every five-year increase in age (ADI, 2010). The disease is characterized by deterioration in cognitive function, including one's memory, thinking, behaviour, and the ability to perform everyday activities. It has significant social and economic implications in terms of health and social costs and costs of informal care (WHO, 2015). Many, if not all persons with dementia (PWD) require some form of care throughout the disease process. The majority of PWD are living at home and informal caregivers provide up to 90% of in-home care (Alzheimer's Society, 2010). Informal caregivers are often family members such as spouses and adult children, but may also be friends or neighbours. Research has shown that caring for a PWD is overwhelming and puts significant physical, emotional and economic pressures on caregivers at various stages of the caregiving trajectory (WHO, 2015). These caregivers often experience multiple complex transitions as part of their caregiving, which may include distressing changes to their environment, roles and relationships, and physical and mental health (Duggleby, Swindle, Peacock, & Ghosh, 2011).

Multimorbidity, also referred to as multiple chronic conditions (MCC), further complicates the management of care in older adults. Given that the prevalence of chronic conditions increases with age (Canadian Institute for Health Information [CIHI], 2011b)
and that the majority of PWD are over the age of 65, it is no surprise that dementia rarely exists alone. Older adults with MCC represent 33% of community-dwelling older adults (Broemeling, Watson, & Prebtani, 2008). Many older adults in the community have at least one chronic health condition which could be physical or mental (CIHI, 2011b). In particular, PWD have a high prevalence of co-morbid medical conditions compared to those without dementia, with almost 70% of PWD having at least two co-morbidities (Bunn et al., 2014; Doraiswamy, Leon, Cummings, Marin & Neumann, 2002; Schubert et al., 2006; Poblador-Plou et al., 2014). This complicates the management and experience of caregiving as caregivers are required to focus on more than just a single disease process. Nurses are one of the largest groups of health professionals providing direct care to these older adults and their family caregivers in the community. It is therefore imperative for nurses and other health care professionals (HCP) to develop a greater understanding of the impact of MCC on the dementia transition experience in order to better support these caregivers.

Little is known about the transition experiences of providing care to a PWD within the context of additional MCC. It is crucial to examine how the complexity of chronic conditions affects the experience of providing dementia care. Greater insight into how the role of MCC influences dementia caregiving will help HCP determine the best way to manage complex chronic conditions and support caregivers in managing the health of PWD.
Reflective Summary

As a registered nurse (RN) who has worked with the geriatric population across multiple settings, I have been influenced by the stories and experiences shared by both caregivers and older adults with dementia and MCC. In my experience as an RN working in acute medicine, I cared for older adults who were often acutely ill with an exacerbation of at least one chronic condition. I was always shocked to see that many of my patients had a long list of chronic conditions alongside their presenting diagnosis. Similarly, when I worked in a specialized outpatient geriatrics setting, I encountered a unique population of older adults who not only had MCC, but were also presenting with cognitive impairment or dementia. The diagnosis of dementia complicated the plan of care as these patients required significant assistance from their informal caregivers to manage their health and care. I noticed that many of the referrals for these caregivers and patients came from family physicians and nurses who often asked for a primary assessment of cognition, with little consideration of the other chronic conditions. I also found in my practice that the majority of my education and health teaching was with family caregivers, who were often more concerned with the day-to-day management of dementia, and less about the management of other chronic conditions.

In my current role as a geriatric clinical nurse specialist in the emergency department, I have become more aware of the current gaps in care for caregivers of PWD and MCC, as well as the PWD themselves. More PWD are now coming into the emergency department because their primary caregiver is burned out. Recently, this has become an issue across Canada; it is not uncommon for news outlets to report that
Caregivers are "dropping off" their family members in hospitals and "refusing" to take them home. As HCP, we lack an understanding of the complicated transitions and changes that these caregivers experience, and how this affects their day-to-day lives. Because we do not have an in-depth understanding of the different transitions they experience, we are unable to provide the appropriate supports for these caregivers in the community. They continue to struggle with care on their own and become fatigued and stressed. As such, they often have no choice but to bring the PWD to the ED.

Another issue that I have seen in my practice is the obvious discomfort and lack of understanding of physicians and nurses in treating and managing PWD and MCC. What is even more concerning is that HCP tend to focus on single diseases, rarely taking into consideration the other chronic conditions aside from the presenting issue. Most treatment plans and prescriptions for medications focus on one acute issue, and caregivers and PWD are discharged back into the community with little guidance on how to manage the other MCC. This results in repeated visits to the hospital with subsequent deterioration in health and quality of life, because we as HCP focused on the PWD responsive behaviours and ignored their underlying heart condition. Likewise, we may have treated the patient for a hypoglycemic episode, but forgot that their underlying dementia affects their ability to monitor their blood sugars. Most importantly, HCP sometimes forget to include the family caregiver in discussions, as well as ask them how they are coping at home. These experiences with this population have triggered my interest in developing a greater understanding of the transition experiences of caregivers of PWD and MCC.
Overview of Thesis

The purpose of this study is to explore the transition experiences of informal family caregivers of older persons with dementia and MCC. The thesis is divided into five chapters. This first chapter has provided the reader with an introduction to the problem and the reasons for why I have decided to embark on this journey to understand transition experiences. Chapter 2 provides a general overview of dementia caregiving, multiple chronic conditions, and dementia transitions. Within this chapter, I will also describe findings from the literature search and gaps in the current literature. In Chapter 3, I describe the methodology used in this study, including details on context, setting, data collection and analysis procedures. In Chapter 4, I describe the demographics of the participants and present the five key themes identified in this study. I also describe the potential factors and outcomes of transitions as experienced by participants in this study. Finally, I provide a discussion of the key findings in Chapter 5 with implications for practice, education, policy and research. I end with the strengths and limitations of the study.

Chapter 2: Literature Review

The purpose of this literature review is to provide an overview of the context of three key issues being addressed in this study based on available empirical literature; dementia caregiving, multimorbidity in older adults, and transitions. The chapter begins with a general overview on dementia caregiving, highlighting the current demographics of dementia caregivers and the impact of dementia caregiving. Next, I provide a general overview on multimorbidity. These two sections are meant to provide readers with insight
on the significant impact of these two issues on the older adult population. Following this, I describe the literature search conducted (see page 18) and provide an overview of the literature relevant to this study. I highlight key relevant articles retrieved from the literature review search that includes an analysis of the studies. I then provide an overview of transitions before concluding the chapter with a synthesis of the gaps in the existing literature.

**Demographics of Dementia Caregivers**

Informal family members and friends provide the majority of elder care for PWD in Canada (ADI, 2010). The term *family caregiver* is used broadly in the literature, and can be defined as a family member, partner, friend, neighbour, or any person who provides or manages the care of a PWD. The relationships between the caregiver and the care receiver can affect the nature of caregiving. An increasing number of caregivers are 65 years of age or older. In Canada, spouses are most likely to take on the caregiving role, followed by daughters or sons (Sinha, 2012). In many cases, spousal caregivers are elderly themselves and at an increased risk for injury and negative health effects. Spousal caregivers are also less likely to have backup support from family and friends and more likely to be caring for a person with severe dementia (Dupuis, Epp, & Smale, 2004). Traditionally, research has reported that the majority of caregivers are women, often wives and daughters (Alzheimer's Association, 2016; ADI, 2009). However, this has been changing as an increasing number of males are taking on the role as the sole caregiver, with men now accounting for 41% of spousal caregiving (Brown, Chen, Mitchell, & Province, 2007). Within filial caregiving, adult daughters are more likely than adult sons
to provide caregiving. More recent research shows that although caregiving sons provide less hours of care compared to caregiving daughters (Alzheimer's Association, 2016), they are often committed to care but in different ways, and influenced by life circumstances, level and intensity of involvement in caregiving, and available social supports (Campbell, 2010). In cases where there is no family, extended kin, friends and neighbours have taken on the role of the caregiver (Quinn, Clare, & Woods, 2010).

The demographics of caregivers are changing. The baby boomer generation (persons between 50 and 69 years of age) are the largest group of caregivers to older adults (Statistics Canada, 2008; Statistics Canada, 2014a). The baby boomer generation is unlike the previous generation as boomers are more likely to have delayed marriage, postponed having children, and had an increased number of women in the workforce (Statistics Canada, 2008; Statistics Canada, 2014a). Further, these caregivers are more likely to be employed. The baby boomer generation is made up of adult children who continue to share caregiving responsibilities and are involved both directly and indirectly in care. This generation continues to provide care for their children and their aging parents as well as juggle the responsibilities of work and day-to-day responsibilities. In addition to managing the changes and responsibilities related to dementia, these caregivers play a significant role in the management of multiple co-morbid conditions in the PWD. The management of co-morbidities in dementia presents its own unique and complex challenges, further complicating the transition experiences of the caregiver and affecting their health and well-being.
Impact of Dementia Caregiving

According to the Alzheimer Society of Canada's [ASC] Rising Tide Report (2010), family caregivers of PWD provided up to 231 million hours of informal unpaid care in 2008. Caregivers who live with care receivers provide a greater range of caregiving tasks and more hours of unpaid care than those who live in separate residences (Dupuis et al., 2004). It is estimated that family caregivers of PWD contribute to over $5 billion dollars of unpaid care every year. Informal caregiving duties may include transportation, grocery shopping, housework, household finances, meal preparation, personal care and day-to-day living activities, as well as supportive emotional care, including social engagement and affection (Alzheimer Society of Canada, 2010; Dupuis et al., 2004). Caregiving roles and responsibilities change over time, and are often energy intensive, time consuming and financially draining.

Positive Effects of Caregiving

Although caring for individuals living with dementia is associated with a number of negative effects, more research that is recent has shown that dementia caregiving also has potentially positive aspects. According to the World Alzheimer's Report (ADI, 2009), 80% of caregivers of PWD are able to identify positive aspects of caregiving. These include companionship, fulfillment, enjoyment, providing quality of life, and meaningfulness (ADI, 2009). Other positive experiences identified in the literature include: (a) a sense of satisfaction, (b) gratification and pride, (c) increased sense of mastery and self-efficacy, (d) competence and accomplishment, (e) a sense of purpose or meaning in life, (f) personal growth, and (g) improved social relationships (Acton &
Caregiving provides a way to connect emotionally and experience a sense of reciprocity in care. Caregivers have reported developing stronger emotional bonds with their spouses following the onset of dementia for various reasons (de Vugt et al., 2003). These include having to deal with the diagnosis together, cherishing the limited time that they have together, and empathizing with the daily struggles of physical and cognitive impairment (de Vugt et al., 2003). Many of these emotional benefits stem from the idea that giving and caring are inherent social needs; they are rewarding and provide a sense of accomplishment and self-efficacy (Carbonneau et al., 2010; Nolan, 1996). Caregiving therefore provides an outlet for spousal caregivers to maintain their marital relationships through companionship, affection, love and commitment (Dupuis et al., 2004; Motenko, 1989). Caregiving has also been described as an opportunity to give back or repay the PWD (Dupuis et al., 2004). In both cases, caregivers experience greater satisfaction if they provide care out of love or reciprocity rather than duty (Dupuis et al., 2004; Motenko, 1989). It is important to emphasize the positive aspects of caregiving when supporting families as it benefits the caregivers' physical and mental health (Carbonneau et al., 2010).

**Negative Effects of Caregiving**

Most of the literature on the impact of dementia caregiving focuses on the negative physical, mental, social and psychological burdens. The majority of care is provided in the home, with few opportunities to go out of the home due to the nature of
the disease. Caregivers are therefore isolated and may find it difficult to receive adequate supports. Family caregivers of PWD experience a multitude of feelings, including fear, uncertainty, guilt, frustration, anger, sadness and loss, stress, and chronic fatigue (ASC, 2012; Schulz, O’Brien, Bookwala, & Fleissner, 1995; Richardson et al., 2013). Many experience psychiatric and emotional disturbances throughout the caregiving career. Over 75% of caregivers of PWD experience psychological illness or distress, and between 15-32% suffering from depressive symptoms and in some cases, depressive disorders (ACS, 2012; Ask et al., 2014). Family caregivers of PWD have also been shown to have high levels of anxiety symptoms and low levels of life satisfaction, subjective well-being, and self-efficacy (Bass et al., 2012; Papastravrou, Kalokerinou, Papcostas, Tsangari, & Sourtzi, 2007; Sorensen & Conwell, 2011).

Studies have shown that nearly one quarter of caregivers provide 40 hours or more care per week compared to 16% of non-dementia caregivers (Brodaty & Donkin, 2009). This in itself has an impact on their social and personal lives. Family caregivers of PWD report having to give up pleasurable hobbies, vacations, and personal activities, and feel that they have less time for other family members (Schulz & Martire, 2004; WHO, 2012). The negative implications of caregiving extend beyond their personal lives and affect their work lives as well. These caregivers have reported disruptions and problems to paid employment because of their caregiving duties. In particular, they describe having to: (a) take on less demanding jobs, (b) take early retirement, (c) turn down job promotions, (d) lose job benefits, (e) attend work feeling overly tired, (f) miss work, and/or (g) give up work entirely (Black et al., 2010; Pinquart & Sorensen, 2003). As a result, family
caregivers of PWD may face financial hardship as they struggle to balance the safety and care of the care recipient and maintaining their employment.

Strained caregivers are also at greater risk for physical consequences to their health. Evidence shows that family caregivers of PWD providing care on a full-time basis are less likely to engage in preventive health behaviours; they neglect their own health care appointments and maintain a poor-quality exercise and diet lifestyle (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003). Caregivers often suffer from disabling, painful conditions (e.g., back problems, arthritis) (Graesel, 2002) and stress-related problems (e.g., migraines, colitis, elevated blood pressure, slower wound healing, sleep disturbances) (ASC, 2012; Dupuis et al., 2004). Further, caregivers show evidence of impaired immunity, increased risk for serious illness, and an overall higher risk of mortality (Brodaty & Donkin, 2009). These conditions put significant strain on the caregiver's overall health and well-being. Overall, there is substantial evidence to illustrate the negative effects of dementia caregiving on caregivers.

**Dementia and Multiple Chronic Conditions**

Most of the research on the effects of dementia caregiving focus on dementia as an isolated disease and focus on the effects directly related to the disease. However, dementia is associated with older age and often coexists with other chronic conditions (Bunn et al., 2016). The presence of these additional chronic conditions introduces an array of challenges that affect the caregiver's approach to care management (Bunn et al., 2016). As dementia progresses and affects the PWD's cognitive ability to manage their own health, caregivers need to take on more health-related tasks. It is possible that the
presence of MCC in the PWD will negatively affect caregivers' physical and mental well-being, as they need to consider and manage more health activities on a daily basis.

**Overview of Multiple Chronic Conditions**

Over the years, the rising prevalence of MCC has become a global issue (WHO, 2012) and it is now recognized that patients with MCC represent the rule rather than the exception (CIHI, 2011a; Fortin et al., 2007; Fortin et al., 2004). Multimorbidity is the co-occurrence of chronic illnesses within an individual, typically referring to two or more conditions (Grundberg et al., 2012; Kuluski 2012; Loeb 2003), or three or more conditions (Bayliss, 2008; Roberto, 2005). The prevalence of multiple chronic conditions (MCC) increases with age and is most common among older adults (Boyd & Martin-Fortin, 2010). According to a survey done by the Canadian Institute for Health Information (2011b), 74% of older adults reported having at least one chronic condition, with the most commonly reported chronic conditions being heart disease (57%), diabetes (37%), high blood pressure (39%) and arthritis (31%) among persons over the age of 65. Approximately 11.3% of older adults (65 years and over) have three or more chronic diseases (Roberts et al., 2015). Evidence shows that older adults with MCC are more likely to report poor health, and MCC itself has been linked to decreased quality of life and increased risk and severity of disability (CIHI, 2011a, 2011b; Fortin et al., 2007; Terner et al., 2011). The decrease in quality of life of PWD and MCC has the potential to affect their family caregivers who provide a large proportion of care for this population.

Research has also shown that the increasing number of chronic conditions is the driving force of health care service use as opposed to increasing age (CIHI, 2011b;
Lehnert et al., 2011; US Department of Health and Human Services, 2010). Older adults with three or more chronic conditions account for 40% of reported healthcare use in Canada (CIHI, 2011b). Older adults with MCC tend to use health services more frequently and use a greater array of services than others (Vogeli et al., 2007). A recent systematic review examined health care utilization and costs of older adults with MCC (Lehnert et al., 2011). They found that older adults with moderate (1-2 chronic conditions) to high morbidity burden (five or more chronic conditions) had significantly more primary care physician visits, specialist physician visits and hospital utilization. The same study found that older adults with high morbidity burden were eight times more likely than those without MCC to be hospitalized via the emergency department (Lehnert et al., 2011).

The impact of MCC on the health care system is significant. Older adults with three or more chronic conditions are more likely than older adults without chronic conditions to have a high number of annual visits to their primary care provider (CIHI, 2011a). Patients with chronic conditions stay in the hospital for twice as long as patients without chronic conditions (8.2 days versus 3.8 days), and have 2.3 times more emergency department visits than those without chronic conditions (Ontario Ministry of Health and Long-Term Care, 2015).

Older adults with MCC also require more prescription medications to manage a variety of conditions. MCC is positively associated with the use and costs of prescription medications, with 90% of older adults with two or more MCC taking prescription drugs (Lehnert et al., 2011). In addition to hospitalization, polypharmacy is a common issue
among this population that puts them at an increased risk for adverse drug events, thus increasing the risk of morbidity (Lehnert et al., 2011; Vogeli et al., 2007). Caregivers play a central role in managing prescription medications, given that many PWD have complicated medication regimens (Bunn et al., 2016).

The literature also indicates that older adults with MCC receive suboptimal quality of care. Most primary care physicians struggle to properly manage MCC due to various organizational and health care systems factors including, but not limited to: lack of time, uncertainty with the management and treatment of chronic diseases, and patient adherence (Fried, Tinetti, & Iannone, 2011; Junius-Walker et al., 2012; Luijks et al., 2012). Literature on the experiences of older adults in self-management of MCC has revealed varied perspectives. Recently, Liddy, Blazkho, and Mill (2014) conducted a systematic review that included 23 studies looking at the qualitative perspectives of patients living with MCC and their challenges with self-management. The review found that patients with MCC experienced several physical and emotional health barriers that affected their ability to manage their own care (e.g., pain). Other factors that complicated self-management included lack of social supports, lack of financial resources, and lack of therapeutic relationships with HCP leading to confusion and contradictory information (Liddy et al., 2014). As the population ages and lives longer, multimorbidity is an issue that continues to be associated with suboptimal health outcomes and rising health care expenses, thus putting a strain on our health care system and those who provide support to older adults.
Overview of Dementia and Co-morbidity

In recent years, there has been increased recognition of the complex challenges that dementia brings to multimorbidity, and vice versa. PWD have among the highest levels of multimorbidity compared to persons with other chronic conditions (Banjerjee, 2015). Older adults with dementia have on average anywhere from two to eight additional chronic conditions compared to those without dementia (Guthrie et al., 2012; Sanderson et al., 2002; Schubert et al., 2006). Most studies on co-morbidity and dementia are related to prevalence and have been conducted outside the Canadian context (Bunn et al., 2014; Doraiswamy et al., 2002; Sanderson, 2002; Schubert et al., 2006). The prevalence of co-morbid conditions in dementia varies slightly between studies and is challenged by factors such as under diagnosis and under reporting of both dementia and chronic conditions in the primary care setting (Maslow, 2004).

A scoping literature review focused on the prevalence of three target co-morbidities in the context of dementia: diabetes, stroke and visual impairment (Bunn et al., 2014). The authors found that diabetes was prevalent in 6% to 39% of PWD, and stroke in 3% to 34% of PWD. Although they looked at visual impairment as well (such as glaucoma and macular degeneration), results were too varied across studies for comparison (Bunn et al., 2014). This review was updated in the first phase of Bunn et al.'s (2016) larger mixed method study where prevalence findings were similar to the original findings. In phase II of the mixed methods study conducted by Bunn et al. (2016), they conducted a cross-sectional analysis using data from two longitudinal multicentre population-based studies in the United Kingdom. They found that for PWD, over one-
third had at least one of those target co-morbidities and approximately one in six had diabetes, stroke and visual impairment (Bunn et al., 2016).

Findings from Vassilaki et al. (2015) indicate that multimorbidity in itself is associated with the risk of mild cognitive impairment and/or dementia. One explanation for this finding is that some chronic conditions have subclinical and detrimental effects on the brain (Vassilaki et al., 2015). For instance, the prevalence of stroke in patients with dementia is 2.5 times greater than in those without dementia (Bunn et al., 2016). Stroke is a risk factor for post-stroke dementia (Saposnik et al., 2011). Other studies have shown that in addition to stroke, other cardiovascular risk factors such as hypertension and atrial fibrillation are among the most common comorbid conditions in PWD that increase the risk for the development and progression of cognitive impairment (Bauer, Schwarzkopf, Graessel, & Holle, 2014; de Brujin et al., 2015; Poblador-Plou et al., 2014; Saposnik et al., 2011). Cognitive decline is also especially accelerated in older persons with pre-existing diabetes, likely due to difficulties with managing blood sugar levels and the subsequent effect on cerebrovascular health (Bunn et al., 2014; Poblador-Plou et al., 2014). Ultimately, this population represents a highly vulnerable subset of the older population given the complex and potentially synergistic association between dementia, MCC and other complex geriatric conditions.

The multiplicity of health conditions interacts in complex ways that affect how a person manages their daily tasks, activities and personal health. The presence of dementia and MCC undermines a person’s ability to engage in self-management behaviours and health maintenance activities (Bunn et al., 2014; CIHI, 2011b; Schubert et al., 2006). For
instance, over one fifth of older people with diabetes also have cognitive impairment, which may affect their ability to understand their condition, manage medications and monitor their blood glucose (Hewitt et al., 2010). Cognitive impairment can also affect a person's ability to identify symptoms and describe changes in their health. PWD may struggle with medication adherence and may not be able to accurately and adequately report symptoms related to body systems and conditions, such as pain (Doraiswamy et al., 2002). Treatment therefore may be delayed or inadequate, resulting in poor quality of life and an increased risk of morbidity and mortality (Bunn et al., 2016; Sanderson et al., 2002). The presence of dementia within the context of MCC means that PWD are less likely to receive the same quality of care or access to services compared to those without dementia (Bunn et al., 2014).

Cognitive impairment and MCC make it difficult for PWD to manage their own personal care, leading to greater dependency on their family caregivers to assist with self-management activities, to remain independent and active, and to stay connected to their communities (Eales et al., 2015). Caregivers themselves struggle with assisting the PWD; the behavioural and psychological symptoms of dementia can disrupt the caregivers' efforts in caring for and managing their coexisting health conditions (Bunn et al., 2014). Research suggests that as the number of chronic conditions increases in the older adult, so does the level of caregiver strain, thus contributing to negative health outcomes and greater health service utilization in caregivers (Schulz & Beach, 1999). Despite the fact that caregivers are an important part of the older adults' social networks of support, there
is very limited qualitative literature that looks at caregivers' experiences of caring for someone who has multimorbidity, especially within the context of dementia.

**Literature Search**

The focus of this literature search was to examine studies on caregivers' transition experiences with caring for an older person with dementia and MCC. Any literature that looked at patient transitions between care sectors and organizations were not included as the focus of this study was to examine transitions experienced at a personal level of the caregiver.

The following databases were searched: PubMed (from 1980 to July 2016), MEDLINE (from 1980 to July 2016), Cumulative Index to Nursing and Allied Health Literature [CINAHL] (from 1982 to July 2016), AgeLine (from 1983 to July 2016), PsycInfo (1990 to July 2016), and grey literature search using Google® Scholar (from 2000 to July 2016). Grey literature was explored to see if there were any government, technical or organization reports published on the topic.

In addition to the electronic databases mentioned, I also searched the website of the *International Research Community on Multimorbidity (IRCMo)* to identify any recently updated relevant studies (IRCMo, 2016). The IRCMo is funded by the Canadian Institutes of Health Research (CIHR) Applied Research Chair in Health Services and Policy Research on Chronic Diseases in Primary Care and provides regular updates to their library with recent evidence-based research on multimorbidity from around the world.
Key search terms or combinations thereof included: *dementia, Alzheimer's, multimorbidity, co-morbidity, multiple chronic conditions, caregiver, caregiving* and *transitions*. Unpublished manuscripts, editorials, and dissertations were excluded from the review. Each database was searched for English-language articles. Citations from key studies were analyzed and reviewed. Further, citations from key studies were also analyzed and critically appraised using evidence-based tools and checklists that are described at the beginning of each section.

**Findings from the Literature Search**

The literature search revealed two different categories of studies. The first category of studies refers to the qualitative experience of caring for an older person with MCC, not specific to dementia. The second category of studies was specific to caregivers' experience of caring for an older person who had dementia and MCC.

Each of these groups of studies was analyzed for their strengths and limitations using Forchuk & Roberts (1993) and Letts et al. (2007) criteria for evaluating qualitative studies. I used the following criteria to examine the qualitative research: (a) clearly stated and suitable purpose or research question, (b) relevant background and literature review, (c) congruent and appropriate methodology, (d) accurate, clear and complete description of data collection and analysis, (e) appropriate strategies for establishing procedural and analytical rigour, and (f) relevant findings (Forchuk & Roberts, 1993; Letts et al., 2007). See Appendix A for an overview of the studies.
Qualitative Experiences in Caring for a Person with MCC

I located two qualitative studies (one of which is represented by two papers) that explore in greater depth family caregivers' experience of caring for persons with MCC (Gill et al., 2014; Kuluski et al., 2013; Williams et al., 2016). Both studies were conducted in Canada, however they were varied in regards to research objectives. One study (published in two papers) which involved interviews that included informal caregivers, persons with MCC, and HCP explored the alignment of care goals as well as health systems issues from multiple perspectives (Gill et al., 2014; Kuluski et al., 2013). The second study focused on experiences from the perspective of informal caregivers only (Williams et al., 2016).

Kuluski et al. (2013) conducted a qualitative descriptive study exploring goals of care between 28 patient-caregiver-family physician triads, with a focus on goal alignment between the three groups. Caregivers' goals fell into one of six categories. The first two were to maintain the patient's current level of health as well as their symptoms in order to allow patients to engage in usual activities. Some caregivers described establishing goals for the future by getting care supports in place. However, they expressed frustrations as they struggled with patients who were resistant to accepting help from outside services. Further, despite recognizing that detrimental effects of stress to their role as a caregiver, caregivers often took it upon themselves to do tasks for the patient, in part to promote their safety.

There was moderate alignment in the goals of care expressed by caregivers, patients and HCPs, particularly around symptom alleviation and maintaining health status.
(Kuluski et al., 2013). Caregivers tended to focus on the need to create an environment that would foster patient independence. In one case with a patient with dementia and MCC, there was a lack of goal alignment in this regard. While the patient and caregiver focused on securing the patient's ability to age at home, physicians were concerned about long-term care planning due to the severity of the situation. The study suggests that goal divergence occurs when patients are less medically stable due to different roles and responsibilities of each player. Ultimately, goal setting is an important endeavour in supporting individuals with MCC and their caregivers in managing MCC.

A second paper of the same study by Gill et al. (2014) explored the care challenges related to broad health care system issues, experienced by older patients with MCC, their informal caregivers, and family physicians. Participants expressed both system and patient-level frustrations. On a systems level, caregivers and patients identified frustrations with the lack of efficient and timely information as well as a lack of care coordination. Both caregivers and patients felt there was poor communication from and between care providers. This made it difficult for caregivers and patients when making challenging decisions regarding their care. Similar to Kuluski et al.'s (2013) study, caregivers in this study expressed frustrations with the patient's attitudes and behaviours towards plans of care. They often felt they had little control over the patient's non-compliance to treatment plans, which complicated goal planning. Family physicians shared similar frustrations to those of caregivers and patients. The study found that the complexity of the patient's diseases often made it difficult for caregivers to assist in managing multimorbidity. Patients, caregivers and providers shared similar frustrations
on different levels, and had competing demands in self-management practices. They required support, better access to and more resources in the community to help navigate health system barriers.

The study employed a qualitative descriptive approach and authors were explicit in their research questions and objectives for the study (Gill et al., 2014; Kuluski et al., 2013). Purposeful sampling was congruent with the study purpose and both papers provided transparent and detailed explanations of their sampling strategies. Further, the papers provided some explanation on how they monitored methodological rigor. Gill et al. (2014) published a detailed protocol and audit trail of their decisions and utilized triangulation to strengthen confirmability of the results. Both papers provide adequate description of the demographics of the caregivers and the patients, including the number of chronic conditions in the patients. They could have benefited from reporting the type of chronic conditions that the patient's had in order to provide greater context to the findings. Other limitations include the fact that study participants were predominantly Caucasian and English-speaking. Participants were sampled from single family practices in an affluent urban city. Most caregivers were female spousal caregivers and therefore may not have captured the perspectives of the current changing demographics of caregivers (e.g., adult children caregivers and male spousal caregivers). These factors limit the transferability of the findings to similar individuals and settings.

The second study explored the influence of social location on caregivers of older adults with MCC (Williams et al., 2016). It is important to note that despite the fact that Williams et al. (2016) focused on caregivers of persons with overall MCC, a large
The proportion of their sample were caring for PWD and MCC. The caregivers (n=40) from Ontario and Alberta were caring for a person with a median of seven chronic conditions, with the greatest number of care recipients having dementia, diabetes and stroke. Interestingly, caregivers of PWD and MCC in the study found caregiving more arduous than caring for persons with other conditions. Cognitive impairment, lack of ability to comprehend the situation, and personality changes associated with dementia/Alzheimer's complicated the caregiving experience.

Williams et al. (2016) identified four main themes. The first theme suggested that the caregiving journey was made up of three stages, starting from when the caregiver takes on the caregiver role to showing and gaining confidence in their role. The second theme addressed the impact of caregiving on participants' work (difficulty integrating and balancing paid and unpaid work), family (conflict between family members, and changes in spousal physical/sexual intimacy), and health (deterioration in caregiver health due to increased demands of MCC). The third theme highlighted the importance of personal and structural determinants as they affect caregiving; these included gender and cultural influences as well as attitudes and beliefs towards caregiving. The last theme described caregivers finding meaning and self within caregiving. The study not only highlights common challenges of caring for someone with MCC during three phases of the caregiving trajectory, but also brings light to the importance of considering social location in the caregiving experience.

The study provides an extensive and relevant literature review and background to support their research question (Williams et al., 2016). Further, rich descriptions of the
context and participants were provided which helps readers to ascertain applicability to their own settings. The study provides transparency in their analytic process by describing and providing a figure to illustrate how their analysis evolved over three stages. The study has a few limitations. Firstly, the sample was taken from an existing quantitative study. This may have limited the researchers in purposively recruiting additional participants to inform the findings and to achieve maximal variation in the sample. As with Gill et al. (2014) and Kuluski et al. (2013), the majority of participants were Caucasian and lived in urban areas. This affects the transferability of the results to other contexts as caregivers of different ethnic and social backgrounds may experience different challenges in regards to culture, inequities and social justice (Williams et al., 2016). As well, the study focused on the overall experiences of the participants, with a focus on social location, and not on their experience of transitions.

**Qualitative Experiences in Caring for a PWD and MCC**

Six studies explored the qualitative experience of caregivers of persons with PWD and MCC (Bunn et al., 2015; Bunn et al., 2016; Feil, Lukman, Simon, Wlaston, & Vickrey, 2011; Lawrence, Murray, Ffytche, & Banerjee, 2009; Sanders, 2007; Sanders & Power, 2009). The first is a scoping literature review looking at a wide variety of studies, including qualitative studies, on co-morbidity and dementia (Bunn et al., 2014). The next article is a large mixed methods study by Bunn et al. (2016) that took place in the United Kingdom. Two other studies looked at rural male caregivers of older adults with dementia and MCC (Sanders, 2007; Sanders & Power, 2009). The last two articles focused on caregivers of PWD and one other co-morbid condition [diabetes and visual impairment]
(Feil et al., 2011; Lawrence et al., 2009). Similar to the previous section, qualitative studies were analyzed for their strengths and limitations using Forchuk and Roberts (1993) and Letts et al. (2007) criteria for evaluating qualitative studies. For the scoping literature review, I used Hutchison's (1993) criteria for evaluating literature reviews. For the quantitative portion of the mixed methods review, I used the appropriate Critical Appraisal Skills Programme [CASP] checklists (2014). Please see Appendix B for an overview of the studies.

The scoping literature review by Bunn et al. (2014) sought to explore the extent and range of research around dementia and co-morbidity. The authors looked at a wide range of studies, from prevalence to patient and carer experiences. The review included 74 papers grouped into four categories: (a) prevalence, (b) quality of care, (c) views and experiences, and (d) health service organization and delivery. The prevalence rates of diabetes, stroke and visual impairment (VI) were previously reported. In regards to quality of care, the studies included in the review reinforced that PWD were less likely to receive the same quality of care or access to services compared to those without dementia. While reviewing clinical guidelines, the authors found that most guidelines failed to take into account multimorbidity or the needs of PWD. Further, the review included 11 studies focused on the views and experiences of PWD, their caregivers, and HCP. Most studies were focused on the PWD and MCC and their challenges with care coordination and systems navigation. Only one study included in the review looked at caregivers' perspectives and found that they felt that they received inadequate support in
planning for and managing the PWD and MCC’s care (Feil et al., 2011). This study will be analysed further in the next few pages.

The aim of the review (Bunn et al., 2014) was very broad, although appropriate in this case for two reasons. First, little research has been done on the topic of PWD and MCC and thus a broad question facilitated the exploration of a variety of studies. Secondly, it was consistent with scoping review methodology, which seeks to summarize a wide range of evidence in order to convey the breadth and depth of a field (Levac, Colquhoun, & O’Brien, 2010). The strengths of the study include a very detailed explanation of their search strategy. Because scoping studies are used in areas of emerging evidence and to inform the decision to undergo a systematic review, it is not customary to assess the quality of included studies. The limitation of this is that the quality, rigour, and effectiveness of the included studies were not ascertained. Further, high heterogeneity between studies makes it difficult to make accurate comparisons across studies.

The second study in this category is a mixed methods review by Bunn et al. (2016). The study consisted on three phases. Phase I aimed to update the scoping literature review conducted by Bunn et al., (2014). The team conducted a cross-sectional analysis of a population cohort database in phase II and conducted interviews/focus groups with PWD and MCC, family caregivers and HCP in phase III. The scoping review in phase I included an additional 12 articles to the original 74 in the earlier scoping review. Findings were consistent with the earlier scoping review. In phase II, the researchers analyzed data from two longitudinal multicentre population-based studies in
the United Kingdom. Their analysis revealed prevalence statistics that I have previously reported. When comparing PWD and MCC versus PWD alone, they found that the former had increased inpatient hospital service use, as well as increased service use related to home care assistance, day centres, chiropody and care workers. Nursing services were more frequently used among PWD and diabetes or VI. Further, the use of unpaid care (e.g., informal help from family and friends) was higher for PWD and diabetes, stroke and/or VI, with eight out of 10 people reporting daily informal help.

The third phase of the Bunn et al. (2016) study was to conduct interviews and focus groups with PWD and MCC (n=28), family caregivers (n=33) and HCP (n=56). Two overarching themes found in the study were: 1) negotiating continuity of care, and 2) negotiating access to care. Within the overarching theme of negotiating continuity of care, PWD and MCC and family caregivers valued relationship continuity with their HCP. Caregivers were seen to be key players in care coordination of the PWD and MCC. The authors also described management continuity in relation to self-management activities. Caregivers supported PWD and MCC in managing their co-morbidities but eventually, the PWD would transition to dependency. Lastly, caregivers identified poor information transfer between multiple specialists, thus interfering with information continuity. Within the overarching theme of negotiating access to care, HCPs identified challenges with health-care systems and environments (e.g., clinical guidelines not applicable to dementia). The next challenge was related to comprehensiveness and equity of health care. Findings in this section overlap with the frustrations expressed by caregivers in the Gill et al. (2014) study, where caregivers struggle with decision-making, particularly
when confronted with ethical situations where they need to balance the risks and benefits of high risk procedures.

The study by Bunn et al. (2016) has a number of strengths and limitations. Phase I of the study is limited by the scoping review methodology as described for Bunn et al. (2014). In phase II of the secondary analysis, the authors worked with two large databases that drew random samples from primary care and institutions across the UK; thus, it is representative of the general population. One drawback with secondary analyses is that the authors have no control over how the original data were collected. They must rely on and work within the constraints of the primary data which may have methodological flaws, thus affecting the validity of the findings. Lastly, the qualitative portion of the study has many strengths, particularly in the large sample size which includes a diverse range of participants. The context and demographics of participants are described in sufficient detail. However, strategies to ensure rigor were not discussed. One major limitation of the entire study is that the authors focused solely on three tracer conditions, specifically diabetes, stroke and vision impairment. The findings may not be applicable to other PWD with other chronic conditions aside from the ones specified in this study.

The next two studies conducted by Sanders (2007) and Sanders & Power (2009) in the United States focused on rural male caregivers of older adults with dementia and MCC. Both studies utilized phenomenological methodology. Sanders (2007) explored the experiences of 20 male caregivers with their informal support networks. The results indicate that the majority of male caregivers were providing care in isolation in that their children, extended family and friends had expressed unwillingness to provide assistance
to the PWD. Some caregivers felt their children were detached from the situation or were available only in case of an emergency. Caregivers also perceived informal support networks as crucial to assisting with caregiving decisions and offering respite care. Results revealed caregivers’ willingness to ask for assistance with caregiving responsibilities. While some caregivers were receptive, grateful for, and actively sought assistance from informal network supports, others felt guilty and did not ask for help at all. The study demonstrates the unique relationship that male caregivers experience with their support networks.

Sanders and Power (2009) undertook a study to look at the changes in the roles, responsibilities, and relationships that husbands experience as they provide care for their wives with memory loss and other MCC. The participants (n=17) were sampled from Sanders' (2007) study described above. Researchers found that caregivers adapted old roles within the marital system to their new caregiving roles and responsibilities. They describe taking pride in protecting their wives and preserving their dignity and self-esteem as central to their new caregiving roles. Researchers also found that the onset and progression of memory loss and other chronic conditions stimulated changes within the relationship between the caregiver and recipient. Husbands described finding new forms of intimacy and closeness with their spouses. They learned to deal with personality changes in the PWD because of progression in their chronic illnesses. This forced caregivers to transform by developing new ways of coping with their new relationships, and also with the finality of relationship.
Both studies provide insight into male caregivers' experiences in caring for a PWD and MCC, and how the progression of chronic illnesses affects their roles, relationships and interactions with informal support systems (Sanders, 2007; Sanders & Power, 2009). The authors stated clear research questions and provided extensive background and literature to support the need for research focused on male caregivers. Further, both studies were transparent in their data collection and analysis procedures, as well as provisions to ensure rigor. Sanders (2007) engaged in peer debriefing with experts in the field and maintained an audit trail via field notes. Sanders and Power (2009) enhanced the trustworthiness of their findings by verifying their data through two coders (researcher triangulation) and member checking with the participants. The studies do have some limitations. The authors did not document their philosophical orientation, although lack of documentation could be due in part to limited space in research publications. Finally, the sample is limited to Caucasian husbands from a rural community, thus limiting transferability of the results to other ethnic and culture groups.

The final two articles in this category focused on the caregiving experiences of caregivers of PWD and one other co-morbid condition (Feil et al., 2011; Lawrence et al., 2009). Feil et al., (2011) explored caregivers' (n=21) challenges and quality of life issues in managing diabetes in PWD. The study was conducted in the United States. Findings show that caregivers started to assist with diabetes management when memory started to decline. At the same time, they found that they also had to monitor all the other medications the patient was on for other conditions. Responsive behaviours also affected diabetes caregiving. Physical and verbal aggression as well as the denial of diabetes or
dementia complicated caregivers’ ability to manage diabetes. Finally, caregivers expressed a lack of support and guidance from HCP on diabetes management, particularly around diabetes adjustments based on sugar readings and diabetes education.

The final study in this category is by Lawrence et al., (2009) who investigated the experiences and needs of older adults with vision impairment from the perspective of patients (n=17), their family caregivers (n=17), and HCP (n=18). Results showed that caregivers were concerned about the safety of the PWD who could no longer manage everyday tasks due to poor memory and sight. As the PWD’s sight deteriorated, they became increasingly disoriented. Some experienced visual hallucinations resulting in distress. Family caregivers took on the role of reorienting patients, which in some cases was highly stressful. Poor memory and sight loss also resulted in loneliness and isolation for patients, thus increasing their emotional dependency on family caregivers.

Unlike other studies, the caregivers in Feil et al.’s study (2011) represented diverse ethnicities, with only 1 out of 21 caregivers being Caucasian (the majority were African American). There is an adequate description of data collection processes, however the processes and steps taken during data analysis are unclear. Further, there is a lack of congruency in the description of methods. The authors refer to the study as a "qualitative study using focus groups". However, they later state in the analysis section that they used grounded theory methodology, despite the fact that the research question is not congruent or appropriate for grounded theory. Lawrence et al. (2009) provided greater clarity in their data collection and analysis procedures. They maintained rigor by convening an
advisory panel of national user/caregiver groups and leading academics to help confirm emerging findings.

**Summary of Qualitative Research on Caring for a PWD and MCC**

As evident in a number of studies reviewed, caregivers of older adults with MCC were often primary organizers and "doers" of care. They often helped the care recipient navigate and coordinate their care. As such, many caregivers ended up bearing the burden of the recipient's care, which involved complex fluctuating and interacting symptoms as well as declining health in the patient (Kuluski et al., 2013). The studies highlight the added stress and burden that dementia brings to the management of MCC.

There are still significant gaps in the literature, particularly around transition experiences. Williams et al. (2016) suggested that caregivers of persons with MCC experienced various phases of transitions in their caregiving trajectory that corresponded with their role as a caregiver. Other studies alluded to the fact that caregivers with dementia and MCC are faced with transitions in their relationships and roles, particularly in the area of taking on self-management activities for the PWD (Bunn et al., 2016; Lawrence et al., 2009; Sanders 2007; Sanders et al., 2009). It is important to have a more in-depth understanding of these transition experiences of caregivers while taking into consideration both dementia and MCC.

**Overview of Transitions**

The second part of the literature review search was focused on studies that examined transition experiences of caregivers of PWD and MCC. While the search did not reveal any studies that captured both dementia and MCC, there have been studies that
have focused on different transitions experienced by caregivers with a focus on dementia only. Most of the studies on transitions have been around transitions between care sectors and organizations (e.g., from acute care to the community, or from the community into long-term care. The purpose of the section that follows is to provide a brief summary of Meleis' Transition Theory and an overview of the different transitions experienced by dementia caregivers as described in the literature.

**Meleis' Transition Theory**

The concept of transitions is important to nursing practice and universal across all human experiences. A transition is defined as, "a passage from one fairly stable state to another fairly stable state, and it is a process triggered by a change" (Meleis, 2010, p. 11). Transitions encompass a time when a person undergoes stressful responses to predictable and unpredictable changes. Although there are multiple theories of transitions in the literature from various origins, Afaf Meleis' Transition Theory is grounded in the discipline of nursing and originated from the theory of role supplementation. It has been used widely and extensively, not only in the area of nursing transitions, but also in the area of parenting role transitions and new immigrant transitions. Transitions as a nursing concept was developed in 1994 (Schumacher & Meleis, 1994) and serves as the foundation for the expansion of transitions as a midrange theory (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). The theory focuses on the changes experienced by human beings in their lives, health, relationships and environments (Meleis et al., 2000). Meleis states that transitions are central to the discipline of nursing as nurses provide a significant amount of attention and care to individuals, families and communities.
experiencing changes in their lives. Therefore, a key hallmark of the theory is to focus on the role of nurses in preparing and supporting clients undergoing transitions. There are four main concepts in the theory: the nature of transitions, transition conditions, patterns of response, and nursing therapeutics (Meleis et al., 2000).

The nature of transitions refers to the characteristics that make up a transition experience. These include types of transitions (e.g., situational transitions), patterns (including single, multiple or simultaneous transitions) and properties (which includes awareness, change and difference, and critical points and events). Transition conditions refer to several factors that can either facilitate or inhibit a healthy transition, such as socioeconomic status and societal factors. The patterns of response represent indicators of healthy transitions. They are conceptualized as process indicators (such as feeling connected and developing confidence and coping) and outcome indicators (which include mastery of skills and fluid integrative identities).

Transitions Experienced by Dementia Caregivers

Family caregivers of PWD experience multiple concurrent transitions throughout the dementia caregiving trajectory. According to Transition Theory (Meleis, 2010), transitions are triggered by periods of change in which a new situation is incorporated into one's life; they can be complex, multidimensional, and fluid. Although transitions can be positive in nature, many are disruptive and unpredictable, often resulting in uncertainty and distress. Many factors influence the nature of transitions experienced by dementia caregivers. Change and difference are at the core of transition experiences, and can affect relationships and routines, ideas, perceptions and identities (Meleis, 2010).
In particular, dementia is marked by several critical events that influence both the caregiver and the PWD. These include diagnosis, disease stage transitions, the need for formal care at home, placement in an institution, and death and bereavement (Gaugler, Roth, Haley & Mittelman, 2011; Lethin, Hallberg, Karlsson, & Janlov, 2015; Montgomery & Kosloski, 2000). The level of engagement in the PWD's care and the time span in which care is provided also affects how caregivers cope with changes to their daily lives (Adams, 2006; Meleis, 2010). Further, the availability of formal and informal social and community supports and services are important factors in helping caregivers manage care.

Most notably, family caregivers of PWD encounter various changes as they transition into the caregiver role. Caregivers often notice behavioural changes as the first symptoms of dementia as opposed to cognitive or functional changes (de Vugt & Verhey, 2013). On average, it can take approximately 1-2 years from the time a caregiver notices the first symptoms of cognitive impairment before they reach out to family members, friends and/or HCP for advice (Chisp et al., 2011). During this period and following diagnosis, caregivers gradually undergo and adapt to multiple transitions, including the transition to the social status as a caregiver and other shifts in their familial roles (Bunn et al., 2012; Gaugler et al., 2011). Caregivers experience conflict and isolation from family members and friends starting from diagnostic disclosure (Quinn, Clare, Pearce, & van Dijkhuizen, 2008). Early changes related to the transition into the caregiver role also have a significant effect on most caregivers who may feel negative emotions related to their lack of confidence in their new role; they experience feelings of frustration, fear, anger
and denial (Adams, 2006). The fear of stigma as a caregiver of a PWD can inhibit caregivers from seeking professional help in a timely manner. As such, the transition into the caregiver role can lead to an increase in depressive symptoms and psychological stress, as well as decreased self-care behaviours (Robinson et al., 2011; Schulz & Sherwood, 2008).

Family caregivers adjust to the onset of dementia and the early stages of caregiving by taking on many new responsibilities that include decision-making, dealing with daily practicalities, and supervision (Adams, 2006; Robinson et al., 2011). They adapt to new roles and become "emotional cheerleaders" where they need to come to terms with the everchanging dynamics of their roles and relationships with the PWD (Adams, 2006; Robinson et al., 2011; Schumacher, 1995). The transition in having to define and redefine one's self and identity is often a difficult one for both spouses and children caregivers where some only come to accept these after some time (Donorffio & Kellett, 2006; Sanders & Power, 2009).

The majority of literature on dementia caregivers and transitions focuses on the transition between care sectors. The caregiving journey may involve the PWD transitioning between various care sectors before permanent institutionalization. This in itself has been associated with an increased risk of medical errors, inefficiency, and poor quality of care and coordination (Coleman, 2003). Many studies have looked at the caregivers' experience of having their loved one transition into a long-term care facility. The decision to admit their relative to a long-term care home can result in negative emotions and feelings of grief and guilt (Bramble, Moyle, & McAllister, 2009; Sury,
Burns, & Brodaty, 2013). While many caregivers experience an initial relief after institutionalization (Gaugler et al., 2007; Sury et al., 2013), the majority continue to exhibit the same levels of psychiatric morbidity, emotional distress and negative physical and mental health post-institutionalization (Gaugler et al., 2011; Schulz & Sherwood, 2008). Regardless of the transition, it is clear that the disruption in the flow of their daily routines and relationships have a significant influence on quality of life (Bond, Clark, & Davies, 2003; Duggleby, Swindle, Peacock & Ghosh, 2011).

Duggleby et al. (2011) looked at the relationship between demographic variables, hope, quality of life and transitions of family caregivers of PWD. Participants identified various ways in which they dealt with changes, including taking things one day at a time, actively seeking knowledge and assistance, connecting with family and friends, relying on one-self, and through negative emotions. Caregivers who had higher hope scores and dealt with transitions by actively seeking out knowledge and assistance had the highest overall quality of life. The authors concluded that there is a need for ongoing support and services as informal caregivers transition through various phases in dementia care. The study suggests that such supports can be helpful for this population.

It is crucial to support these caregivers as PWD have a greater risk of institutionalization when caregivers have poor physical health, low satisfaction with social and community support, symptoms of depression, and high levels of caregiver burden (Mittleman, Haley, Clay, & Roth, 2006). By supporting the health and well-being of caregivers, we are therefore better able to prevent early institutionalization, promote aging at home, and enhance the health and quality of life of the PWD.
Conclusion

There are multiple gaps in the current literature in relation to our understanding of the transition experiences of family caregivers of PWD and MCC. The current literature on PWD and MCC focuses on the prevalence of co-morbidities in PWD and issues that they encounter with quality of care and coordination of care. The majority of available studies have focused on single co-morbidities with dementia, or on the coexistence of a small number of common diseases (such as cardiovascular diseases and diabetes) rather than the broad range of chronic morbidity affecting the older person. The experiences and supports needed by these caregivers may differ from those with more complex needs.

Qualitative literature highlighting the experiences of these caregivers is sparse. It is important to capture the voices of these caregivers and to develop a comprehensive understanding of their transition experiences as evidence shows that PWD and MCC do not have the same access to treatment, monitoring and services as those with similar co-morbidities but without dementia (Bunn et al., 2016). The different chronic conditions must be considered as interacting and influencing one another as opposed to independent disease processes. By understanding the transitions that these caregivers experience, policy and practice recommendations can be made regarding access and availability of services to support these caregivers and their care receivers.
Chapter 3: METHODOLOGY

Chapter 3 addresses the research methods used in this study. This chapter begins with an explanation of the rationale for a qualitative research design, as well as an overview of the research purpose and question, including specific sub-questions related to transition experiences. Following this, the principles of interpretive description are described as they relate to recruitment, sampling, data collection and data analysis (Thorne, 2008). The chapter concludes with strategies used to ensure trustworthiness.

Rationale for Qualitative Research Design

A qualitative approach is suitable to facilitate the exploration and development of complex, holistic and detailed understanding of human or social phenomenon, specifically from the perspective of individuals who have experienced the phenomenon (Creswell, 2013; Miles & Huberman, 2002). A qualitative approach is therefore the favoured methodology for my thesis, which aims to describe the transition experiences of caregivers of PWD and MCC who provide care and support on a daily basis.

Research Purpose and Questions

The purpose of this interpretive description study was to develop an understanding of the transition experiences of family caregivers of PWD within the context of MCC, from the perspective of informal family caregivers themselves, as well as clinicians who were working with such family caregivers. The main research question for this study was:

1. What are the transition experiences of family caregivers in providing care to PWD and MCC?
Within this research question, several sub-questions were developed in order to provide a better understanding of the processes of transition experiences. They were:

1. What are the transitions that occur for family caregivers of PWD and MCC?
2. What key factors influence these transitions?
3. What are the perceived outcomes related to the transitions?
4. What is the influence of MCC on dementia caregiving?

**Interpretive Description Methodology**

The current study used Sally Thorne's interpretive description (ID) methodology to explore the transition experiences of family caregivers of PWD in Ontario, Canada. ID is an inductive method that seeks to provide a thematic or integrative description of a phenomenon (Thorne, 2016). The researcher explores themes, elements, patterns and relationships of a common issue while honouring their inherent complexity based on each individual's experience (Thorne, 2016). The approach is suitable for advancing knowledge and documenting subjective elements that have not been previously or adequately reported (Thorne, 2016).

Nursing scholars originally developed ID as an alternative method of generating applied nursing knowledge and facilitating a better understanding of human health and illness experiences (Hunt, 2009; Thorne, Kirkham & MacDonald-Emes, 1997). Nurses and other health care providers need to combine and identify knowledge about patterns and themes within people to better inform the care of each unique individual and the larger population. Thorne (2016) argues that this nursing knowledge evolves in dialectic through complex interplay between objective and subjective data, formal evidence, shared clinical wisdom, and practical experiences. Therefore, ID is uniquely grounded in the applied clinical context as it seeks to answer questions arising from complex clinical
issues that aim to yield practical applications (Hunt, 2009; Thorne et al., 1997; Thorne, 2016).

ID is therefore the most appropriate qualitative methodology for this study based on two key facets guiding its purpose: (a) a practice goal, and (b) an understanding of what we do and do not know on the basis of empirical evidence (Thorne, 2016). The practice goal for this study is to provide insight and understanding into the relationships and patterns associated with dementia caregiving within the context of MCC and transitions in order to provide knowledge not only for nurses, but also for other clinicians and researchers. My hope is that clinicians will be able to tailor their approaches to care based on a better understanding of caregivers' experiences. The study will therefore help to generate practical recommendations for care management (including treatment of dementia and MCC) and service delivery from a systems-level for clinicians working in the field as well as caregivers. The development of the overall research purpose was informed by a number of sources including: (a) a review of available empirical evidence of the experience of dementia caregiving, (b) discussions with team members and colleagues with experience in working with the population (through research and direct practice), and (c) my personal experience as a nurse in working with and supporting caregivers and PWD in various health care settings.

Context (MyTools4Care)

The current study is a sub-study of a larger multi-site pragmatic mixed methods randomized control trial examining the effectiveness of a self-administered online toolkit called MyTools4Care (MT4C) for family caregivers of PWD and MCC. MT4C was
developed based on the original Transition Toolkit that was in a paper format. The development, content and feasibility of the toolkit are described in an earlier study (Duggleby et al., 2014). Duggleby et al. (2014) found that in addition to being easy to use, feasible and acceptable, the Transition Toolkit had strong potential to help family caregivers of PWD deal with transitions. The toolkit was developed based on Meleis' Transition Theory, which helps to explain the nature and conditions of caregiver transitions, as well as the development of interventions to support persons undergoing transitions (Meleis et al., 2010). Participants in the study recommended that the toolkit be revised into an online format to increase accessibility to multiple caregivers. As such, MT4C was developed and includes interactive activities to help caregivers with transitions. The purpose of the MT4C trial is to support caregivers through transitions using an Internet toolkit that is hypothesized to increase self-efficacy, hope, and improve quality of life at no additional cost from a societal perspective.

**Setting**

The current ID study was conducted in Ontario, Canada. Participants were identified as living in rural or urban Ontario through self-identification at the beginning of each interview. Interviews took place at a location most convenient for the caregivers and clinicians to minimize disruptions to work and appointments. Among caregivers, most interviews were conducted in their homes. In some cases, caregivers were not comfortable with conducting the interview in their homes due to privacy concerns, as the PWD was often also present. In these cases, the researcher met with caregivers at local
coffee shops closest to the caregivers' home. All interviews with clinicians took place at their workplace in their offices during their breaks or after office hours.

**Sampling Procedures**

Thorne (2016) suggests that both purposive and theoretical sampling be used in ID studies. Purposive sampling is used to identify participants who share the same experience of the phenomenon of study and is used to facilitate in-depth contextual study of these participants (Creswell, 2013; Thorne, 2016). A purposeful sample of caregivers from the MT4C study and clinicians who work with caregivers of PWD on a daily basis were invited to participate. Theoretical sampling helps to build a sampling strategy from evolving theoretical variations derived from the data as the study is being conducted (Thorne, 2016). Thorne (1997) states that a participant's experience cannot be known until data collection is underway. By actively sampling participants throughout data collection and analysis, the researcher is able to develop more complex interpretations of patterns. Thus, as patterns and themes emerged from the initial phases of data collection and analysis with the first 8-10 participants, I sought out additional participants (specifically male caregivers, working caregivers, and caregiver relationships other than spouses), in order to achieve maximum variation in the findings and to provide a better understanding of the emerging themes.

Studies utilizing the ID approach have had sample sizes ranging anywhere from 12 participants (Thorne, Con, McGuinness, McPherson, & Harris, 2004) to 200 participants (Thorne et al., 2005). Although ID can be conducted on samples of any size (Thorne, 2016), it is important to consider the complexity of the issues of concern.
Thorne (2016) suggests that if a phenomenon is common and what is needed is a more in-depth exploration of the underlying subjective experience, then a smaller number of individuals (between 5-30 participants) may be sufficient. As previously stated, transitions among family caregivers of PWD and MCC are not uncommon, however a better understanding of the factors influencing these transitions, particularly MCC, is needed. As such, the estimated sample size for this study was 20-25 caregivers and 4-5 clinicians. An active effort was made to achieve maximum variation; the goal being to gain greater insights into a phenomenon by looking at it from all angles (Patton, 2015). I aimed for a heterogeneous sample representative of caregivers with variations in length of time of caregiving, gender, age, and relationship to the care recipient. Similarly, the goal was to have maximal variation sampling among the clinicians, with varying years of experience and supporting caregivers in different ways (e.g., providing health-related support as well as emotional and social support).

Data Collection Procedures

Participant Recruitment

Recruitment of caregivers and clinicians took place between October 5, 2015 and January 25, 2016. Family caregivers of PWD were recruited from the control group of the MT4C trial. The rationale for this was that participants in the control group were most representative of the normal population as they were receiving usual care in the community. The student investigator used the Study Referral sheet from the MT4C trial, which included the participant's name, phone number, email address, and preferred time
for contact. Only participants who provided verbal consent to be contacted for future studies were invited to participate in this study.

I contacted potential participants by telephone using a script to explain the study and answer questions. Participants who met the following criteria were eligible for the study: (a) an informal caregiver (18 years or older) of an older adult (65 years or older) with Alzheimer Disease/related dementias (ADRD) and two or more additional chronic conditions, (b) English-speaking, and (c) able to use and have access to a computer. For this study, an informal caregiver was defined as a family member or friend who was providing physical, emotional, or financial care to an older person with ADRD. Participants were excluded from the study if the PWD was designated as alternative level of care while in hospital or living in a long-term care home.

Clinicians who worked with family caregivers of PWD were recruited by telephone or email. Clinicians were eligible if they had or were currently providing some sort of physical, mental, emotional or psychological support to family caregivers of PWD and MCC living in the community. I consulted key informants from the Alzheimer Society of Hamilton, Halton, Brant and Haldimand Norfolk and members of the supervisory committee to identify clinicians with experience in working with this population. Supervisory committee members made introductions between myself and potential clinician participants by email.

Among those who agreed to participate, a copy of the consent form as well as the interview guide and demographic form were emailed prior to meeting in-person.
Participants were encouraged to look over the interview guide and to prepare for the interview by jotting down their thoughts and experiences.

**Data Sources**

According to Thorne (2008), the "more probable truths" must arrive from multiple angles of vision (p. 78), meaning that it is important to explore the perceptions and experiences from a variety of sources, not just from those who have directly lived through the experience, to facilitate a more confident and comprehensive interpretation of the phenomenon. Thus, ID emphasizes the importance of having a range of data sources in order to get as close to the subjective experience as possible (Thorne, 2008, 2016; Thorne, Kirkham, & O'Flynn-Magee, 2004). Multiple data sources also help to counterbalance the limitations of one data source. Two data collection sources were used in this study: interviews with family caregivers and interviews with collateral sources (clinicians). Individual interviews with family caregivers were useful for the development of knowledge and understanding of the different transitions they face. Thorne (2016) states that there is considerable value in utilizing collateral data sources to enlighten underlying beliefs, opinions and attitudes about the phenomenon. The "thoughtful clinician" is one whose perspectives have developed based on experiencing many cases over time. More importantly, the thoughtful clinician is in a unique position to augment one's data by identifying potential variations and diversities that account for clinical phenomena across time and context. Thus, their experiences can be triangulated against the primary source of interviews with caregivers to develop a more powerful and in-depth set of findings (Thorne, 2016). In this study, clinicians who provided support to
caregivers of PWD were targeted to augment the experiences that the interviewer was discovering from the interviews with caregivers.

**Face-to-Face Semi-Structured Interviews**

To gain a better understanding of transitions, semi-structured in-depth interviews were the primary source of data for this study. Face-to-face semi-structured interviews are the most widely used form of interviews in qualitative research (DiCicco-Bloom & Crabtree, 2006). Individual in-depth interviews allow for deep exploration into social and personal matters by exploring individual perceptions (DiCicco-Bloom & Crabtree, 2006). Semi-structured interviewing begins with pre-determined questions and probes with follow-up questions to elicit more information (DiCicco-Blood & Crabtree, 2006; Morse & Field, 1996). The face-to-face interviews were important for this population as they not only helped to develop rapport, but they also made it easier for the caregivers who were worried about leaving the PWD alone.

Interview questions for caregiver participants were initially developed in the summer of 2015 in collaboration with the supervisory committee members. The questions were developed and revised based on the original research objective and compared to the interview guide from the MT4C trial to ensure that there was no duplication and that the questions would provide a rich exploration of transitions with a focus on MCC. A copy of the final interview guide can be seen in Appendix C. Prior to the interview, participants were asked to complete a short demographic questionnaire which focused on key areas such as age, gender, employment status, relationship to PWD, number of years spent caregiving, as well as any medical conditions that the caregiver and the PWD had
The list of chronic conditions was taken from the MT4C trial, which was originally adapted from Barnett et al.’s (2012) list of chronic conditions.

Based on the caregiver interview guide, a similar guide for clinicians was developed with the intent of confirming and augmenting the responses from caregivers (Appendix D). The interview questions for clinicians were structured so that clinicians would be asked about the experience of transitions from the perspective of the caregiver, as opposed to their own personal experiences as a HCP. Similarly, participants were also asked to complete a short demographic questionnaire that focused on key areas such as age, gender, education, and current employment (Appendix F). After the first five interviews were completed, I began data analysis and started to compile initial patterns and themes. These were shared with subsequent participants; they were asked about their experiences and perceptions in relation to the existing patterns and themes.

**Field Notes and Recording**

I asked participants for permission to take notes during each interview. As such, field notes were maintained for all participants in the study. These field notes were important to document details regarding vocal intonations, physical expressions (including facial expressions), and gestures that were not necessarily audible on the recording to ensure accuracy. Lastly, all interviews were audio taped with the permission of the participant.

**Ethical considerations**

The basic premise of research ethics involving humans is to ensure protection for participants in the study. This study was considered non-invasive and minimal risk. The
ethical principles of *Respect for Persons, Concern for Welfare* and *Justice* according to the Tri-Council Policy Statement (TCPS) were exercised throughout this study (Canadian Institutes of Health Research [CIHI], Natural Sciences and Engineering Research Council of Canada [NSERC], and Social Sciences and Humanities Research Council of Canada [SSHRC], 2010).

**Respect for Persons**

A primary method of demonstrating *respect for persons* is through autonomy, that is, providing participants the opportunity to deliberate a decision and act based upon their deliberation (CIHI, NSERC, SSHRC, 2010). This study demonstrated autonomy by reiterating to participants that participation was voluntary and that there were no consequences to them or the PWD if they decided to withdraw at any point throughout the study. Details regarding the study and information about voluntary participation and how to withdraw were provided to potential participants to better inform their decision (Appendix G; Appendix H). Throughout the process of recruitment and data collection, all participants were given the opportunity to ask the researcher questions via telephone, email or in-person.

**Concern for Welfare**

The study demonstrated concern for welfare by outlining any potential risks to participants and strategies to mitigate them. In this study, there was a risk that participants would feel stressed or upset during the interview when speaking about their caregiving experiences. Caregivers were always given the option to refuse to answer questions and to stop taking part in the interview if they were uncomfortable. Caregivers were informed
that if they were to experience distress, with their permission, the student investigator would provide linkage to the local Alzheimer's Society to provide appropriate support and services. The potential risk for discomfort and inconvenience was also minimized by ensuring that the interview time, date and location were in the most convenient and comfortable environment for the participant. Participants were able to contact the student investigator at any time to cancel or reschedule an interview appointment.

Within concern for welfare, there is a potential risk for breach of privacy or confidentiality. Confidentiality was maintained by creating an anonymized protocol of all study materials and ensuring proper storage of data through encryption of electronic files and locked storage for paper files within McMaster University. Participants were informed that all interactions and information shared were confidential and would not be shared with anyone.

Justice

The final ethical principle of justice refers to the researcher's obligation to treat all people with fairness and equitability (CIHI, NSERC, SSHRC, 2010). Justice was maintained throughout the study by ensuring that participants for the study were not excluded arbitrarily during recruitment. All participants who had provided previous consent to be contacted for future related studies at the time were contacted and provided the same opportunity to be informed about and deliberate the decision to participate in the study.
Consent and Ethics Approval

Ethics approval was obtained from the Hamilton Integrated Research Ethics Board (HIREB #0418). At the time of the interview, I reiterated that participation was voluntary, confidentiality would be maintained, and participants could withdraw their involvement in the study at any time. Participants were given the opportunity to ask any questions during this period. They were then asked to sign a copy of the consent form and were given a signed copy for their records.

Data Analysis and Interpretation

The analysis and interpretation of results focused on themes pertinent to answering the stated research questions. All interview recordings were transcribed verbatim and checked for accuracy by the student investigator. Early data analysis consisted of data immersion through journaling and hand written notes, thus allowing for sense-making of the data as a whole (Thorne, 2008; Thorne et al., 1997; Thorne et al., 2004). Each interview recording was listened to twice. During transcription, early patterns were captured through highlighting and memos. Prior to coding, I read over each transcript twice and considered the data alongside my field notes. Initial thoughts were shared between my supervisor and myself prior to developing a coding structure. Data were later managed, uploaded and further analyzed using NVivo 10 software.

Data analysis employed an inductive approach where new explanations, concepts, and/or understandings were generated from a specific set of data (Patton, 2015; Thorne et al., 1997). ID is characterized by a constant comparative approach, where emerging data and interpretations are continuously compared and contrasted in order to determine
similarities and differences between and across all participants (Thorne, 2008, 2016; Thorne et al., 2004). In order to create meaningfully relevant and applicable knowledge to the clinical context, I maintained a balance between abstract and concrete analysis (Thorne et al., 1997). I immersed myself in the recordings and transcripts of each case to develop familiarity with each individual experience. Throughout analysis, the relationship between dementia caregiving and MCC was considered as inseparable entities that were crucial to the context of transitions.

To begin, my supervisor and I reviewed five transcripts together, sharing ideas about common pieces, patterns and potential themes. We then developed an initial coding scheme and definitions. As I continued to collect data, this coding scheme evolved and my supervisor and I had multiple discussions on renaming and moving codes. ID encourages intellectual inquiry as opposed to line-by-line transcript coding in order to pull overarching themes and ideas (Thorne et al., 2004). The researcher is encouraged to ask questions such as “What does this mean?” and “Why is this happening?” (Thorne et al., 2004, p. 13). Thus, during the coding process, codes were generated from both large and small sections consisting of simple sentences to long paragraphs in each transcript. These codes represented themes with which particular data were linked. This helped to preserve the context of the participants' experience and helped to maintain an overall macroscopic view of the data (Thorne, 1997; Thorne et al., 2004).

An initial coding structure of 14 codes constructed from 15 transcripts was shared with the supervisory committee for further analysis and comparison of pieces of emerging data in December 2015. Following two rounds of extensive discussions and collapsing of
themes with the committee, we agreed upon 10 overarching themes (two of which pertained to factors and outcomes related to transitions). With the committee's approval, I completed further data collection and analysis. As the data evolved, codes were further collapsed together and reorganized following the addition of transcripts. To assist with the conceptualization of themes, I began sketching and drawing diagrams to help myself understand the complex, overlapping relationships between the transitions, factors and outcomes. Participant's quotes and the image of transitions helped to guide my conceptualization. The outcome of this conceptualization was a water lily diagram, explained under the results section. The final coding structure consisted of five overarching transitions (themes), factors and outcomes of transitions.

In order to confirm my bases of analysis (Thorne, 2008) and test early patterns and themes, I engaged in the iterative process of constant comparisons and intellectual inquiry (Hunt, 2009). My analysis moved between caregiver's individual experiences, clinician's individual experiences, the experience of caregivers and clinicians as separate groups, and then finally the entire sample as a whole (Hunt, 2009; Thorne et al., 1997; Thorne et al., 2004). I drew on past empirical literature and previous clinical experiences, comparing them to the current emerging data, and asking why certain themes and patterns were similar or conflicting (Thorne, 2008; Thorne et al., 2004). I added probes to the interview guide, particularly around how MCC influenced the experience of caregiving in order to expand on patterns related to MCC and dementia caregiving (Thorne et al., 1997).
Theoretical sampling ensured that caregivers with a range of relevant contextual and demographic characteristics were represented within the sample, thus ensuring maximal variation and a broad understanding of a wide range of transitions (Miles, Huberman, & Saldana, 2013; Thorne et al., 1997). Early on, I noticed that patterns were based on the experiences of older spousal caregivers. Given that there is a growing population of adult children caregivers, I felt that it was important to understand the transition experiences from the perspective of this group as well. I asked multiple questions such as: Did they experience the same level of confinement as spouses, and do they have other responsibilities that they need to manage? By theoretically sampling for participants who were younger and had different caregiver relationships to the PWD, I gained insight into the experience of finding work-life balance and managing multiple roles. As per Thorne (2016), I returned to the raw data of three diverse transcripts, re-reading and re-analyzing to build my understanding of the caregivers' experiences. This helped to build new understandings and explanations of how themes related to one another.

Other strategies used to confirm my testing and evolution of analysis included sharing early patterns in the data with participants, using examples from my early analysis and seeking further explanation for the findings. In particular, I found that caregiver participants tended to focus on the dementia, despite the presence of MCC. I was able to share these findings with clinicians and ask them about their thoughts, experiences and possible explanations. Further, external expert critique and discussions with my supervisory committee members and clinicians in the study allowed me to explore
potential patterns. Expert guidance to novice researchers can support the researcher in sense-making of emerging concepts and themes (Thorne et al., 2004). Ongoing intermittent external critique throughout analysis conducted by my thesis supervisor and committee challenged me to deepen my analysis and understanding in my interpretation of the results (Thorne, 2008).

**Methodological Integrity and Rigor**

A number of strategies were used to promote rigor and valid inquiry throughout the study. In qualitative research, an important measure of rigor is the trustworthiness of findings, evaluated according to credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). The processes of data collection and analysis were guided by procedures such as keeping an audit trail, field notes, checking transcripts for accuracy among the committee members, and using participants' words as much as possible in order to maintain scientific rigor and trustworthiness throughout the study. These procedures are helpful for readers to evaluate the relevance of the data on which findings were based and conclusions were drawn (Thorne, 2008; Thorne et al., 1997).

Credibility refers to how accurately the findings reflect the experiences of the participants (Lincoln & Guba, 1985; Creswell, 2013). Throughout the study, transparent descriptions regarding the research process, including data collection and analysis, were ensured. The credibility of findings was enhanced by referring to several data sources (Thorne, 2008), including available literature, self-reflection, field notes, as well as subjective accounts by participants (Patton, 2015). Further, efforts were made to triangulate the data from participants in the study to promote credibility. Triangulation is
a validation strategy whereby different data sources and collection methods are used to provide perspective and confirmation on a topic (Creswell, 2013; Lincoln & Guba, 1985). The use of multiple investigators enhances the credibility by facilitating creativity and convergence of data findings (Miles & Huberman, 2002). In this study, triangulation occurred through the sharing of data analysis with the participants, supervisor and committee members in order to ensure that the initial understanding of themes was consistent. This helped to reduce threats to the accuracy of findings and ensured concepts and themes were credible.

Transferability refers to the extent to which findings can be applied to other similar contexts/subjects (Lincoln & Guba, 1985; Thorne, 2008). By providing detailed, rich accounts of the research process, readers are able to make decisions regarding the applicability of the identified patterns and themes in this study to their contexts (Lincoln & Guba, 1985). Further, the use of field notes helped to gather contextual information and link these contextual factors to the phenomenon under study (Thorne, 2008). I kept detailed field notes during every interview, which helped me provide a richer description about the study context and the participants in the study. Lastly, the use of purposive sampling, with the intent of maximal variation, captured and described a great deal of variation within the sample (Miles et al., 2013). I purposively selected caregivers and clinicians with varying demographics, experiences and backgrounds to increase the diversity of perspectives obtained, thus enhancing the transferability of findings to future studies looking at similar phenomena.
Dependability refers to the consistency and quality of data collection and analysis (Creswell, 2013; Lincoln & Guba, 1985; Patton, 2015). All participants were asked comparable questions in numerous ways. Further, evidence of dependability is provided through demonstration of systematically searching for meanings within the data (Patton, 2015). Although I did not conduct second interviews with the participants due to time constraints, following the first three interviews, I provided each subsequent participant with a review of patterns and themes I noticed from previous interviews and challenged them to reflect on their personal experiences. This validation technique ensures accuracy and is an important step in completing the analytic process (Patton, 2015). By sharing the analysis with participants and my committee members, I was creating opportunities for the team to provide context, clarification, alternative perspectives and explanations to increase the dependability of the results of the study.

Confirmability refers to the degree in which the data and interpretations are grounded in the events and free from the researcher's own bias (Lincoln & Guba, 1985; Patton, 2015). In order to achieve this, I included as many key words and quotes used by participants in the findings, staying true to their exact words and stories (Thorne, 2008). As with other qualitative approaches, it is important in ID to have some means to retrace the analytic directions and conclusions throughout the study (Thorne et al., 1997). An audit trail helps readers to understand how findings were derived from the initial research questions (Lincoln & Guba, 1985; Thorne et al., 1997). Throughout the entire study, a personal journal was maintained; the journal tracked all my thought processes, field notes, and analytical decisions, thus serving as an audit trail (Lincoln & Guba, 1985; Patton,
Further, team meetings were recorded and minutes were circulated and approved by all committee members. These minutes outlined all the decisions made throughout the study and were included as part of the research log and audit trail to enhance auditability and confirmability of study results. Overall, the audit trail allows other researchers to follow the decisions made in order to repeat the study and obtain similar results (Thorne et al., 2004).

**Funding**

This study was funded and supported by The Alzheimer Society Foundation of Brant, Haldimand-Norfolk, Hamilton and Halton.
Chapter 4: RESULTS

Chapter 4 focuses on the results of this study. It is organized into various sections to facilitate a better understanding of this unique population as well as the complex transitions they experience. The chapter begins with a description of the demographics of the sample. I then provide an overview of the context of caregiving, highlighting the crucial influence that MCC has on all aspects of dementia caregiving. This is followed by a discussion of the key transitions experienced by these caregivers. This section concludes with a synthesis discussion of the various factors, trigger events and outcomes across all transitions. Throughout the results, direct quotes are provided from participants. Please note that quotes from caregiver participants start with the letter P followed by their number. Likewise, quotes from clinician participants start with the letter C.

Demographics

The average age of the 19 caregivers was 68 years (SD=9.95) (Table 1). All caregiver participants were Caucasian and the largest group were spouses (57.8%). The overall sample included 11 spouses, six daughters, one niece, and one friend. There were more females (78%) compared to males (21.1%), reflecting the larger proportion of females taking part in the MT4C trial in the control group compared to males. I interviewed all available and consenting male participants in the control group of the MT4C study. Approximately half of the participants reported that they lived in an urban region (57.8%). Most caregivers were retired, educated beyond high school (post-secondary education) and married. On average, caregivers had spent about four years as a caregiver. The majority of PWD (56.2%) had anywhere from 7 to 10 chronic conditions
in addition to dementia. The five most common chronic conditions in addition to dementia were: hypertension (73.7%); arthritis, osteoporosis, and/or osteoarthritis (63.2%); painful condition, including chronic back pain or fibromyalgia (57.9%); depression (52.6%), and anxiety (52.6%). Sixteen caregiver interviews were conducted in the caregivers' home. Three caregiver interviews were conducted at local coffee shops at the participant's request.

The average age of clinicians was 43.6 years (SD=9.6) (Table 2). All but one of the seven clinicians was female. All participants worked full-time and had been working in their current position for approximately 11.7 years. Clinicians had various backgrounds and came from different disciplines, including medicine, nursing and social work. They worked for various organizations, such as outpatient clinics, the Alzheimer Society, and crisis outreach teams. All interviews were one-on-one with the exception of one interview where two clinicians from the same organization were present. All interviews with clinicians took place at their workplaces, often in their offices.
Table 1. Demographic Characteristics of Caregivers (n=19)

<table>
<thead>
<tr>
<th>Demographic Variables</th>
<th>Total n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age of Caregiver in Years [Mean(SD)]</strong></td>
<td></td>
</tr>
<tr>
<td>50-60 years</td>
<td>68(9.95)</td>
</tr>
<tr>
<td>61-70 years</td>
<td>56(3.03)</td>
</tr>
<tr>
<td>71-80 years</td>
<td>65(3.21)</td>
</tr>
<tr>
<td>81-90 years</td>
<td>74(1.67)</td>
</tr>
<tr>
<td>88(2.12)</td>
<td></td>
</tr>
<tr>
<td><strong>Age of PWD in Years [Mean(SD)]</strong></td>
<td>84(8.72)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4(21.1)</td>
</tr>
<tr>
<td>Female</td>
<td>15(78.9)</td>
</tr>
<tr>
<td><strong>Region</strong></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>11 (57.8)</td>
</tr>
<tr>
<td>Rural</td>
<td>8 (42.1)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>18(94.7)</td>
</tr>
<tr>
<td>Widowed</td>
<td>1(5.2)</td>
</tr>
<tr>
<td><strong>Highest Level of Education Completed</strong></td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>2(10.5)</td>
</tr>
<tr>
<td>High School</td>
<td>6(37.5)</td>
</tr>
<tr>
<td>Post-secondary</td>
<td>11(57.8)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>14(73.6)</td>
</tr>
<tr>
<td>Working Full-Time</td>
<td>3(15.7)</td>
</tr>
<tr>
<td>Working Part-Time</td>
<td>2(10.5)</td>
</tr>
<tr>
<td><strong>Relationship to the PWD</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>11(57.8)</td>
</tr>
<tr>
<td>Daughter</td>
<td>6(37.5)</td>
</tr>
<tr>
<td>Niece</td>
<td>1(5.2)</td>
</tr>
<tr>
<td>Other</td>
<td>1(5.2)</td>
</tr>
<tr>
<td><strong>Do you live with the PWD?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14(73.6)</td>
</tr>
<tr>
<td>No</td>
<td>5(26.3)</td>
</tr>
<tr>
<td><strong>Number of Years Caregiving</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1(5.2)</td>
</tr>
<tr>
<td>2</td>
<td>3(18.7)</td>
</tr>
<tr>
<td>4</td>
<td>4(21.1)</td>
</tr>
<tr>
<td>5</td>
<td>2(10.5)</td>
</tr>
<tr>
<td>7</td>
<td>3(18.7)</td>
</tr>
<tr>
<td>9 or more</td>
<td>3(18.7)</td>
</tr>
<tr>
<td><strong>Number of Chronic Conditions in PWD (includes dementia)</strong></td>
<td></td>
</tr>
<tr>
<td>3 to 6</td>
<td>3(18.7)</td>
</tr>
<tr>
<td>7 to 10</td>
<td>9(56.2)</td>
</tr>
<tr>
<td>11 to 14</td>
<td>4(21.1)</td>
</tr>
<tr>
<td>15 or more</td>
<td>3(18.7)</td>
</tr>
</tbody>
</table>
Table 2. Demographic Characteristics of Clinicians (n=7)

<table>
<thead>
<tr>
<th>Demographic Variables</th>
<th>Total n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age of Clinician in Years [Mean(SD)]</strong></td>
<td>43.6(9.6)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>Female</td>
<td>6 (85.7)</td>
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<tr>
<td><strong>Employment</strong></td>
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<tr>
<td>Full-time</td>
<td>7 (100)</td>
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<tr>
<td><strong>Years Working in Current Position</strong></td>
<td>11.7(7.8)</td>
</tr>
<tr>
<td><strong>Discipline</strong></td>
<td></td>
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<tr>
<td>Nurse Practitioner</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>2 (28.5)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>2 (28.5)</td>
</tr>
<tr>
<td>Geriatrician</td>
<td>1 (14.3)</td>
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**Context of Caregiving: Dementia and Multiple Chronic Conditions**

The context in which results were interpreted is the experience of caring for an older person, often a family member, who not only has dementia, but also has multiple other chronic health conditions. Family caregivers in the study described having to manage up to 15 additional chronic health conditions (mean=10; SD=3.5) in addition to the dementia. Clinicians identified "that having the dementia now impacts all their other medical conditions as well" (C004). Memory issues related to dementia affected the PWD's ability to manage their own care and health, and often complicated medication management, mobility (e.g., forgetting to use the walker), and their ability to manage basic activities of daily living. PWD would often refuse or forget to take medications, thinking that they did not need it. Caregivers struggled in some cases with medication compliance. Caregivers were always making sure that meals were prepared and that they adhered to certain diet instructions for other co-morbid conditions such as diabetes. Many
of these tasks needed to be properly managed, as they would affect the status of other co-morbid conditions. The presence of MCC meant, "it's a little more frustrating to also have multiple chronic conditions. It's sad because it's not just the dementia, but you also have to take into consideration these other possible issues" (C007). Whenever the PWD became sick, the caregiver had to manage multiple changes in their physical and cognitive status because many of the co-morbid conditions affected memory and cognition. Caregivers were generally providing care 24/7. This context reflects the added complexity, stress, and burden experienced by this particular subset of caregivers where they attempt to manage multiple health conditions while dealing with the unique transitions they were experiencing.

**Introduction to Transition Themes**

Caregivers in the study identified five overarching transitions experienced at different points in the caregiving journey, as seen in Figure 1: (a) *There's no turning off (progressive increase in responsibilities)*; (b) *I'm filling in many role (changes in roles and relationships)*; (c) *I'm sick, too (changes in overall health and well-being)*; (d) *Dementia defines my social life (changes in social boundaries)*, and; (e) *I know that day will come (changes in preparing for the future)*. The experience of transitions is depicted by the aerial view of a water lily, with each flower petal representing a transition.

I gravitated towards the image of a water lily after hearing many caregivers talk about transitions as a necessary part of life, where they need to continuously grow and adapt to changes. I chose the water lily because traditionally it has been a symbol of life and creation (Kandeler & Ullrich, 2009). The flower itself symbolizes the centre of each
caregiver's life, with each petal representing a different transition yet to be experienced. Transitions were influenced by various factors, including: (a) the progression and nature of the dementia, (b) the presence of MCC, (c) the relationship with the PWD, (d) support networks, and (e) finances. These blue ring of water surrounding the flower represents these factors.

Water lilies tend to blossom and thrive amongst wet, muddy waters (Encyclopaedia Britannica, 2016). Similarly, humans tend to thrive in difficult situations and circumstances. This is especially true in the case of caregivers, who demonstrate resilience despite the turbulent transitions that may arise throughout their caregiving journey. The water lily environment (factors) is important in nourishing, encouraging, or inhibiting its growth (Encyclopaedia Britannica, 2016). The waves around the diagram represent the chaotic waters and the "ripple" effect from the floating movements of the lily; these waves represent the potential transition outcomes.

This section outlines each of the main transitions in detail. Where appropriate, factors influencing each transition will be touched upon within each theme. At the end of this section, there is a synthesis of all the factors and outcomes across the various transitions. Throughout the results section, it is important to note that not all transitions are linked to a factor or triggering event. Similarly, lack of discussion of a triggering event/factor does not mean that it does not apply to that particular transition. One clinician described the experience of caregiving as a myriad of constant change: "You are in this constant mode of change; you are going to be on a treadmill and not going to be able to press stop. You will always be moving" (C007). The transitions described by
caregivers are complex, continuous, and often changing, recurring or occurring simultaneously.

**Transition 1: There's No Turning Off (Progressive Increase in Responsibilities)**

The first transition experienced by caregivers of PWD and MCC was a progressive increase in responsibilities. When prompted to reflect on the process of acquiring new tasks, caregivers explained how "gradually, [the PWD] has given up pretty much everything, so I've had to take everything on" (P009). Initially, as the PWD's short-term memory was affected, caregivers started with practical tasks such as "only doing the cleaning and cooking at first" (P013). Some caregivers had to learn how to work new equipment in order to "cut the lawn" (P003) or "maintain the car and the house" (P009). Many explained how they took over meal preparation, which included grocery shopping and preparing meals. In some cases, caregivers found that if they were not there to prepare the meals during the day, the PWD would forget to eat. Thus, caregivers constantly had to "keep on top of the meals to ensure [that they were] eating and eating right" (P005). Similarly, caregivers described managing finances, as the PWD was unable to remember if they had paid a bill or had taken money out of the bank. Spouses described taking over the book-keeping completely, whereas adult children often had to keep their parents' bank book and debit card because they were "forever misplacing it" (P010).
Figure 1. Transitions of caregivers of older adults with dementia and multiple chronic conditions
Despite the fact that caregivers were able to provide concrete examples of tasks they had taken on over time, only some caregivers came to the realization that the amount of responsibilities was overwhelming. Some caregivers became emotional when talking about the struggle to keep up with increased demands. Clinicians explained how caregivers did not always realize the insidiousness of the accumulation of tasks and weight of responsibilities:

It's so insidious that you go from being in the house to just supervising, to just standing by, to coaching, to mild assist and mild contact, to a bit of an assist, to a heavier assist and then to a total assist. And that's over a slope and the family has kept adapting without knowing. Now they don't actually realize that they're actually doing the hands on work. [...] They're not even able to say when did this start and how it happened. [...] Eventually, it's a sudden realization that they can't do it anymore; they've taken on too much. (C001)

The accumulation of responsibilities and tasks was often gradual and related to the slow progression of the dementia and other chronic conditions. Caregivers "slid into taking over tasks, very gently, over a long period of time" (P001) and thus, were not always able to put into context the magnitude of responsibilities. As the dementia progressed, some caregivers transitioned to helping with more intimate activities of daily living, such as changing their clothes and getting them into the shower. Each of the new responsibilities affected caregivers differently, with some caregivers focusing more on certain tasks than others. Regardless of the circumstances, all caregivers and clinicians spoke extensively about three particular responsibilities: (a) they would double dose and miss doses (managing medications), (b) I am always listening (ensuring safety), and (c) we are balancing the best that we possibly can (striving for balance).
A. They would double dose and miss doses (managing medications)

Medication management and administration was one of the most important responsibilities that caregivers had to take over. As their memory deteriorated, the PWD lost the ability to engage in self-management activities such as taking prescription medications. Caregivers ended up taking over; they managed multiple medications for the PWD, many of which were prescribed for conditions other than the dementia itself. There was always a potential risk that the PWD would forget to either take their medications or overmedicate. As such, caregivers developed their own routines to medication management, which involved picking up medications, organizing and preparing them on a weekly or daily basis, and administering or supervising the PWD to take them. Having complete control over medications was the "only way it would work for [the caregiver] to know for sure that [the PWD] was only taking the pills that they needed to take" (P010).

Some PWD also had complex medical conditions alongside dementia that required more intense medication management. For instance, one caregiver described how her diabetic spouse could sometimes require up to five insulin injections per day. She would oversee his medications because he would forget to check his blood sugars and take his insulin before eating. Diabetes management alongside dementia required caregivers to be vigilant towards medications and meals. Caregivers had to learn how to respond to "dips and spikes" in blood sugar though insulin adjustments and carbohydrate counting:
There are days that his blood sugar dips quickly. And at 4:30PM, it might be 3.2, which is not good because he can’t go below 4. And, there’s lots of spikes. Sometimes it’s 18 or 19. So, I’m dealing with that, too. Not just the regular dosages; I have to decide how I’m going to tweak that insulin. [...] I’m very concerned about carbohydrates. It affects his sugars. I do most of my own baking and soups and things instead. (P004)

Caregivers who were caring for persons with chronic pain described close monitoring of medications. Often, the care receiver would have a combination of pain medications taken at various times throughout the day. Caregivers tracked the administration of these medications to ensure adequate pain relief and to avoid accidentally giving too much:

She's always in pain. She only has the one pain pill in the morning, Dilaudid, and she's on a [long-acting] pain patch, Fentanyl. [...] The Dilaudid, which was for breakthrough pain relief, at one point we gave too many. Every four hours we were giving her Dilaudid and she was lethargic all weekend. [...] The pain patch is every three days, but I have trouble remembering that. I try to mark it on the calendar, but I forgot one time and it was a day and a half before I realized it! (P013)

Lastly, the presence of MCC and dementia complicated the management of drug regimens. There were often contraindications between medications, which meant that certain conditions would be left untreated as the risks outweighed the benefits. An example was not being able to take a memory pill because the PWD had a heart condition and they could potentially have a heart attack. Similarly, that same medication could have side effects and drug interactions with other medications. In addition to the daily management of medications, caregivers worked with HCP to make decisions on which pills the PWD should or should not take.

B. I am always listening (ensuring safety)

The second new responsibility that caregivers took on was to ensure the safety and protection of the PWD from wandering behaviours and medication mismanagement. In
many ways, caregivers found themselves taking on new roles and responsibilities related to safety, with medication management being one of many ways in which caregivers safeguarded the PWD. Caregivers were especially concerned about leaving the PWD alone. Many PWD had at least one other chronic condition that affected their mobility and gait, making them quite frail and unsteady on their feet. Memory impairment further increased the risk of falls as the PWD sometimes lacked insight into their physical limitations, thus forgetting to use their walker. Caregivers were often "watching over them", worried that they might fall: "she's very unstable; I'm worried about her walking with her cane to the washroom, falling and breaking a hip or hitting her head on the floor" (P006).

Caregivers also turned to different methods to maintain safety. Some caregivers physically accompanied and held onto the PWD wherever they went, whereas others hired private care or used "a video monitor [...] so I know when she's getting up at night" (P013). Caregivers identified other concerns related to safety and the environment. Memory impairment made it dangerous for the PWD to operate common kitchen appliances. Further, some PWD had behaviours related to dementia, namely wandering. Caregivers were constantly aware of their surroundings, ensuring that doors and windows were locked. They were often up at night listening for movement and wandering around the house:

*When he is sleeping, I wake up at any noise. So it’s like having a baby—you hear any noise, you’re up [...] It’s totally time consuming ‘cause you’re always on it. That’s what I tell my husband, I’m always on. So when he finally goes to bed at night, I go to bed at night because I can’t think of doing anything else.* (P011)
Other caregivers had experiences where the PWD had wandered outside the house and became lost in the past. Because of the unpredictability of their behaviours, caregivers had to stay close to the PWD and monitor them constantly:

*About two months ago, all of a sudden I thought, "Where the heck is he?!" He'd been gone out of the house for a while. I peek out and see a black car and he's leaning in it talking to the man. When he came in, he said "Oh, that was the fella who took me home. I guess I made a wrong turn." And he wasn't sure where he was, and this man had taken him home. So I have to watch him 24/7 or he'll get lost again. He has been lost three times! (P003)*

Ultimately, there were few opportunities for caregivers to switch off as they were constantly watching, listening or thinking about the PWD at all times throughout the day. As such, caregivers were "always on", leading to various other transitions in health and affecting their ability to cope.

**C. We are balancing the best that we possibly can (striving for balance)**

The third task that caregivers took on was related to constantly striving for balance. The fact that caregivers were constantly "on" disrupted many aspects of their daily lives, therefore creating a world that was imbalanced. Despite this, caregivers tried to manage multiple priorities alongside caregiving, with the goal of striving for regular routines and balance. Scheduling was an ongoing task for many caregivers. They were challenged with having to find time to complete even the most basic household tasks and chores. There was usually a limited window of opportunity that caregivers took advantage of on a weekly basis, often during respite care. Even when they were out running errands, they were always conscious of the limited time that they had and felt pressures around lack of time in managing and completing daily tasks:
I have a limited window of opportunity; I need that window for grocery shopping and other basic things that I need to do. [...] I usually find myself leaving and watching my time already before I'm out of the driveway. I'm thinking, 'I have to get back... it takes me 20 minutes to get there... I have to get that done by 1:00... so I'll be back by 1:30... or 2:00...' ”(P004)

The presence of MCC meant that PWD had multiple appointments with different doctors. Although PWD were usually followed up by their family doctor or a geriatrician for the dementia, they also saw many other specialists for their other conditions which required regular follow-ups throughout the year.

She goes for her bone doctor. Then she sees an [endocrinologist] because her sodium level continues to be low. Her family doctor is in [name of city]. We have three doctors I have to manage for different things at the moment. [...] Recently, this new thing about cancer has come up. So whether she has cancer or not, I have no idea. If she does, then that's another specialist to worry about. [...] So, I have book all her appointments and track em'. That way, I know myself what's going on. (P019)

As illustrated in the quote above, caregivers were responsible for tracking all of the PWD's appointments. When a new health issue arose, it often meant that there would be a new referral to another specialist. New referrals meant more frequent appointments at the beginning of the diagnosis. Specialists would monitor the PWD more closely during the first year to ensure that the condition was well managed. Similarly, if one of their previously stable chronic conditions flared up, the frequency of their visits to the specialist increased. For example, one caregiver described how a cardiologist had followed his wife for over 20 years. She had been receiving regular annual follow-ups until they found out she had an irregular heart rate, at which time, the specialist instructed them to come back to the clinic every three months.
Caregivers scheduled their daily activities around these specialist appointments. In particular, working adult children were challenged with rearranging their work schedules to accommodate these appointments. Some caregivers worked anywhere from 40-60 hours per week and could not take time off on short notice. It required planning and saving up vacation time for when they really needed it:

*I'm allotted, say, three weeks at work. I do not take all my holidays. I make sure I save X amount of days just in case, like, situations come up where I have to take her to the doctor. [...] When I had to go to that kidney doctor, we had to go for an x-ray as well. I just can't leave work and run out for an hour and come back. It's just something I can't do. So I would book a vacation day, or a half a vacation day, and take her. Anything to do with my vacation days, are really not my days anymore. [...] Those vacation days have basically got to be allotted for if I have to do this with her or if I have to do that with her. (P005)*

Being able to take time off at work often depended on the flexibility of their employment and understanding from management. Caregivers who were self-employed had more flexibility and autonomy in managing their own schedules. Other working caregivers were forced to give up opportunities of work or opt for specific shift work (e.g., straight night shifts) in order to be available to care for the PWD. This small subset of adult children caregivers was therefore uniquely challenged with the responsibility of having to balance both work and family life. Children living separately from the PWD felt like they were "taking care of two households" (P005) as they split their time between their parents' home and their own personal home. Overall, whether it was managing work and personal life, or just day-to-day activities, caregivers sought to find balance, structure and routine in their everyday lives despite the apparent disruption due to increased demands.
Ultimately, caregiving was something that was constant. Over time, caregivers took on more responsibilities to be able to protect and compensate for decline in both physical and cognitive function in the PWD. Caregivers transitioned into this cycle where there were multiple responsibilities they progressively took on which they could not relinquish. The incorporation of additional responsibilities and tasks resulted in an increase in total demands to the point where they could not "turn off."

**Transition 2: I'm Filling in Many Roles (Changes in Roles and Relationships)**

The second transition experienced by caregivers was a change in their roles and relationships with the PWD. As caregivers took on more responsibilities and tasks, they found their roles and relationships changing simultaneously. Many changes in roles coincided with the onset of certain responsibilities. Several caregivers stated that they had become "homemakers" and in some cases, they felt as if they had become a "personal support worker." These roles required caregivers to assume almost a leadership-like position in order to direct various aspects of care. Three shifts in caregivers' roles and relationships were apparent: (a) I supervise everything (becoming a supervisor), (b) I'm the mom now (becoming a parent), and (c) I'm like the octopus caring for everyone (managing multiple roles).

**A. I supervise everything (becoming a supervisor)**

The first transition within the caregivers' roles was the shift into a supervisory role. Certainly, as caregivers started to take on more self-care management activities, they had to learn to supervise the actions and activities of the PWD during medication management and safety monitoring. As the PWD experienced functional decline, they
required greater support than could be provided by the caregiver alone. Some caregivers had formal and informal health and social services come into the home to assist with care and to ensure safety. Although there were changes in their physical environment with the introduction of workers in the home resulting in their homes becoming "a place of employment" (P011), caregivers also found themselves transitioning into a role "like the employer, the evaluator or the supervisor" (C001). It was often difficult to have strangers coming into the home who were not familiar with the regular routine of their lives. As such, many caregivers were present in the home in order to supervise these workers closely:

*It's having people come in and out of your home all the time and cleaning up after them... I like to keep my house in order and I don't like marks left on my wall. I don't like cream left on my light switches. I don't like her towels not folded properly in the bathroom and put back properly [...] So when you have strange people coming into your home and doing things like that, I have to watch them, and then you know, after they leave I go tidy up.* (P006)

Similarly, caregivers who did not live with the PWD often checked in "on the personal support workers [to] make sure they're doing what they're supposed to be doing" (P010). They would also consult with and "keep tabs" on community agencies to adjust the care plan as needed, and to ensure the PWD received what they perceived was "the best care that [they are] entitled to" (P010). In these cases, caregivers found themselves taking on leadership roles where they would oversee, evaluate and direct the care to meet their standards. When new workers were introduced into the home, caregivers had to reorient and retrain them on their daily routines and rituals. This transition into a supervisory or employer role was an example of how caregivers dealt with loss of control. As workers...
were introduced into the home, caregivers had to let go of some control in the intimacy of direct care that they provided in their role as a caregiver. In some ways, caregivers regained a sense of control through directing and overseeing the care that was being provided in a new supervisory role. They were constantly communicating with home care and community agencies to schedule home visits and revisit care plans. Ultimately, caregivers eased into the role of a supervisor through the gradual addition of responsibilities and tasks. As their personal, physical space became a place that was less intimate and more like a place of work, they gave up aspects of their role as a caregiver, and transitioned into the role as a supervisor.

**B. I'm the mom now (becoming a parent)**

The next transition within roles was the transition into the role of a parent. Clinicians explained how "having to assume all these different roles changes the way caregivers view the relationship" (C003). Caregivers generally started to feel as if they had assumed the role of a parent when they started to take on most or all of the responsibilities of the household, as well as aspects of personal care. The more supervision and assistance that the PWD required, the more caregivers talked about changes in their role. The behaviours of the PWD were compared to those of a child; memory impairment meant that PWD would forget tasks and conversations, as well as ask repetitive questions. This behaviour reminded many caregivers of children in the sense that caregivers sometimes were unable to argue back or reason with them:
Well, you start as the wife. And you're now more a mother. You still know they're an adult, but they act like a child. He keeps asking and bothering me. And you can't reprimand them, you can't spank them and say, "Don't do that again." That's how I feel, you know? (P008)

Depending on the stage of the disease, caregivers would also take over decision-making and reasoning for the PWD. The relationship between the caregiver and the PWD became one of dependency. Adult children found that they were seeing their parents in a new light and experienced a similar role reversal where they were now the primary caregiver for their parents. Changes in roles and relationships impacted caregivers emotionally as many of them felt a sense of loss. Although the caregiver participants were all very committed to their family members, one clinician stated that it is important to remember that not all caregivers are "nurturers" by nature, and watching over their family member may not have been something that they had normally done in the past:

*I would say the biggest challenge has been taking on the responsibility of a child and having to do it 24/7. That's not my style. And our partnership never was like this. It wasn't that I looked after him. It was always a mutual effort. And now it's not. Coming to terms with that was very stressful.* (P015)

Caregivers in these situations felt that it took a long time for them to accept and become comfortable with their new roles. Therefore, the transition into the caregiver or "parent" role sometimes resulted in a dramatic shift in relationship dynamics, especially among spousal caregivers. This shift in roles often evoked negative, stressful emotions in the caregiver, further complicating the transition.

**C. I'm like the octopus caring for everyone (managing multiple roles)**

The third transition within changes in roles focused on managing multiple roles. Adult children were prime examples of caregivers with multiple roles. They were the wife
and parent to their own family and children, and now they were also the caregiver or "parent" of their own parents who had dementia and MCC. As expected, these caregivers had increased demands not only from the PWD, but from their own personal family members as well:

*I'm a runner. I was running in the morning for mom's appointment. And I helped my husband who has a heart condition and then I helped my daughter with her pregnancy. And when I go to my daughter's house, not only do I tidy up and fold her laundry, I prepare a meal and watch the grandchildren. I'm like the octopus! [...] So, I help my daughter out, I take care of my mom, and I take care of my husband. And I take care of the home!* (P006)

Adult children caregivers often shifted between roles. Biologically, they were the daughter or son for many years, despite the fact that some PWD would forget. Within each day, they would transition and wear different hats, sometimes putting on the daughter hat, and other times putting on the parent hat particularly when providing personal care or reminding their parents to eat. Certainly, taking on multiple roles was not limited to adult children. Some spousal caregivers were challenged with not only providing care to their spouse who had dementia and MCC, but also their adult children who also had complex health issues:

*You see, my daughter is another one. Because of her brain tumours, she can't make decisions. So she's always calling me saying, "Mom, what should I do about so and so?" She has trouble with financial things, decision-making. So, I'm constantly filling in for her, as well. It isn't just my husband, it's her too.* (P003)

The shift into multiple roles meant that the identity of the caregiver as a person was changing over time. Who they were and where their responsibilities and commitments were directed towards often shifted with the changes in the PWD's health, as well as changes within their own personal families. In summary, an increase in responsibilities
meant that caregivers were simultaneously assuming new roles that would affect their relationship with the PWD. Changes in roles and relationships made it even more difficult to balance multiple priorities while providing the best care as a caregiver.

**Transition 3: I'm Sick, Too (Changes in Overall Health and Well-being)**

The third over-arching transition experienced by caregivers was a change in their own overall health and well-being. All caregiver participants spoke about various ways in which their health and well-being had been affected by caregiving. Many of these changes in health were related to the previous two themes of changes in responsibilities, roles and relationships. As caregivers took on more demands, the majority of their time and attention went to the PWD and they gradually had less time to focus on themselves. Clinician participants described the role of a caregiver as a "sick role", where caregivers gradually ease deeper into the role without realizing that their life now revolves around it. One clinician stated that "it's almost like caregivers are accepting these responsibilities; they know this is their role, not realizing that eventually they're in a sick role because they're experiencing burnout" (C002). During the interviews, caregivers were visibly exhausted and did not hesitate to show the interviewer how their own physical limitations in health made it difficult to provide care. The changes under this theme are composed of three different categories: (a) *I’m not sleeping, I’m tired (physical health)*, (b) *you get very depressed (emotional and mental health)*, and (c) *you still need time for yourself (self-care activities)*.
A. I'm not sleeping, I'm tired (changes in physical health)

Caregivers first described changes in their physical health. The "chronicity of being a caregiver and being trapped in the role is very, very difficult" (C004) and meant that caregivers were "constantly doing things" (P005). As a result, many caregivers felt fatigued and tired over time. Some caregivers were up every night listening for the PWD, therefore not getting a good night's rest. This was especially true if the PWD experienced day-night reversals and wandering behaviours during the night. In addition to the dementia, some care recipients had concurrent conditions that affected their physical and functional abilities. Caregivers who had to provide hands-on care were constantly engaged in repetitive physical movements; this resulted in caregivers becoming physically worn out. Some even injured themselves when providing care to the PWD: "When I'm taking her socks off at night, or if I have to put cream on her back, I hurt my back. I get numbness in my back" (P013).

Many caregivers also had their own pre-existing health conditions that affected their ability to care for the PWD. Caregivers were often challenged with having to manage their own MCC, which included management of their own personal medications and appointments. Many of their chronic disorders, particularly the chronic inflammatory disorders, were associated with recurrent acute exacerbations. These exacerbations meant that caregivers struggled to physically meet the demands of caregiving:
I recently came through a COPD [chronic obstructive pulmonary disease] exacerbation where I was on antibiotics. I had a great deal of difficulty catching my breath doing physical labour. [...] So, my chronic condition makes it very difficult to be physically on top of everything [...] My COPD doesn't cause me pain, but it causes me to get weak, I get breathless. The chronic pain from the scoliosis means I have to slow down. I'm limited. (P009)

Caregivers were limited in how much care they could provide for the PWD; arthritis and scoliosis meant that many lived day-to-day with chronic pain, whereas recurrent infections such as cellulitis caused caregivers to be "tired". Many of these caregivers who had their own pre-existing health conditions were: (a) spousal caregivers over the age of 65, (b) lived alone with the PWD, and (c) had limited family support (either family had previously expressed unwillingness to be involved in care, or family did not live nearby). This meant they had few opportunities to step away from caregiving to recover. As such, they were often the only and primary caregiver who felt they had no choice but to continue to push through their fatigue. In some cases, caregivers described that their immune system was depressed and that they had prolonged illness because they were unable to take time for themselves:

The doctor feels that my immunity is down a fair bit. I'm not really over it yet, but I've had eight weeks of pneumonia. And I was very, very sick. My family felt that I should be in a hospital, but there's no place to put my husband. So here I was, a patient so to speak, sick, but still having to look after him. Which made it very difficult [...] The doctor and my family feel that I would've gotten over it much sooner if I could stay in bed and look after myself, rather than looking after him. I really think that it was a deterrent to me getting better sooner. (P012)

In some extreme cases such as the one below, this resulted in a crisis where the caregiver could have potentially ended up in hospital or died. One caregiver with severe coronary
artery disease describes a situation where he was having a heart attack and was unable to leave his wife alone to seek treatment:

*I was sittin' and my chest was heavy. I called my daughter but she was out. I sat in my chair for who knows how long and kept pumping nitro, trying to keep going, you know? Because I couldn't leave [my wife] alone! I didn't know what to do! [...] Eventually my daughter came over and she called the hospital. They took me in there and the doctor there says, "You're having a heart attack!"* (P017)

The participants attributed changes in their physical health to the constant demands of caregiving. Their own chronic conditions often exacerbated the negative effects on their physical health and affected their ability to provide care. Further, lack of time for recovery from physical illness meant that caregivers were often at risk of further decline in their health and subsequent hospitalization. Despite the distressing changes to their physical health, caregivers noted "the most difficult part of being a caregiver is the emotional and mental aspects" (P005).

**B. You get very depressed (emotional and mental health)**

Within the transitions in health, caregivers experienced a variety of changes to their emotional and mental health. The changes in the PWD's personality, and functional and cognitive abilities affected caregivers' relationships and roles, and often brought about intense negative emotions. These changes in emotions started right from the beginning, prior to the diagnosis of dementia because "carers [were] pulling their hair out so frustrated waiting a year and a half for a diagnosis" (C007). Some caregivers "had a feeling there was something going on" (P004) and while the diagnosis provided some relief, it also brought about shock as it was something "you would never dream of happening to someone you love" (P010).
As they adjusted to their new roles, almost all caregivers described feelings of increased frustration with the changes in the PWD's behaviours. In particular, memory impairment resulted in repetitive questioning and the inability to remember recent events or daily schedules. Caregivers stated that "it's the questioning, over and over and over again [...] that gets on my nerves!" (P003). Caregivers often had the best intentions and wanted what was best for the PWD's safety and well-being. However, some PWD did not have insight into their disease, often overestimating their physical and cognitive abilities, thus putting them at risk. In addition, they often did not recognize caregivers' concerns and refused help from community services or the caregiver themselves:

Yeah, it is really frustrating because she doesn't appreciate that she has a problem. It's the frustration that she just doesn't appreciate the situation. She doesn't realize what kind of risk she has put herself in [...] She insists that she's fine. We went to the Community Care Access Centre (CCAC) to ask for help or to take her to a day program. And of course she said, "No, I don't want it!" (P014)

This made it difficult for the caregiver to provide the care that they felt the PWD needed to stay safe. As the disease progressed, the PWD's ability to perceive, think and understand conversations and situations were affected. This made it difficult for PWD to communicate and sometimes led to unintentional hurtful comments that affected caregivers emotionally:

Sometimes she's nasty and tells me to shut up in front of people. I think she understands that I'm trying to take good care of her, yet she's still being nasty. She brings me down. It frustrates me. I get upset and I ask myself, why am I doing this? What's the point? She doesn't really understand what I'm trying to do for her. [...] It is super hurtful! (P006)

Hurtful comments forced some caregivers to reflect on whether their approach to caregiving and relationships was "right." This resulted in feelings of guilt because caregivers generally "want to be there and want to be able to do their best" (C003) in
order to "measure up to their own expectations" (C001). Guilt was a particularly difficult emotion experienced by caregivers as it was often associated with feelings of shame. Caregivers tended to be hard on themselves, particularly if they had a bad day, stating that they felt "guilty and terrible at night because [they] got mad or blew [their] stack that day" (P016). Guilt was also present when it came time to making decisions for the future as they often felt as if they had failed, especially if they had to place the PWD in assisted living.

Furthermore, some caregivers were physically and emotionally exhausted from having to manage the additional demands of managing the MCC. Chronic pain was one condition that complicated the situation by bringing about feelings of helplessness. One caregiver talked about how hard it was for her to watch the care recipient sit there and suffer from pain:

*He has a circulation problem in the legs so he is in constant pain. I find that very exhausting and... sad to hear him in pain, knowing that there is nothing I can do to make him comfortable. [...] I noticed that more and more he's squeezing his fingers... maybe that's the rheumatoid arthritis. It... can be very difficult to watch somebody in pain all the time. I feel helpless.* (P002)

The isolating and constantly changing nature of caregiving meant that caregivers "get very depressed sometimes" (P008). Most prominently, caregivers were overwhelmed with sadness and loss as they reflected on who the PWD used to be and how they had deteriorated. They often felt helpless that they could not help to end their suffering. Many caregivers were teary-eyed and emotional when reflecting on and speaking about the past. They shared stories about previous memories and provided concrete examples of tasks they used to be able to do:
It's hard for me to see her in this condition. Yeah, it's really heartbreaking... Oh... it's... [sighs, teary-eyed, staring at wife]... it just breaks my heart. Sometimes I feel like going and crying, you know... because she's been such an active, such a wonderful person all her life. You know? (P017)

For many caregivers, sadness seemed to be the most difficult emotion. As described above, caregivers were heartbroken and often had certain days or moments where they would break. It was a challenge to manage these complex overwhelmingly negative emotions, especially because caregivers were overworked and fatigued.

**C. You still need time for yourself (changes in self-care)**

The third change in overall health and well-being was related to a change in self-care activities. As described above in the section on physical health, caregivers struggled with self-care activities, particularly with finding the time and energy to manage their own health conditions or recover from illness. This section on self-care activities focuses on caregivers' struggle to engage in hobbies and personal activities outside of caregiving that would otherwise serve as beneficial to their emotional and mental well-being. There were multiple barriers to engaging in self-care activities. Time was a common issue for caregivers. Availability of respite care was important in allowing caregivers the opportunity to take some time off. Respite included formal services as well as informal support by family members coming in to help for a few hours. Some caregivers received a few respite hours during the week. Most used these hours to catch up on housework and chores: "every other Tuesday is when I do my heavy grocery shopping […] it's the only time I've got to catch up on my housework" (P002). Fewer caregivers described using their respite time to engage in an activity for themselves. Those who did often spent part
of the day catching up with a friend or going for lunch, an activity that allowed them to socialize with others:

My oldest daughter takes [my wife] to get her hair done and I have an afternoon or couple hours to myself just to go to the hardware store and look around there. Just to get away. Sometimes I have a friend and he comes out and we go for coffee, too. Again, so I have some time away from her (P007)

These small opportunities to break away from caregiving were important as they were opportunities for self-rejuvenation. It provided caregivers with the opportunity to engage in the world outside of caregiving and to clear their minds and emotions. Not all caregivers were able to take time off on a regular basis to enjoy some time away. Some caregivers talked fondly of hobbies that they used to engage in or wanted to start. Without an option for respite, these caregivers were glued to the PWD; there was little possibility of leaving to complete any task:

I want to learn how to play the piano again. So I bought a little keyboard. And I'm trying to get time to spend an hour or so to do it, a day to do that. But I could never leave him. (P008)

As such, caregivers "gave up everything that meant anything to me as a person" (P011), including hobbies, interests and dreams. In some cases, caregivers described giving up their creativity, something that served as a means of self-care as it provided deeper meaning and fulfillment to their lives:

Well, I'm an artist and I can't paint because I haven't got enough time. [...] And the sad thing is, for me personally, I find that that's what fulfills me. Like I guess if that's how you want to explain it. And not being able to paint, is part of the problem because [make a fist and holding it to her chest, brows furrowed] I just, I want to get my emotions out and express it! And I can't! (P014)
In the above example, the participant used painting and art as a way to care for herself; art for her was a way of expressing emotions and coping, similar to how caregivers would get together with their friends to chat. Art was a hobby that stimulated therapeutic self-reflection as it would have allowed her to channel her stress and frustrations of caregiving in a creative manner. Because she was unable to partake in the hobby, she felt more depressed; the emotional and mental burden of holding in her emotions and not being able to express them negatively impacted her overall well-being. Although caregivers often acknowledged the importance of self-care and had every intention to take time for themselves, there were multiple barriers such as availability of support and time. Because caregivers were unable to pursue these personal activities and take time for themselves, there was more strain on their physical, emotional and mental health as a result of bottling up emotions and stress.

**Transition 4: Dementia Defines My Social Life (Changes in Social Boundaries)**

The fourth major transition experienced by caregivers was a change in their social boundaries. Many had their social lives defined by dementia. A handful of caregivers described not being able to get out at all due to the nature of dementia. Some of the chronic conditions that the PWD had caused significant physical disabilities, making them completely dependent on the caregiver all the time. Clinicians described it as being "trapped" in the world of caregiving where it could sometimes be "suffocating" (C006). As their relationships changed with the PWD as well as family members and friends around them, caregivers found themselves experiencing several shifts in their social
boundaries: (a) I gave up my social life *(becoming more confined)*, and; (b) *My social network keeps me sane* *(changing networks of support)*.

**A. I gave up my social life *(becoming more confined)*

Many caregivers described their lives becoming more confined. Interestingly, there were varying levels of confinement that depended on factors such as: (a) whether or not the PWD could be safely left alone, (b) whether or not the caregiver had available support networks or respite care options, and (c) whether or not the PWD would accept strangers coming into the home. As previously mentioned, spousal caregivers were often older and lived alone together. These caregivers described a very tight level of confinement where they were constantly physically together with the PWD. They stated that the PWD "stays by my side all the time" (P003) and that one of "the biggest transitions is that I have to take her everywhere with me" (P017). Aside from watching over them every day, some PWD would follow the caregiver around the house like a "shadow." There was a very intense level of inseparability where all activities, tasks, and outings were done together:

*He watches me. Like, if I'm in the basement, he shadows me. I turn around and he's right there behind you. He finds me. I never go anywhere without him because he's very competitive for my time. [...] I have to wait until he goes to bed at night [to talk on the phone]. He doesn't want me talking to someone else.* (P008)

In some cases, the PWD was resistant to having strangers come in for a few hours to give the caregiver some relief. These caregivers were not only confined within their homes, but they were also confined in their immediate personal space making it extremely
difficult for them to have any time alone. This caused some level of anxiety among caregivers who felt that they were unable to separate from the PWD.

Whereas some caregivers experienced a very close, physical level of confinement, other caregivers felt a different level of confinement related to decreased opportunities for socialization and travel. Caregivers described not being able to go out and socialize with friends and family for months or years at a time. Practically, the most common reason was due to a lack of what some caregivers called "a babysitter" (P005) to help supervise and care for the PWD while they were out.

Travelling far and for long periods was especially difficult as it was challenging to arrange for care and find someone who the PWD would be comfortable being with. Even when caregivers were able to arrange care and get out to socialize with others, they were plagued with intense feelings of guilt. Regardless of whether they were away from the PWD or just thinking about the possibility of travel, caregivers found themselves worrying about the PWD, as well as asking themselves, "Can I enjoy where I'm going? Do I feel guilty that I'm going and having a good time? Do I have the right to enjoy?" (C001). There was a general perception among caregivers that if they were going to take some time to do something "good" for themselves, that they should also be doing it with the PWD. These feelings of guilt and sense of obligation resulted in confinement as caregivers often chose not to socialize with friends or travel.

Ultimately, the varying levels of confinement affected caregivers physically and emotionally. In one way, caregivers were physically attached to the PWD and were unable to separate from them for safety reasons. Caregivers were also emotionally bound
by their own emotions and self-imposed rules regarding their right to socialize and enjoy life away from the PWD. Either way, caregivers found themselves unable to live their own lives, because the dementia that affected the PWD had also begun to take over and define their lives.

**B. My social network keeps me sane (changing networks of support)**

As caregiver participants move between new social boundaries, they developed changing networks of support that further push and pull at these boundaries. Some caregivers developed new positive networks of support, while others found new strengths and bonds within existing networks of support. This helped to expand their world in that caregivers were building relationships with friends and family members who were able to support the caregiver, physically or emotionally. One caregiver stated that "hopefully, [other caregivers] have a social network of friends and other acquaintances that they can unload on; I think that's a critical piece" (P010) because caregivers "still need to lead their own life, too" (P015). Being able to share feelings, experiences and thoughts with someone allows caregivers to "stay grounded" and build resilience over time. In some cases, friends and family members also provided spiritual guidance and support:

_I have a friend and she is my rock. She is my spiritual advisor. I can say anything I need to say or want to say and she doesn't make me feel crappy. I don't know what I would do without her. I tell her all the time, "You are my gift from God. God sent you to me." I say to her all the time, what would I do without you? I can send her a text message, at any time of day or night, and I usually end up waking her up in the middle of the night. But it doesn't matter because we are friends. She is my friend. And my advisor. She is one of my branches. And I have another friend who is my other branch. Together, those branches hold me up. They keep me grounded. They keep me sane._ (P019)
Given that caregivers found the emotional part of caregiving the most distressing, talking with others supported them during difficult times. Similarly, caregivers who attended dementia support groups and day programs made new connections with "people you've never met before, but you become good friends" (P016). By connecting with others who had something in common, caregivers experienced "comradery as we all help each other through it" (P002). Other caregivers who connected with their family members felt that they were building stronger family bonds and relationships by working together as a team. Together, they divided various caregiving tasks and responsibilities, which helped to relieve both the emotional and physical burden of caregiving:

*I'm there [with mom] at least once a week, often two. The last couple of years, we finally had a sit down meeting with the rest of the family to say, "Hey, this is becoming a little bit too much for the couple of us. And we need to have a system where we rotate through weekends." So now we have a standard routine. Every fifth or sixth weekend, we know that's our weekend on. And so, whether you're from this city or that city, and whatever the weather is [there's always someone there] [...]The onus isn't just on you. (P010)*

Caregivers who worked together with their families were better able to find balance and divide their time between caregiving and living their own lives. The availability of community support networks, such as respite care, was crucial to caregivers' ability to find time for self-care activities and to decrease feelings of confinement. Through these community networks, caregivers were also able to develop positive relationships with workers from various agencies such as counsellors from the Alzheimer Society and personal support workers from home care agencies. They supported caregivers by providing education, and assisting with care management and delivery. Caregivers also described a positive relationship with their family physicians
and how the presence of their family physician supported them throughout the transition process.

*What has helped me through my transitions, I think, has to come back to the support that I have. I have a very supportive doctor who is really understanding [...] During appointments, he often interviewed me beforehand and he'd hand me the kleenex. He tells it as it is; he helped to explain mom's behaviours and why she acted so nasty. He also linked me with the Alzheimer's Society which has taught me so much.* (P012)

Ultimately, caregivers were able to expand their social boundaries through new positive networks of support, which helped to decreased confinement, isolation, and the burden of having to provide care on their own. It helped to increase their knowledge about the disease as well as provide them with ways to support the health and management of the PWD.

On the contrary, a lack of support networks, or the development of negative networks of support further constricted the caregiver's social boundaries and increased feelings of isolation and stigma. Some caregivers simply did not have family members nearby to assist with caregiving. Because family members were not always around, caregivers felt that they "just don't understand; they don't see the real thing and they don't understand the nature of it all" (P017). This lack of understanding further isolated caregivers as they felt that there was very little recognition and appreciation for the caregiver role.

*My family for example, [wrinkled brows, a little frustrated] do any of them ever think to call and say, "Is there something I can do?" No! Because they see it going so smoothly so it's like, "Oh, mom's coping just fine!" [shakes head, throws hands up in the air] Piece of cake to them!* (P009)
Family members and friends sometimes ended up distancing themselves from the caregiver and the PWD and MCC. Both caregivers and clinicians believed that this was in part due to the stigma around dementia and a lack of public awareness and understanding of the disease. As one clinician explained: "we live in a generation where dementia is still feared; people still think it's contagious" (C006). A sudden change in behaviour by family members, friends and even strangers when they were out in public meant that the doors to their networks were closing and the caregiver suddenly found their world shrinking, becoming smaller. Some caregivers genuinely felt that if those around them were more open and understanding of the disease, it would help them cope better:

[It would help to have] the love and support from other people that they're more understanding of dementia. That it's not this terrible disease that you can catch. People will look at my husband and say, "Well, he looks fine to me." But when they start talking to him, they think to back off” (P002).

The stigma associated with dementia resulted in fear due to lack of understanding, thus isolating caregivers. Ultimately, there was an interesting contrast in the development of positive and negative networks. While positive networks of support pushed and expanded social boundaries resulting in greater support for the caregiver, negative networks of support pulled and constricted these boundaries, thereby confining caregivers. These forces often occurred simultaneously and resulted in the caregivers' world being defined by new, fluid boundaries that continued to change over time.

**Transition 5: I Know That Day Will Come (Changes in Preparing for the Future)**

The final transition that caregiver participants experienced was changes in preparing for the future. Caregivers had or were currently thinking about the future of the
PWD. There was a focus on the PWD's health status and how long they would be able to maintain it. For most chronic conditions, caregivers felt that as long as the PWD was on regular medication and attending regular follow-ups, they were able to "keep things under control" (P007). Most chronic conditions are progressive in nature, and the trajectory can be prolonged and somewhat unpredictable. Acute exacerbations can further complicate the process of care management. Clinician participants felt that the lack of a clear disease trajectory and cure for dementia put caregivers in a difficult position when they realized that "it's not going to get any better" (P007). Staging of the disease is often more difficult in dementia compared to other chronic conditions. Together, this made it difficult for caregivers to plan ahead.

During the interviews, some caregivers were hesitant to touch on the topic of future planning, while others expressed that they had thought about it many times in the past. Although caregivers acknowledged that they were aware that they had to prepare for the future, they felt that they had very little control over when or how things would turn out. Interestingly, there were tensions related to planning for the future. Some caregiver participants anticipated the future and wanted to be much more active in future planning. On the other hand, some caregiver participants took minimal action in preparation for the future. The nature of the disease influenced caregivers' thought processes about the future, resulting in two key changes: (a) I have to be ready (anticipating the future), and (b) I want him to remain active (holding back the future).
A. I have to be ready (anticipating the future)

The majority of caregivers were well-informed and had basic knowledge about the progression of the disease, and were able to anticipate certain aspects of the future. Caregivers with previous knowledge and education on future planning approached the idea of "future" differently than those who did not. Those who had attended support groups and education sessions from the Alzheimer Society described how it prompted them to be proactive by taking small steps towards preparing for the future: "Alzheimer's Society was also really helpful in preparing us on the next steps. They have lots of information and lots of literature, so you aren't doing this blindly" (P010).

The physical environment was important to caregivers; spousal caregivers acknowledged that they may not be able to manage in their current homes in the future. Alternatively, adult children thought about having their parents move closer or move in with them. In particular, a handful of interviews were conducted inside caregivers' homes amidst house renovations. Many were renovating their current homes, or looking at smaller homes as a way to prepare for a potential move in the future: "I'm just sort of getting the house renovated and organized so that in the event that I have to move, it wouldn't have to be a mad dash to get things done. I just figure now's the time, don't wait" (P004).

With thoughts around relocation in the future, caregivers were also concerned about finances. Caregivers were cognizant about saving money for the future as many PWD were on a fixed income. Many expressed concerns about the price of retirement homes and long-term care homes as they did not want to "have them in just any old
place" (P016). Many were thinking about paying extra to upgrade services should the
time come in the future. Some caregivers struggled to keep up with the price of living for
the PWD and felt very uncertain about sustainability of care in the future:

_The problem that I have is that mom's money is running out very fast. She had gone
from a $500 apartment into a retirement home. It's a very small room. She's very well
cared, but her rent is almost $2,000 a month. There's no subsidy for a retirement home
[...] I'm not sure what I'm going to do if we can't get her into a nursing home that will
subsidize her. Because I don't have any idea how I'm going to look after her. What do I
do? I do not have the resources to give her the care that she needs... the care that she
deserves._ (P019)

It was hard not to think about finances when anticipating the future as options for housing
were expensive and caregivers recognized that providing proper care on one's own was
not always feasible or safe in the longer term. As caregivers began to think more about
the future, they developed a greater sense of self-awareness of their own abilities and
limitations. Caregivers often planned for the "worst case scenario" by anticipating how
different scenarios could potentially unfold. This helped them to solidify their own mental
lines or restrictions on what and how much care they could provide. They began to look
at their situation more objectively, asking themselves, "when is it out of our control?"
(P005). Often, caregivers decided that functional decline was the tipping point in which
they would no longer be able to provide care and would require a care facility:

_I am concerned about when I can't lift her and I can't help her. That will be the time
when she has to go into a home. [...] I tell [mom] that as long as you're mobile, you get
to stay with me. As soon as I can't pick you up to bring you to the bathroom or I can't
pick you up out of bed... as soon as I can't do that, you're going to have to go to a home._
(P006)

During this process, caregivers also reflected on their goals for care in the future.
Caregivers often spoke about long-term care homes with mixed opinions. For some,
nursing home placement was not part of their goals for care. Many were conflicted with previous promises and commitments to the PWD about not placing them in a home. Other caregivers felt that by placing them in a home, they would deteriorate rapidly because the care provided in a nursing home could never be the same quality as what they provided themselves. Others were more open to having placement as part of their goals of care. These caregivers felt that a nursing home was the best option for the PWD, especially if they were currently living alone. A nursing home, in their opinion, provided increased socialization and supervision.

Lastly, in anticipating for the future, caregivers also reflected on their goals of care for the PWD during end-of-life. Consistent with a majority of interviews was the desire to maintain and respect the dignity of the PWD until the end. Caregivers wanted to "give him the dignity of his happiness until the day he's gone" (P011), which often involved "letting him be happy with what he remembers and what he doesn't remember" (P011).

Regardless of the amount of physical, mental and emotional preparation for the future, caregivers admitted that it was ultimately difficult to determine how long the PWD would remain "stable." They acknowledged that "[things] will change again; how things are right now is not how they're going to be a year from now [...] he is deteriorating so it won't remain the same" (P015). Thus, despite the fact that the future was uncertain, some caregivers took steps towards anticipating and preparing for the future. While some caregivers were proactive in preparing for the future, others were more hesitant and focused on holding back the future.
B. I want him to remain active (holding back the future)

Within changes in thought processes about the future, some caregivers were conflicted between wanting to anticipate and prepare for the future, but at the same time, wanting to hold back the future and focus on what could be managed in the moment. Caregivers were focused on the PWD's current level of health; they wanted to maximize their independence and mobility while maintaining their identity. Caregivers described encouraging the PWD to still engage in the self-management of their own co-morbid conditions whenever possible. Although caregivers may have had to oversee their activities or assist with set up, they created an environment where the caregiver could still exercise their own independence and manage their own co-morbid conditions to a certain extent:

*I monitor the numbers and ensure he has the right doses. But, he still does physical testing, like, the finger prick and the injection part. I will have to do it eventually. But until I have to, he’s still doing it himself. He prefers to do it himself. And I encourage him to […] He still makes his own breakfast in the morning. Everything’s laid out though for him though, mind you. But he is able to prepare it himself.* (P004)

While most caregivers were providing care to a PWD who had cognitive deficits, many were still physically robust and healthy. Caregivers made a concentrated effort to promote physical activity and mobility for a variety of reasons. Some caregivers recognized that promoting physical activity could help to prevent functional decline as well as help manage other MCC such as cardiovascular disease:

*She's gotta get her out of the chair. It would be easier for me to hand her a plate of food and let her sit in the chair all day. Sure, I can do that, but I choose not to. Because, the more she gets out of that chair, the more she moves, the better she'll feel, the better it is for her feet that swell. It's better for her heart. I try to get her up and moving while she still can.* (P009)
Other caregivers hoped that by promoting their physical health, it would help to slow the decline in memory. Similarly, many made it a goal to engage the PWD in hobbies and activities, as they believed that this would help strengthen their brain and memory. Caregivers often encouraged the PWD to attend adult day programs or social groups where they would be able to play cards, do puzzles or engage with others. Similarly, caregivers involved them in daily tasks and chores not only to promote their functional status, but also their identity as a person who is still contributing to everyday activities. In order to do this, some caregivers had to use creative methods to compensate for any cognitive deficits, usually in the form of calendars, sticky notes and other reminders:

_I put a chart up with a great big calendar and I wrote everything in big, black magic marker, what he was to do each day. And then I gave him a pink magic marker so he could put an X when he took his pills at night. That way, he knew he took his meds and that it was the end of that day._ (P015)

Ultimately, caregivers tried to keep the PWD active and involved in their daily lives by involving them in routines and tasks. They encouraged the PWD to engage in their own self-care and management of chronic conditions for as long as possible. Despite the efforts caregivers invested into maintaining the PWD's current abilities and functional and health status, they seemed to always be aware that the PWD would deteriorate over time. The need to continue to promote cognitive and physical exercise shows that these caregivers were trying to hold back the future, even if they had already taken steps towards preparing for the future. This contrast between anticipating and holding back the future is interesting in that caregivers were almost trying to fight or deny the process of
the disease by hanging onto the PWD's current abilities, in hopes that perhaps, the future could be delayed.

**Factors Influencing Transitions Experiences**

The changes that caregivers experienced were influenced by multiple factors and circumstances. These factors could positively or negatively influence each of the main transitions and could be associated with more than one transition. There were five key influencing factors across the five transitions. The following section serves to synthesize these factors across the transitions, with a more detailed focus on the presence of MCC. The five influencing factors included: (a) progression and nature of the dementia, (b) the presence of MCC, (c) relationship with the PWD, (d) support networks, and (e) finances.

**A. The progression and nature of the dementia**

Throughout the study, it was apparent that caregivers were mostly concerned about the dementia despite the fact that older adults had many other chronic conditions. The progression and nature of the dementia, including its staging and the way in which it presents itself, was an important and overarching factor that encompassed all the transitions. One of the main reasons why caregivers focused so much of their attention on dementia was because of the way the disease presented. Clinicians explained that generally speaking, "the dementia's the squeaky wheel that gets the attention" (C004). Many caregivers were consumed with managing day-to-day tasks that the PWD was no longer capable of safely managing on their own. Caregivers spent a large part of their day monitoring behaviours related to dementia, such as wandering:
Well, the dementia's the big part. Right? When she doesn't remember, it's hard on her. Hard on us. But other than that, her chronic diseases are uh... I don't think they don't cause a lot of problems. I don't notice them. The dementia, the lack of memory, that's the killer right now, you know? Because I'm focused on looking after her safety, watching her, getting her through the day [...] Her heart disease, her blood pressure, it's all good. Don't even notice it. [chuckles] (P007)

In this sense, compared to other chronic conditions, the "dementia is more in your face because it is more visible in terms of the symptoms" (C005). Clinicians explained that if a person is "wandering out or causing a ruckus at 5AM, that's going to get all the attention! As it should! I have to deal with this person who is running around my house right now!" (C004). Therefore, it was not because caregivers did not care about the other chronic conditions, rather it was because they were providing care in a context where dementia was more evidently disruptive to their everyday lives that they had no choice but to prioritize dementia care over everything else.

The progression and staging of the disease also had an impact on how the caregiver perceived their overall caregiving experience. Rapid progression of the disease meant that caregivers had increased physical demands and were at a greater risk for negative effects to their overall health and well-being. These caregivers were generally the ones who were constantly with the PWD, finding little time for themselves.

They tell me [name of husband] is in the later stages of dementia. His thoughts are very mixed up now, because he's moved onto the next stage. It's like the part of the brain that controls his mobility is saying "you can't move anymore". You know, so he tries to move that leg and it just won't go. [...] He gets seven hours [of home care] a week. Someone comes in to bathe him. But in between, I have to do everything for him. You know, getting him in and out of the bed, it requires a lot of lifting. Lifting him in the wheelchair to get him close enough to the toilet so that I can help off of the wheelchair and onto the toilet. (P002)
In the above example, the caregiver has taken over to assist with mobility. Her experience and perception of caregiving was focused more on the dementia than the other conditions. Caregivers providing care for someone in the later stages of dementia were also more likely to talk about future plans and goals for care. It is likely that as the dementia showed its true colours in the physical, cognitive and emotional sense at the end stages that caregivers were more likely to come to terms with the reality of the illness, thus affecting their perception of the transition experience. Caregivers of a person in the earlier stages of dementia were often experiencing a different type of transition. One clinician described how the early stages of diagnosis and caregiving are an important time for caregivers as they are just learning about the disease:

*Well it depends on the person with dementia, how things are unfolding for them. I always say in the beginning when you're kinda not sure what's going on, you're in this unknown mine-field, you ask questions [...] The caregivers at the beginning are focused on preventing the dementia. What can I do to slow it down? What pill can I take? Will exercise help? I think in this stage... we educate caregivers about minimizing their risk factors such as hypertension. Not that it will cure the dementia. But it gives them hope and it helps them understand the importance of the whole picture.* (C007).

It is possible that caregivers are more likely to be open to look at ways to not only learn more about dementia, but also understand how MCC can affect the progression of the disease. Depending on whether or not the caregiver pursues these questions is dependent on multiple factors, including the HCP's expertise and willingness to share information. The progression, nature and staging of the dementia has an influence on how caregivers experience transitions and plays some part in determining their perception of the management of MCC.
B. The presence of MCC

Similar to how the experience of caregiving was dependent on "how one is dementing" (C004), it was equally important to take into consideration the type(s) of chronic conditions co-existing alongside dementia and how those were manifesting. The presence of chronic conditions, as well as the extent of the need for disease management had a large impact on the transitions experienced by caregivers. Often, caregivers stated that the other chronic conditions did not affect their daily caregiving, and that they "don't cause a lot of problems" (P007). Caregivers were often helping to manage conditions such as high blood pressure and osteoporosis through medication administration. The caregivers who did not perceive MCC as affecting their caregiving were the ones providing care to someone who had a condition that did not necessarily have an evident impact on physical function. One clinician explained:

*When you have people with end-stage heart failure that need daily weights because it affects their breathing [...] or the chronic pains where it impacts their function [...] or the left-sided stroke with poor mobility and pivot transfers... It's the tremendous functional loss from these chronic diseases that caregivers focus on. Because you could have 50 diseases in the world and be up and running and travelling the world. And nobody even knows you're sick. It's when you become functionally dependent that it becomes the challenge. (C001)*

It is possible that if the PWD had other chronic conditions that were physically and functionally disruptive (e.g., pain from cancer, altered level of consciousness from hypoglycemia, etc), then those conditions would become the "squeaky wheel" that gets the attention as opposed to the dementia. Therefore, the impact of the chronic disease on the PWD's functional status played a large role in caregivers' experience of transitions and caregiving.
Furthermore, there was a relationship between the existence of certain chronic conditions and dementia itself. In particular, many co-morbidities were known to "feed into the dementia" (C006). For instance, many chronic conditions such as cardiovascular disease, chronic renal failure, hypertension, and chronic obstructive pulmonary disorder were conditions that put the PWD at risk for vascular changes. Those with unmanaged cardiovascular risk factors were putting themselves at risk for recurrent mini strokes, thus contributing to a vascular dementia. Likewise, dementia itself was seen as a "risk" to other co-morbid conditions. For instance, it was not uncommon for PWD to resist or refuse to take medications, many of which were crucial to the management of other co-morbidities. What some caregivers failed to notice was that poor management of co-morbid conditions could affect cognition as well:

_We have seen for example someone who stopped taking their thyroid medication. Instead of fighting, a lot of families just give up because they're think, "Well it's his dementia; I can't fix it." But, they don't realize that if they found a way to get him to take the medication, it could help with the thyroid or help with the other chronic conditions which could potentially impact the dementia. So they don't really see the bigger picture_ (C005)

Similarly, some PWD had conditions that were previously undiagnosed and therefore not properly managed. This is a significant concern because the lack of management of chronic conditions could potentially contribute to a decline or sudden change in the person's cognition:

 _My husband had an appointment for a continuous positive airway pressure (CPAP) test. When we went in, his pulse was so low, the doctor said "You better get to the specialist. I think he needs a pacemaker." So then we start the process, we get the pacemaker. We go back to the sleep clinic and they give him the overnight test. Within a couple of minutes, he goes into severe sleep apnea and they have to put the CPAP machine on him. So, it has been a month now. And the difference in him is amazing! His memory has_
improved SO much. His personality is more relaxed, he has more energy, he is not napping very long during the day... his sense of humor has returned, his colour is terrific! I cannot say enough good about the combination of the pacemaker and the CPAP mask on his memory! (P009)

Thus, certain co-morbid conditions and dementia affected one another. It was important for caregivers to understand the interaction and dependency between the different conditions in order to advocate for and understand the management of MCC.

The co-presence of MCC and dementia also made it difficult to determine whether or not changes in health were due to a true worsening of the dementia, an exacerbation of an existing chronic condition, or the onset of an undiagnosed and untreated condition. Clinicians found that "caregivers are unclear about where the chronic conditions end and where the dementia starts. If there are changes, is it a result of the dementia or a result of the other conditions?" (C003). Caregivers also found that their HCPs were not always able to discern between the flare up of a co-morbid condition versus the progression of dementia:

One time she had pain in her stomach so I called the doctor. He checked her out and he gave her some medicine for the pain. I called the doctor again because the pain continued and I took her in on the Monday. He says, "I think it's all in her head." I said, "Let's get her into [the hospital] and find out what part of her head it's in." Because I know she doesn't complain. If she's got pain, she's got pain. I know that! So we sent her to [the hospital] and well, she had a gallstone the size of a golfball! They operated on her within an hour of being in there. But see, the doctor thought it was all in her head just because she can't express herself because of her memory. (P017)

This made it very difficult for caregivers to manage the care as well as make decisions for treatment because the underlying causes of a change in health status were not easily discernable.
C. Relationship with PWD

The nature of the caregiver's relationship with the PWD had an interesting influence on the transition experiences of caregivers. The majority of caregivers described positive relationships prior to the diagnosis of the dementia. Clinicians pointed out that the nature of the previous relationship with the PWD was crucial to the caregiver's experience of transitions and ability to cope with changes. One caregiver described the dynamics of her relationship with her husband prior to the diagnosis as a harmonious one based on trust:

*Well I think what is key to why we can get along now is, all his life, he was dependent on me to really work out the decision making. He has always had a great deal of confidence in me. His trust in me has always been very strong. You know, I've met up with some couples at the Alzheimer's Society, and the husband was the dominant person and now he has Alzheimer's and the wife is now struggling with taking charge of things. And he's not used to trusting his wife. For me, I didn't dominate my husband. But he always trusted my decision making. So that has helped with our relationship after the diagnosis. I'm fortunate.* (P015)

It is perhaps the nature of their previous relationship that facilitated her positive experience in the caregiving journey. Similarly, spousal caregivers in particular often talked about their strong bonds based on love and commitment to their partner: "when you live together for so long you just take what comes" (P016). This sense of duty and unique relationship propelled spousal caregivers forward and encouraged them to push through many of the challenges faced during their caregiving journey. These caregivers stated "as far as I'm concerned, we're one" (P017). This influenced their thought processes about the future as many had made prior commitments and promises to their partner to keep them at home as long as possible and to stay by their side.
To have him with me, you know, right to the end would be wonderful. [smiles] That's what we all got married for, to have that security, that love and to be together right up until the end. (P002)

Adult children's relationships with their parents were also a driving force and influenced many of their decisions during transitions. Many grew up with a close family where "mom gave us a lot of caring and compassion, that's the way it was" (P006). Although they had to take on new roles and responsibilities, many saw it as a way of giving back. Again, this influenced many caregivers' thoughts around the future as they thought about having their parents move in with them. These caregivers may have been willing to take on more roles and responsibilities based on previous positive relationships and feelings of altruism. Positive bonds built on previous relationships also encouraged them to advocate for and direct their parents' care by community organizations. These relationships built on a foundation of love influenced caregivers' transition experiences by adding meaning and purpose to their role as a caregiver, making it easier to accept transitions as a part of their duty and as a part of life.

D. Support networks

The findings emphasized the importance of the availability of and access to various support networks, both formal and informal. Having a strong network of family members and friends provided caregivers with options for respite as well as emotional and mental support. Families and friends helped to facilitate a positive transition and helped caregivers cope over time. Depending on the stage of the disease, some caregivers also sought assistance and support from the community. The Alzheimer's Society was an invaluable source for caregivers as it provided education and respite services.
The family physician was often another key person in the care circle who helped link and refer caregivers to other services in the community. Often, caregivers approached their family physician and nursing staff first for advice on dementia. In addition to dementia support, some caregivers described how these HCP played an important role in noticing changes in the PWD's health.

*Our family doctor is really nice and really kind because she can see that mom's struggling with her mind and the million other [health conditions] she has. [...] She was the one who referred mom to the bone specialist because mom was falling. [...] Her doctor was the one who switched some of the medications because mom kept forgetting to take them in the afternoon. So we played with it and got a schedule that works for her now. Most of her medications are in the morning in the dosette. That’s what she recommended. So I set it up in the morning for her and she just takes it.* (P019)

Caregivers often relied on their HCP for information support as well as guidance in the management of the PWD's health conditions. HCP worked with caregivers and PWD to adjust medication scheduling, refer to specialists when needed, and provide direction when it came down to making decisions around care.

In contrast, many clinicians and caregivers who had been in contact with community agencies for home care support and relied on their services felt that there were issues with obtaining help due to strict eligibility criteria. One caregiver felt she was in a "catch-22" situation where they were not eligible for services because her mother was not "sick enough":

*[Community organizations] weren't supporting us. [I was looking for] somebody to come and do this and that for mom but there's been nothing like that. You're in a catch-22, where you aren't sick enough to get [any help]. See, for my mom to get help... I don't think she's at that stage where she's sick enough to get it. There's a fine line, you know, a real fine line. I think a lot of it is just talk. It's really... it's really iffy. It really is. My mom just never seemed to fall into that category.* (P005)
Other caregivers were looking for support to help manage co-morbid conditions with the dementia and felt that the system currently does not offer services for persons with complex concurrent co-morbid conditions in addition to dementia. For example, caregivers of persons with dementia and diabetes were unable to find any support in the community for insulin management for PWD:

*Anyone I've contacted, including the Diabetes Association and Alzheimer's Society, they don't have provisions for type I diabetics with Alzheimer's. That is probably one of the biggest gaps in their whole system. I can't get a nurse who is willing to come down and make sure he gets his insulin dosages during the day (P004)*

Formal support networks in the community were just as important as informal support networks as they provided the opportunity for the PWD to remain longer in their homes. PWD and MCC have complex needs and often required just as much support for their co-morbid conditions as they did with the dementia piece of their care. The lack of appropriate support networks in the community therefore made it difficult for caregivers to continue to provide adequate care for these seniors who had complex multi-faceted needs.

**E. Finances**

The final factor that influenced many of the caregivers' transitions was related to adequacy and availability of finances. Finances affected caregivers' thought processes about the future. It influenced the decisions that were made by caregivers and how they anticipated and prepared for the future. Because there were inadequate community supports and services, caregivers often had to look at different ways to supplement care for the PWD if they wished to keep them at home in the long run. The problem was that
"the only option now would be private care; that's all you can get right now and it comes at a fairly costly price" (P018).

Some caregivers also struggled with personal finances. Adult children tended to have their parents move in with them into their own house. In some cases, adult children moved into their parent's house instead to provide care. In these cases, there was a question about what would happen financially, if the PWD moved permanently into an institution.

Well... I stopped working and I was able to live with her. When we got the CCAC involved, they were involved for long-term care. [...] The whole thing got me thinking, "Where am I going to go after?" Because when she is out of here, this house is going up for sale. This is her house. I sold mine when I moved here. And I didn't make much out of it, and now I have nothing. (P013)

Housing, whether it be residential, apartment or retirement homes, seemed to bring up many questions and issues with finances. Caregivers were often willing to go as far as quit their jobs and sacrifice opportunities of employment to provide care for the PWD. Others had no choice as they were not eligible for any support from the community. Finances were a huge barrier and negatively affected their transition experiences.

On the contrary, although there were some great services in the community through organizations such as the Alzheimer's Society, some of them still came with a price. Some caregivers and seniors who were tight on cash could not even afford subsidized volunteer or respite visits. Others were unable to afford transportation to attend support groups or day programs. Others simply did not want to have to pay for any services. As a result, many caregivers had no choice but to stay with the PWD and had no opportunities to turn "off" as a caregiver. Availability of funding support would have
ensured that caregivers had the opportunity to take time away from their role as a caregiver and focus on themselves. The availability of funding facilitated successful transitions in that families were better able to afford services and help to keep the PWD and MCC safely at home. In some ways, this also helped to facilitate previous commitments related to staying at home.

**Conclusion: Factors influencing transitions**

Both caregiver and clinician participants acknowledged that "caregiving is a very individual thing because each dementia patient is unique, and each caregiver is unique" (P001). Therefore, the ways in which each of the factors affected each transition were different. There were often multiple other factors (such as demographics) that overlaid the situation and had to be considered. As such, although these are some key factors that influence transitions, they are not all-inclusive and cannot always be predictive. They are however, important and should be considered in the main transition experiences that these caregivers go through.

**Outcomes Associated with Transitions**

The final results section concludes with a synthesis of outcomes identified across the transitions in this study. Caregivers were at different points in their caregiving journey. While some people were new to the caregiver role and slowly easing into some of these transitions, other caregivers were well into the process, and others had been able to make it through the process and arrive at various outcomes. The three main outcomes of transitions identified were: (a) acceptance and/or denial, (b) coping, and (c) new meanings in relationships.
A. Acceptance/denial

The first outcome of transitions was acceptance and/or denial of the situation. Caregivers often felt shocked and upset when they first found out about the diagnosis of dementia. Initially, caregivers felt a lot of anger and resentment towards the PWD. Over time, some caregivers actively sought out support, education and knowledge about the disease in order to better understand their situation. When caregivers finally understood that the behaviours and changes in personality were not the fault of the PWD but instead, the disease, they were better able to manage their own emotions and accept the person for who they were:

*I think the hardest thing is the management of my feelings. I try to keep reminding myself that it's the disease, it's not her. The things that she sometimes says are really hurtful. But she doesn’t really mean them. So it's... it's trying to keep the resentment out of the situation [...] I understand now and can keep reminding myself, “This isn't her. It's the disease that's causing this.”* (P014)

By accepting that any hurtful behaviours and comments were not intentional, they were able to see the PWD in a new light and come to accept the situation. Some caregivers went through trial and error and observed the fluctuations in changes in behaviour day-to-day before they were able to come to a place of peace with where they were at:

*Caregiving is both frustrating and it's demanding, and... yet it's a necessary part of life right now [...] It's a learning experience, it's day-to-day. It's not something you can predict over a long period, you just have to work at it one day at a time. And that's okay.* (P004)

These caregivers understood that they could not have total control over every aspect of caregiving and sometimes had to go along with the journey just as one did with life. On the contrary, thoughts about not having control over the future often caused conflict
within some caregivers. Arguably, caregivers who were holding back the future were in
denial. Despite knowing the eventual outcome of the disease, they were still trying to stall
the process. These caregivers usually anticipated the future, however they did not take
steps towards preparing for it. Many went with the philosophy that they "will cross those
bridges as they show up" (P001). Despite acknowledging that future planning was
difficult and that plans did not always work out, many caregivers still described holding
off on making any big decisions until the time comes:

Five years ago, I set down a five year plan. We're four years into it and we're still here!
I had figured in five years, with the way he was, I figured he'd be in a [nursing home]
and I would be in an apartment. Well obviously, that's not happening! [...] Now I may
not be able to maintain this building for much longer and give him the flexibility to go
downstairs [holding back tears]. I don't know where I would go. But, to get to the point
that I can't manage this building, and I have to sell it, I'll make that decision when the
time comes."(P009)

Often, for these caregivers, the thought of not having control over the future was
overwhelming. They were in denial and often did not start to accept and appreciate the
situations that they were in until they ended up with a "catastrophic event" such as
hospitalization.

As the dementia and other MCC progressed to later stages, caregivers often had to
make difficult decisions regarding the PWD's care on their behalf. Caregiver participants
who had reached some level of acceptance about the situation seemed to be able to cope
better when it came down to making difficult ethical decisions regarding care. For
instance, some PWD had chronic conditions that required invasive surgical management.
Some caregivers sat down with the PWD's family physician and specialists to talk about
the risks and benefits of certain treatments, and to discuss options for care. Caregivers
often chose not to have the PWD undergo surgical intervention for tumours and large kidney stones because of the risk of delirium and prolonged post-operative recovery. They had to make the difficult decision around the management of many end-stage co-morbid conditions. Caregivers generally opted for comfort care as opposed to aggressive medical treatment as they felt that they did not want them to suffer anymore.

*I'm tired of putting mom through tests. There has to be an end to it. You know? I can't do this to her anymore. I know she doesn't want to be poked and prodded. [...] I'm all for her being healthy and whatnot but, now it's just a matter of getting her through the next two [oncologist] appointments, and then I'm going to let it go. Leave it as it is. Let her be happy. At her last doctor appointment, we talked about Do Not Resuscitate forms. If anything happens, we decided to just let her go. That's not easy but... I—I don't want her to suffer. And I think she is suffering the way she is. You can just see it. You know? It's terrible. I feel very, very badly. (P019)*

It takes a certain level of strength, understanding and acceptance on the caregivers' part to be able to make the decision to not pursue certain treatments near the end-of-life. Overall, as caregivers learned to accept the PWD for who they are, let go of control over the future, and understand caregiving as a learning experience, many were able to accept the situation and better cope with the disruptive changes in their emotional and mental health.

**B. Coping**

The next outcome of transitions was related to coping. Clinician participants explained that "some caregivers transition and cope beautifully, while some just crash and burn out like no other" (C002). It is important to note that coping was very individual and depended on various factors, including the caregiver themselves. When caregiver participants talked about coping, they often referred to dementia as opposed to other chronic conditions. For the most part, as caregivers learned more about how the disease
affects one's awareness and comprehension, they learned positive coping strategies and were better able to deal with difficult situations:

_Seriously, to keep a healthy mind, you gotta let it go. You gotta let it go and just focus on the moment. Focus on what's going on, right now. [...] Cause five minutes from now, she doesn't remember. And, it's gone. It's gone from her memory, you know, a lot of the time she doesn't remember anyway, you know what I mean? So you have to let it go.”_ (P006)

A large part of caregivers' ability to focus in the moment was an understanding that the PWD would never change and accepting the reality of the disease. As one caregiver said, "You gotta learn to mellow out, because, she can't change" (P005). As caregivers better understood and accepted that the behaviours of their family member were related to the disease and not the person, they were able to reflect in the moment and focus on the positive aspects of their experience. They could accept the unpredictability of the disease and started to take things day by day:

_We just live with it. We don't dwell on it. I don't let it affect me that way because I know it's not good. I try to drop what's not good and focus on what is good. [...] Definitely take it day by day. Yeah, because we forget about yesterday and we don't worry about tomorrow._ (P013)

Ultimately, caregiver participants who had knowledge of the disease process and had come to a level of acceptance were better able to "choose which particular battles [they were] going to fight" (P007). This helped caregivers get through difficult times as they were able to let go of situations that were out of their control and understand how the disease affected the PWD.
C. New meanings in relationships

The final outcome of transitions was related to finding new meanings in relationships. Spousal caregivers described developing new positive relationships with their partners despite the dementia and MCC. The relationship with the PWD was an important factor that influenced this outcome in that spousal caregivers who had a strong relationship built on love and commitment were able to find further joy and appreciation for their role as a caregiver. A few of the more elderly spousal caregivers found that "taking care of them is very rewarding" (P002). These caregivers made it a priority to ensure that the PWD knew that they were loved and cared for. This helped the caregiver to feel a sense of fulfillment, where both the caregiver and the PWD were sharing and giving love and affection:

_I make sure to never raise my voice or something like that. I make sure she knows she's loved and cared for and needed, and she is. You know? It's a fact. I need her as much as she needs me. Once you get that through your head, everything changes. [...] As far as caring for her is concerned, there is nothing I would want to do more than to look after her because she's such a wonderful person, eh? And she's been a wonderful person to me all her life._ (P017)

These caregivers recognized that "dementia people still have a lot of love to give; as long as you're giving, they give in return" (P002). This sense of reciprocity and duty to watch over the PWD helped caregivers cope day-to-day and look at caregiving in a positive manner. Many caregivers, not just spousal caregivers, were grateful for the opportunity to remain beside the PWD. Many felt that compared to other situations, they were quite lucky in that they were healthy and were financially stable. This allowed caregivers to be appreciative of their situations and their relationships with the PWD.
Conclusion

Caregivers experienced various outcomes such as acceptance/denial, coping, and finding new meanings in relationships, depending on the process of transition and the factors influencing those transitions. Again, this list is not comprehensive; however it covers the common overarching outcomes, both positive and negative, experienced by caregivers in this study. Because caregivers were at various stages of caregiving, not all of them experienced transition outcomes.

Chapter Conclusion

Caregivers experienced five main complex transitions throughout the dementia trajectory, including a progressive increase in responsibilities, changes in roles and relationships, changes in health and well-being, changes in social boundaries, and changes in preparing for the future. These transitions were influenced by different factors, with MCC playing an important role by adding a layer of complexity to the caregivers' transition experiences.
Chapter 5: Discussion

In this final chapter, I provide a discussion about the study's findings on transitions, dementia caregiving, as well as MCC. Four key findings are described in the context of the existing literature. This is followed by a discussion on the implications for practice, education, policy and research. The chapter ends with a summary of the strengths and limitations of the study.

Discussion: Overview

This study makes an important new contribution to the understanding of family caregivers' experiences in caring for an older adult with dementia and MCC. The study highlights the inherent complexity of caregivers' dementia transition experiences when caring for a PWD, and how the presence of MCC further complicates this process. This study makes four key contributions to the literature. First, study findings emphasizes that the co-existing nature of dementia and MCC complicates care management, with dementia often taking precedence over other chronic conditions. Second, the study highlights the multitude of transitions in multiple roles and responsibilities of these caregivers. Third, caregivers of PWD and MCC are often faced with difficult decisions when it comes to preparing for the future. Last, the study supports the importance of formal and informal supports in facilitating positive transition experiences and supporting caregivers through the process. Each of these findings will be discussed in the following sections.
The Interaction Between Dementia and MCC

One of the most important study findings is that the co-existence of MCC with dementia adds complexity to care management for caregivers. The study is unique in that it considers the co-existence of dementia and MCC as a whole as opposed to single co-morbid conditions. Caregiver participants were providing care to an older adult with dementia and at least two additional chronic conditions, with some PWD having up to 15 additional chronic conditions. Despite these high numbers, caregiver participants focused primarily on the dementia, often finding it hard to consider other aspects of care.

The combination of MCC and dementia resulted in challenges related to care management and decision-making, thus affecting caregivers' transition experiences. Clinician participants explained how caregiver participants who were caring for someone who had dementia and related behaviours were more likely to focus on the dementia as opposed to the other conditions. Those caring for someone with responsive behaviours were often focused on managing the behaviours and ensuring that the PWD was safe. Responsive behaviours of dementia such as wandering, agitation, restlessness or aggression are the more frequently endorsed stressors of dementia caregiving (Schulz et al., 2004). Caregivers have reported these behaviours to be more distressing than assistance with daily personal tasks (Schulz et al., 2004). It is suggested that these behaviours often interfere with daily tasks and health care management routines, making it difficult for caregivers to manage other chronic conditions that may not have immediate or obvious physical manifestations.
Clinician participants in this study discussed the importance of considering other chronic conditions during transitions because if left untreated, they would continue to "brew" and contribute to the decline in dementia. There is increasing evidence that demonstrates the link between dementia and common co-morbidities among PWD, such as hypertension, diabetes, congestive heart failure, cerebrovascular disease and osteoporosis (Bauer et al., 2014; Poblador-Plou et al., 2014). In particular, stroke, diabetes, hypertension and atherosclerosis are common dementia risk factors (Bauer et al., 2014; Sahathevan, Brodtmann, & Donnan, 2011). In older populations, a history of stroke doubles the risk of dementia and the presence of more than one risk factor (such as stroke) has a synergistic effect on risk of dementia (Bauer et al., 2014; Sahathevan et al., 2011; Savva & Stephan., 2010).

Despite the fact that co-morbid conditions associated with dementia risk factors have a higher prevalence in PWD compared to those without dementia (Bauer et al., 2014), caregiver participants did not always realize that poor management of co-morbid conditions could affect cognition as they were focused solely on the dementia. For instance, clinician participants explained that caregivers may have difficulties with medication administration, especially if the PWD was resistant to taking their medications or were in denial of their own co-morbid conditions. Some caregivers may accept this resistance as part of the dementia progress and not encourage the PWD to take the medication. Lack of adherence with certain medications can have a significant impact on the cognitive and functional status of the PWD, leading to the perception that the PWD is more advanced in their stage of disease than they actually may be.
These findings can be explained in part by the fact that the public has a poor understanding of the management of risk factors for dementia and related co-morbidities (Scrutton & Brancati, 2016). Further, both HCP and caregivers may be unaware of the presence of certain co-morbidities as PWD are less likely to receive a diagnosis for other health conditions (Sanderson, 2002). A Finnish study on PWD found that 66% of participants had at least one undiagnosed disease compared to 48% of persons without dementia (Löppönen et al., 2004). Caregivers that are unaware of other existing co-morbid conditions in the PWD are unable to seek and receive the care and support needed to manage these conditions (Bunn et al., 2016; Scrutton & Brancati, 2016). This complicates their experience of transitions, as they are not supported with the appropriate knowledge and tools to manage the clinical care for the PWD.

A recent UK report by Scrutton & Brancati (2016) found that PWD were significantly more likely to have undiagnosed hypercholesterolemia, hypothyroidism, hypertension, arthritis, and vision and hearing impairment. It has been suggested that these co-morbid conditions are only detected once caregivers have noticed that these symptoms have become severe. Even when diagnosed, these patients received poorer management and treatment of their conditions (Bunn et al., 2016; Sanderson et al., 2002). Several hypotheses have been proposed for the under-diagnosis and under-management of care including: (a) the presentation of atypical symptoms in PWD; (b) communication difficulties between the PWD, caregivers and HCPs; (c) the focus on single disease processes; (d) a lack of knowledge among HCP and caregivers on how to treat and recognize symptoms, and; (e) poor medication management (Scrutton & Brancati, 2016).
Among caregiver participants who were familiar with other co-morbid conditions in the PWD, many described the challenge in managing the PWD’s symptoms. When a PWD became ill, it was often a struggle for caregivers to determine which symptoms was the result of the dementia. Caregivers often had to wait for the acute illness to pass to determine whether the dementia had progressed. Williams et al. (2016) reported similar results where caregivers were unsure about which condition was causing discomfort in the care recipient. Caregivers found it very demanding to constantly problem solve to determine if the PWD required an intervention by a physician. They often had to determine if symptoms were due to an exacerbation of a chronic condition, or if they were part of the progression of the Alzheimer’s disease (Williams et al., 2016). Further complicating the process is the fact that PWD often have difficulty expressing the symptoms that they are experiencing, making it harder to accurately treat and diagnose acute illnesses (Scrutton & Brancati, 2016).

Caregivers of PWD and MCC have a more difficult time in transitioning into taking over health management tasks, as they are constantly monitoring symptoms of dementia as well as other MCCs. As PWD continue to age, the responsibility of care and management of their MCC will likely fall onto their informal and formal caregivers. It is important for informal caregivers to be educated on dementia risk factors and the importance of health prevention so that they are better able to recognize symptoms of acute changes unrelated to dementia and to promote a more optimal quality of life.
Complex Transitions in Roles and Responsibilities

The second key finding illustrated how family caregivers had to take over more tasks over time and how these responsibilities continued to build up. The presence of MCC complicated this transition process by adding more tasks related to health care management and monitoring. Both spousal and children caregiver participants were overwhelmed with new changes to their roles and responsibilities, which affected their experience of transitions.

In particular, spousal caregiver participants explained how they had to take on new responsibilities that they had not undertaken before. Participants described having to learn many new tasks such as managing finances, learning how to cook, and managing yard and housework. These results are similar to those in the literature, which show caregivers adopting new tasks during the early stages of caregiving, starting with instrumental activities of daily living, which include cooking, driving and banking (Adams, 2006). This process can be particularly difficult for older caregivers who find themselves shifting their focus and in some ways, becoming the head of the household, when they have traditionally settled in different roles and responsibilities in the past. As caregivers take on roles previously fulfilled by the PWD, many have difficulty adjusting to their new responsibilities and often need some time to develop acceptance of their new position (Quinn et al., 2008).

Caregiver participants reported that personal care was a task that many had not imagined they would be undertaking. Caregiver participants who were providing more personal and intimate care for the PWD described the demands on their time as well as
their emotional well-being. These findings are consistent with literature, which shows that caregivers often report higher demands on their own time and energy as the PWD mental and physical well-being are compromised (Brémault-Phillips et al., 2016). Similarly, as the level of support progresses to include activities of daily living, caregivers become increasingly consumed with constant responsibilities. Caregivers often describe having never considered transitioning into the role of a caregiver, let alone assisting with tasks such as bathing, toileting or dressing (Sanders & Powers, 2009). Participant discussions around providing personal care often triggered a reflective process for caregivers, where they described their motivations for supporting the PWD at home, and factors that influenced their ability to provide care.

Some participants accepted the transition in taking on more roles and responsibilities as a natural process that was part of their relationship with the PWD. Caregiver participants who were supporting a parent with dementia felt that this was a way for them to give back to their parents and to show their gratitude. Similarly, spousal caregiver participants felt that the intimate provision of personal care was a way for them to demonstrate their love and commitment. This is similar to the finding in another study of caregivers of PWD (Brémault-Phillips et al., 2016). In this study, the participants described being generally motivated to provide support and take on certain roles and responsibilities out of love; many are motivated by a sense of duty in their role as the protector, and see it as a chance to repay and reciprocate love and dedication (Brémault-Phillips et al., 2016).
Caregiver participants described transitioning into multiple roles and wearing multiple hats, which affected their transition experiences. Some working caregiver participants were balancing paid employment with caring for their own families and young children. For adult children, their responsibilities to their spouse and children were equally as important as their parent's care, even if it meant that they were running around constantly trying to find balance. The same was found among some spousal caregiver participants, who often felt a responsibility to help with their children and grandchildren. These findings are similar to those of a study by Dunham and Dietz (2003), who found that caregivers are concerned that they will have more responsibilities than they can handle and that they will not be able to provide the care that their family members (including the PWD) deserves. Thus, those in the sandwich generation who are experiencing this transition may be particularly vulnerable to role strain and conflict due to the competing demands of caring for their aging parents as well as their own children and families (Dunham & Dietz, 2003; Dupuis et al., 2004).

Although there were only five caregiver participants in our study who were working in some capacity, these participants experienced additional transitions in their caregiving duties in relation to their professional working lives. Adult working children in this study had to rearrange their work schedules in order to accommodate the multiple appointments that the PWD had for their MCC. Some caregivers in the study went as far as giving up work opportunities in order to care for the PWD. These findings are consistent with the literature showing that caregiving has negative implications for work-related outcomes including taking time off work, reduced work hours and unavailability
for overtime work (Dupuis et al., 2004; Ory et al., 1999; Scharlach, 1994). As the baby boomers continue to age, more of this population will transition into the caregiver role while maintaining employment among many other roles.

The presence of MCC made the transition in roles and responsibilities particularly complex because family caregivers were placed in a position where they were expected to take over the responsibility of managing the health care for the PWD as well. In this study, older adults with MCC often had frequent contact with health care services and required care and treatment from different specialists. Furthermore, the presence of dementia in addition to MCC meant that caregiver participants had to compensate for memory difficulties. For example, caregiver participants were challenged with having to manage multiple medications for different conditions, while monitoring for medication side effects in the PWD. Similarly, they were constantly tracking various appointments, requiring them to make time in their own personal schedules in order to accompany the PWD. This finding is similar to other studies focusing on the experience of family caregivers caring for a PWD, where in addition to coordinating appointments, caregivers were also filling in multiple roles within the healthcare system. These other roles have included care coordination, communication with HCP and services, and information sharing/seeking about the care recipients' medical history (Bookman & Harrington, 2007; Gill et al., 2014). Caregivers' transition experiences were therefore challenged by multiple new changes and additions to their roles and responsibilities from both a dementia as well as an MCC point of view.
The third key finding indicated that caregiver participants experienced a transition in the way that they thought about and planned for the future. There was a tension described between anticipating the future and holding back the future. Caregiver participants were generally well informed of the progression of the disease and most had engaged in the thought process around what to expect in the future.

When thinking about the future, caregiver participants used various strategies in hopes of delaying the disease progression in the PWD. They took an active approach to health promotion and prevention by encouraging independence and exercise, hoping to promote both physical and cognitive well-being. The majority of caregiver participants also actively took steps in preparing their physical environment and making legal arrangements for the eventual deterioration of the PWD. In a qualitative study by Adams (2006), caregivers in the early stages of caregiving for someone with dementia or mild cognitive impairment actively sought information about the disease at the beginning of their caregiving journey. Many caregivers wanted to learn more about how to slow the progression of the disease and were less active in preparing for the future during this early stage (Adams, 2006). Authors felt that one reason for this hesitation in making decisions for future care was that the caregivers were overwhelmed with information during the early stages of caregiving. Further, caregivers struggled with envisioning their future as they felt there was too much uncertainty to be able to predict what was to come (Adams, 2006).
In the early phases of caregiving, it is not uncommon for caregivers to experience uncertainty regarding what the future holds (Dupuis, 2002). In a systematic review by Bunn et al. (2012) looking at the qualitative experience of PWD and their caregivers around the transition to dementia caregiving, caregivers described the struggle between living in the present and having to deal with the anxiety surrounding preparing for the future. This is consistent with the findings in this study, as caregivers described a tension between wanting to anticipate and prepare for the future, but at the same time, holding back due to mixed emotions and uncertainty about the future. Consistent in both the systematic review (Bunn et al., 2012) as well as this study was that as the disease progressed, caregivers became more accepting of the disease and their situation. This helped caregivers take active steps towards preparing for the future (e.g., arranging for future care).

As they moved through their caregiving journey, many caregiver participants transitioned to a point where they realized the need to think about goals for care in the future. Caregiver participants often started to prepare and think about the day that they could no longer care for the PWD on their own. Many caregiver participants wanted to have the "best" care for the PWD, which brought about concerns regarding adequacy of finances and quality of long-term care institutions. They were also concerned about maintaining the PWD's dignity and respect near the end stages of the disease. Interestingly, these conversations came up only when caregivers were faced with big treatment and care decisions related to the multiple other chronic conditions, and when the PWD was already in the moderate to severe stages of dementia.
There were several challenges that influenced caregivers' ability to plan ahead and make decisions for care. The process of thinking about the future in dementia caregiving can be distressing and difficult as certain decisions can evoke feelings of guilt and loss. Common fears regarding the future typically include the PWD's health becoming worse, the caregiver's inability to cope, and having to put the PWD in a long-term care home (Bunn et al., 2012). Further compounding these fears is the unpredictability of disease progression, difficulty in mapping out exact timelines for care and decision-making, as well as the other MCC that continue to progress at their own rate and may affect the PWD's health in the future. Caregivers also struggled with balancing their own personal needs with those of the PWD as both parties are often experiencing transitions that affect their preferences for care (Wolfs et al., 2011). Caregiver participants described consideration of the PWD's previous expressed wishes, as well as previous commitments and promises made to the PWD. These were considered within the context of options for care and sometimes complicated the decision-making process.

Some caregiver participants in the current study consulted their family physicians to learn more about the risks and benefits of treatment options such as invasive surgery. Caregiver participants often trusted their HCP and turned to them for advice when it came to making difficult decisions such as refusing surgery, signing *do not resuscitate* forms, or stopping additional testing in the PWD (e.g., bloodwork). This is consistent with a study done by Wolfs et al. (2011), who found that family caregivers of community-dwelling PWD considered several components in decision-making when it came to treatment and care. One key component that facilitated their decision-making process was
the exploration of options for care, where HCP played an important role in guiding and providing advice. This highlights the importance of shared decision-making in chronic disease management throughout the entire transition experience. It may help caregivers and HCP who are planning and preparing for the future in dementia care to consider the initiation of early advance care planning (ACP).

Eliciting health care preferences during the early stages can facilitate end-of-life decision making in dementia care (van der Steen et al., 2014). It is important for HCP to explore ACP and patient health preferences early on as families often find it difficult to distinguish between their own and patients' preferences (Dunn et al., 2013). By opening up the dialogue early on, HCP have the opportunity to educate both the caregiver and PWD about the progression of dementia, as well as the progression of other co-morbid conditions and the potential interactions that may complicate care management down the line. Multiple factors seem to influence family and HCP's initiation of ACP in dementia care, including difficulty initiating discussions due to discomfort or inexperience (van der Steen et al., 2014). Regardless, the lack of discussion about the future trajectory of the disease and management options can create additional stress on family caregivers during acute episodes. It is important for HCP to initiate discussions around ACP as early as possible, as well as reflect on these plans throughout transitions. ACP is an ongoing process that is influenced by changes in health over time. By having these discussions early and regularly, family members can have a deeper understanding of the wishes and preferences of the PWD, thus facilitating future care decisions.
When caregivers were discussing and preparing for the future, many spoke exclusively about the influence of the dementia process itself. Very few participants considered how the presence, progression and management of the other MCC alongside dementia could potentially affect the cognitive and functional status of the PWD near the end of life. Literature shows that decision-making regarding treatment and care in dementia is different from that of other chronic diseases (Bunn et al., 2016; Wolfs et al., 2011). While persons with MCC (without dementia) may have more time to consider options and make conscious choices over time, PWD are often limited by the progression of dementia and resultant cognitive deficits (Wolfs et al., 2011). As caregivers transition in preparing for the future, they will need to make difficult care decisions concerning issues not only related to dementia, but other MCC.

**The Role of Support Networks on Transitions**

The final key study finding showed that support networks were crucial in supporting participants during the transition process. Caregiver participants spoke at length about their changing networks of support. They described the importance of formal and informal support networks in helping them through their transitions experiences of caregiving.

Caregivers in the study described the fluid transitions in their relationships and boundaries with families and friends. In this study, the majority of caregivers did not hesitate to reach out to family and friends for support, which helped to expand their networks of support. The literature, however, reveals mixed findings in regards to caregivers' perceptions of support networks and their willingness to seek help (Adams,
2006; Miller & Guo, 2000; Sanders, 2007). For instance, studies have found that caregivers may limit their reliance on family members and friends; they may be ambivalent about seeking or accepting help from others and choose to hold off for as long as possible, especially if they do not have a close relationship prior to the diagnosis of dementia (Adams, 2006; Sanders, 2007). Whereas some caregivers were reluctant to ask for assistance because they felt the need to protect others from the burden of their caregiving situation, others wanted to maintain a sense of social and emotional independence from their families and friends (Miller & Guo, 2000; Sanders, 2007). Caregivers in other studies are also sometimes concerned that family and friends who do not understand the extent of the problem may criticize and judge the caregiver, resulting in negative relationships and emotions (Adams, 2006; Miller & Guo, 2000; Sanders, 2007). This was true for some of the caregiver participants in the current study who expressed concerns and discontent over the fact that other family members did not understand their situation. As such, the family members tended to distance themselves from the caregiver and the PWD resulting in feelings of isolation and frustration.

Caregiver participants who identified shrinking networks of support alluded to the possible role that stigma played in decreasing their networks of support. For example, caregiver participants suspected that the public’s cognitive attributions, perceptions and opinions about dementia led to the distancing of others from the caregiver and the PWD. They felt that if the public were more understanding and accepting of the disease, they would feel more comfortable going out of the home with the PWD. Research suggests that stigma is a potentially important determinant of caregiver burden among dementia
caregivers (Werner, Goldstein, & Buchbinder, 2010). Family stigma associated with Alzheimer's disease has various dimensions, including caregiver stigma, lay public stigma, and structural stigma (Werner et al., 2010). Together, they can result in caregiver feelings of shame, fear and pity, as well as behaviour consequences such as discrimination, concealment and distancing by those around them (Werner et al., 2010).

Aside from informal supports, caregiver participants also relied on formal support networks to help them in their transition experiences. For example, caregiver participants talked extensively about the Alzheimer Society in providing them with information and education about the disease, and preparatory support for the future. Caregiver participants also described the Alzheimer Society as a gateway to resources and services in the community. Some caregiver participants attended support groups through the Alzheimer Society and developed important new relationships with peers. Many caregiver participants looked forward to their weekly group sessions and found that the support and understanding from skilled counsellors and caregivers going through similar situations helped them better cope with their own situation. Research has shown that support groups provide caregivers with the opportunity to share personal feelings and concerns, overcome feelings of social isolation, and encourage mutuality and validation (Sorensen et al., 2006).

Participants in the study expressed mixed perceptions regarding relationships with physicians and other HCP. Caregiver participants expressed positive relationships with their family physicians, specialists and other HCP. Many felt that their HCP had a good understanding of their situation and were diligent in monitoring, adjusting, and managing
various aspects related to the PWD's other chronic conditions. On the other hand, clinician participants expressed concerns that not all physicians and HCP were trained in dementia care and had limited knowledge in understanding the effects of polypharmacy on cognition. While caregiver participants in the study felt well supported by their HCPs, recent findings show the contrary. In a mixed methods study by Bunn et al. (2016), family caregivers often felt poorly supported by their HCP in their health-related tasks. For instance, caregivers felt that they lacked the knowledge in dealing with the practicalities of medication administration, especially when it came to monitoring medication adherence.

Ultimately, both informal and formal support networks are important to caregivers of PWD and MCC as these caregivers are at risk for depression, burden and isolation. Support networks become even more important when we take into consideration the role of MCC in complicating and increasing the number of tasks and responsibilities that these caregivers must take on. These formal support networks and HCP play an important role in supporting these caregivers in future planning and management of health related tasks (Gill et al., 2014).

In summary, caregivers go through complex, simultaneous transitions that are complicated by the presence of MCC. These transitions impact their daily caregiving tasks and care decisions. Caregivers also experience changes in their roles and responsibilities, their plans for the future, as well as changing networks of support. This study highlights the unique transition experiences of caregivers of PWD and MCC and the importance of considering how MCC affects dementia caregiving experiences.
Results pave the way for important implications related to the way HCP practice, as well as key policy, education and research recommendations that take into consideration dementia and MCC.

**Implications for Practice, Education, Policy and Research**

**Practice**

Multiple practice implications can be drawn from this study to guide HCP as they support caregivers through transitions in caring for the PWD and MCC. Nurses, physicians, and other providers are in a unique position to help these caregivers plan for the future and advocate for their care needs. They play a prominent role in supporting family caregivers, as well as guiding and managing the care of PWD and MCC.

Many decisions made by caregivers regarding treatment for the PWD are made within the context of clinicians' attitudes and perceptions of dementia and MCC (Bunn et al., 2016). HCP can help caregivers understand how MCC can influence dementia, and the strategies they can use to support the management of not only dementia, but also MCC. Medication management is an important aspect of care management among HCP and caregivers. Inadequate treatment can reduce the quality of life of the PWD as well as their caregivers who may struggle with trying to identify symptoms and support the PWD. HCP need to look at medications and treatments to improve health outcomes in patients, whether they are maximizing symptom management or daily function (Holmes et al., 2013). The process of making decisions in regards to medications in PWD and MCC is complicated as treatment outcomes can sometimes contradict one another (Holmes et al., 2013).
For instance, HCPs need to recognize the importance of monitoring high blood pressure as poor management can put a patient without dementia at high risk for developing dementia, and worsen cognition in a person who already has dementia. Not only this, but HCPs need to help caregivers with managing the PWD's blood pressure. The management of MCC should have the same priority as the management of dementia as they can have synergistic negative effects on a person's health when mismanaged. Finding the right balance when it comes to risk management can be difficult in this population, especially given the presence of cognitive impairment. To help determine the most appropriate management, clinicians should consider multiple factors including the patient's age and circumstances, including remaining life expectancy, goals of care, and quality of life (Braithwaite et al., 2007; Scrutton & Brancati, 2016). Competing risks and burden of treatment options for both caregivers and the PWD and MCC should be considered (Boyd et al., 2005).

It is recommended in dementia care as well as multimorbidity that HCP shift their way of thinking and practice to consider an individualized and holistic goal-oriented approach in order to optimize decision-making and treatment appropriateness (Fried et al., 2011). Caregivers as well as PWD often place varying degrees of importance on health outcomes (Tinetti, Bogardus, & Agostini, 2004). Thus, HCP need to routinely engage and involve family caregivers in decision-making and acknowledge the important role they play as partners in care. Maintaining regular communication of information in a timely and sensitive manner with family caregivers can decrease feelings of uncertainty, frustration and isolation in care management (Gill et al., 2014). This can further facilitate
a therapeutic relationship, which is crucial during periods where caregivers are faced with making challenging ethical decisions regarding care and treatment and often feel helpless.

Focusing on building relationships with patients and caregivers will provide HCP a better understanding of their goals, and thus aid in the successful management of their diseases at home as well (Schoen et al., 2008). HCP must also educate and empower family caregivers on how to identify and monitor signs and symptoms in the PWD, and when to notify HCP if there are acute changes in cognition or other aspects of health. Ultimately, clinicians should maintain open dialogue with patients and caregivers to understand their goals in regards to quantity versus quality of life, and symptom relief versus disease prevention.

A good understanding of the caregivers’ priorities and beliefs can facilitate a plan for optimal aging as well as end-of-life concerns. HCP are therefore in an important position to help these caregivers plan for the future. Research suggests that HCP often do not consider the terminal prognosis of late stage dementia in the context of acute co-morbidities, resulting in PWD being subjected to unnecessary treatments and not receiving the appropriate end-of-life care (Scrutton & Brancati, 2016). This puts particular stress on caregivers who are placed in a position where they need to make difficult ethical decisions. HCP should engage in early discussions regarding advance care planning with caregivers of PWD as well as the PWD themselves while they still have to cognitive capacity to do so, and to promote appropriate end-of-life care. Caregivers can sometimes have a hard time coming to terms and accepting the deterioration of the PWD; emotions can inhibit their ability to make rational decisions in
regards to care and treatment (Wolfs et al., 2012). Further, some caregivers may not have recognized the importance of advance planning early on as these discussions can often be challenging. They may not have had the opportunity to have a discussion with the PWD to determine their wishes. HCP need to guide caregivers in the decision-making process by anticipating transitions in care beforehand, and outlining options for care and treatment early on in the care trajectory (Wolfs et al., 2012).

More recently, there is increased interest in the development and use of models of complexity and co-morbidity to help guide clinician practice. Zulig et al. (2015) reviewed several conceptual models and frameworks that have been proposed to help researchers and clinicians understand co-morbidity and complexity, as well as guide service delivery and promote congruence in goals between patients and providers. When utilizing a model to guide practice, clinicians should incorporate patients' health, preferences and expectations that help to shape their treatment and decision-making. What needs to be considered by clinicians when practicing in the context of dementia is the strong presence and role of the caregiver. As time progresses and the PWD's capacity declines, caregivers take over the process of decision-making. Given recent research that shows that dementia caregivers feel they are receiving inadequate support in care planning and that they were often excluded from decision-making (Bunn et al., 2016), they should also be included in the entire process with the PWD. Clinicians may find models of complexity useful in guiding their practice to meet the needs of caregivers of PWD and MCC as well as the care recipient themselves.
Similarly, clinicians may want to consider different theories of transitions to better understand the experience of transitions experienced by caregivers of PWD and MCC. Meleis' Transition Theory can be used to help guide clinicians' understanding and practice in that it focuses on different types of transitions that clinicians encounter when working with patients and their families (Meleis, 2010). The theory also considers the notion of transitions as being made up of patterns of multiple and complex factors that influence outcomes of transitions. This is consistent with the findings in the current study in that caregivers were influenced by complex factors and events, such as their support networks, finances, and the presence of MCC. By considering the various factors that influence each type of transition, both nurses and physicians can use Meleis' theory to understand which factors and patterns can facilitate or inhibit each transition experience, and therefore tailor their approach and interventions to promote positive transition outcomes.

**Education**

Because caregivers in the study identified that they trusted and often relied on their HCP as part of their extended support network, it is important that HCP are comfortable and knowledgeable in supporting these caregivers throughout their transitions. Clinicians require additional and proficient education and training in regards to dementia care. A study in Scotland showed that general practitioners (GP) have difficulties in talking with patients and caregivers about the diagnosis of dementia, responding to behavioural problems, and coordinating support services (Turner et al., 2004). One third of GPs expressed limited confidence in their diagnostic skills and unfamiliarity with current management strategies for dementia and/or local resources. Not
only GPs, but staff on all levels, including nurses, require appropriate training on
dementia care management. Some training may need to be tailored to specific conditions
(e.g., PWD living with diabetes), however all training should consider the interaction
between dementia and MCC. A better understanding of the early signs and symptoms of
mild cognitive impairment and dementia can facilitate more timely and accurate
diagnoses, leading to earlier interventions and linkages to support services for both family
caregivers and PWD through transitions. Further, preventative strategies can be
implemented earlier which may help to slow the progression of the disease and enhance
quality of life.

In addition to dementia, there is a need to educate physicians and nurses on the
importance of timely and accurate identification of co-morbid conditions as MCC is
associated with a greater risk of poor functional status, mortality, reduced quality of life
and greater use of health care services (CIHI, 2011b; Scrutton & Brancati, 2016). As
evidenced in this study, PWD often also have multiple complex co-morbid conditions.
Most concerning is that older persons with dementia suffer from a high prevalence of
undiagnosed medical conditions, many of which are preventable (Bunn et al., 2016;
Scrutton & Brancati, 2016). It is easy for HCP as well as family caregivers to lose sight of
other conditions when dealing with the responsive behaviours and emotional toll brought
on by dementia (Scrutton & Brancati, 2016). Both physicians and nurses need to become
familiar with atypical presentations of diseases within PWD. They should also be
educated on common dementia risk factors and the importance of proper management of
MCC to prevent premature cognitive and functional deterioration, as well as
exacerbations of other chronic conditions. Education related to all aspects of dementia care and the management of MCC should start early; undergraduate and graduate curriculums need to incorporate these elements and train HCP from the beginning.

In addition to physicians and nurses, there is a need to educate other clinicians and providers working in community support groups and organizations about the importance of considering MCC in dementia caregiving. Caregiver participants acknowledged the importance of community organizations and agencies in providing support and education for the caregiver themselves and the PWD. However, many organizations and groups provide single-disease, condition-specific information, peer support and guidance, without considering the impact of other chronic conditions. Not only do these community organizations need to consider the presence of other MCCs, but there is also a need for increased cohesiveness and collaboration between organizations to address the complex needs of caregivers of PWD and MCC.

Policy

Despite the increasing numbers of persons being diagnosed with dementia, as well as the increasing amount of in-home support that caregivers are providing, our system currently does not have the capacity to adequately support them, let alone support the MCC that they may also have to manage (Government of Canada, 2014; WHO, 2012). There is a need for a Canada-wide dementia strategy to help reduce the burden of dementia by providing support for PWD and MCC, and their informal family caregivers. We now know that dementia does not exist on its own (Bunn et al., 2016). Thus, a national dementia strategy should not focus solely on dementia, but should also consider
the management and impact of MCC on the PWD and dementia caregiving. Within the strategy, several issues need to be addressed including: (a) the promotion of earlier diagnosis and intervention of both dementia and other common MCC; (b) the integration of primary, home and community care; (c) increased funding for research on dementia and multimorbidity; (d) enhanced skills and training of HCP in dementia care; and, (e) increased recognition of the needs of caregivers and how to best address these needs (Alzheimer Society, 2015; Canadian Medical Association, 2013).

The Canadian Alzheimer’s Disease and Dementia Partnership [CADDP] (Alzheimer Society, 2015) recommends policy change in regards to increased focused on prevention in the area of targeted dementia screening programs. Given the high co-morbidity associated with dementia, there is also a need for increased screening and monitoring of common co-morbid conditions that also serve as dementia risk factors. As mentioned, early intervention, detection and screening by clinicians can facilitate caregivers' ability to plan for the future, including end-of-life care. Multiple health organizations (e.g., Heart and Stroke, Canadian Diabetes Association, etc) should collaborate and work on early detection and stigma reduction in dementia. They should also work to bring awareness to the fact that chronic conditions rarely exist in isolation. Collaboration between community organizations (with a focus on common co-morbid conditions in PWD) will help to target the "at-risk" group of PWD and support their caregivers through various transitions.

Although public awareness of the existence of dementia has increased over the years, many individuals still do not accept persons who are living with dementia, and few
have an understanding and appreciation of the difficulties of caregiving (ADI, 2012). A lack of understanding about dementia can lead to various misconceptions resulting in stigma on various levels. It is important to educate the public as stigma can further amplify feelings of isolation and hopelessness by caregivers and PWD, thus negatively affecting their transition experiences.

Findings from this study hint at particular challenges for caregivers who may still be maintaining employment in addition to their caregiving roles. As per the CADDP (Alzheimer Society, 2015), we should recognize and support informal caregivers by providing them with access to financial benefits through the tax system. Caregivers should have job protection and income support if they need to leave paid employment in order to care for the PWD (Alzheimer Society, 2015). Other countries have taken different approaches to financial support for caregivers. More work needs to be done to ensure that the underlying objective informing policy should always consider and recognize caregiving as valuable and that caregivers should be supported (Keefe & Rajnovich, 2007).

In regards to supporting clinicians in their practice, evidence shows that existing medical directives and clinical practice guidelines predominantly focus on single conditions, rarely provide direction for patients with multimorbidities, and are not inclusive of the role of family caregivers (Boyd et al., 2005; Tinetti et al., 2004; Upshur & Tracy, 2008). With the wide variety of chronic conditions and different guidelines targeted towards single-diseases, it is difficult for nurses and physicians to determine how to best manage all the conditions as a whole and how to support family caregivers. There
is a lack of decision-making support within these guidelines for HCP to weigh the risks and benefits of treatment for PWD and how to include family caregivers in that decision-making. Nurses and physicians therefore may need to collaborate with several specialist providers as well as draw on their own clinical experiences as well as the preferences of patients to address patients' complex needs (Shaink et al., 2012). This study suggests that HCP also need to draw on and include family caregivers to address patients' needs. Efforts should be made to increase the applicability of clinical practice guidelines and evidence for PWD and MCC and their caregivers.

There is increasing evidence that shows that undiagnosed and untreated co-morbidities in PWD is increasing health care costs by causing rapid deterioration in dementia (Scrutton & Brancati, 2016). This also causes distress in caregivers and negatively affects their experience of transitions and ultimately, their quality of life. Policies and strategies should be developed to assist clinicians with preventing, diagnosing, treating and managing co-morbid conditions in PWD in order to facilitate cost savings at a health systems level (Scrutton & Brancati, 2016). As well, systems, supports and services should be in place in the community to support caregivers in managing co-morbid conditions (e.g., diabetes and stroke). This could potentially prevent caregivers from unnecessarily bringing the PWD to emergency departments and hospitals, which can incur significant costs to the healthcare system and may be distressing to both the PWD and the caregiver.

Lastly, it is important to consider Ontario's recent plan for improving the health system, which focuses on Patient's First. The plan is committed to putting patients and
caregivers at the centre of the health care system by focusing on their needs first (Ontario Ministry of Health and Long-Term Care, 2015). As we move towards an integrated health care system that includes community-based health programs to engage HCP from all disciplines and backgrounds, all formal care providers must consider the preferences, needs, values and beliefs of both informal caregivers and PWD and MCC. HCP should consider that their goals for care may change over the course of the care trajectory as they experience various complex transitions.

Research

This study highlighted a number of areas for future research. The majority of research surrounding multimorbidity and dementia care has focused on prevalence and more recently, issues of access to care. There is a lack of qualitative research exploring patient and caregiver preferences and experiences with care. While researchers are now recognizing the importance of considering dementia within the context of other MCCs, the majority of qualitative research has focused primarily on the experience of living/caring for someone with dementia as a single disease, or the experience of living/caring for someone with dementia and only one other co-morbid condition (e.g., diabetes). Future research should explore the experience of caregiving for a PWD within the broad context of MCC as a whole (as opposed to single co-morbid conditions) to consider the impact of the different conditions on the caregiving experience. Other factors such as the influence of the broader social determinants of health on the transition experiences of caregivers of PWD and MCC should also be explored. Further, PWD in this study had an average of 10 chronic conditions in addition to the dementia. It is
important to explore what constitutes best care for these patients and their caregivers based on the combination of MCC, their stage and manifestation, and the ways in which they interact with the progression of dementia.

Similarly, little is known about HCP experience of managing and caring for PWD and MCC as well as their informal caregivers. Most studies have focused on HCP in primary care practices, which is appropriate as the point of care is currently shifting towards the community. However, it is also important to consider the experiences of HCP working in other sectors as PWD and MCC and their caregivers experience various care transitions throughout the caregiving trajectory. Those working in acute care may face different challenges given the context of their work environment and the fact that the patients they serve are typically in an acute medical crisis. Likewise, HCP in the long-term care sector should also be targeted as residents in long-term care homes have very complex combinations of chronic diseases, which are often compounded by moderate-severe cognitive impairment.

The majority of research on transition experiences has been focused on two extreme transitions. Most has focused on the early, new transition into the dementia caregiving role as well as later transitions such as the movement of the PWD into institutional care. Less research has examined the transition experiences of bereaved caregivers. Another aspect of transitions that has not been explored is the transitions of caregivers in the middle stages of caregiving. It is important to focus on the experience of family caregivers providing care to and older PWD and MCC in the community during these middle stages as they often experience inequities in access to appropriate
community supports and services to help manage their care. It could also be argued that the middle stage of caregiving is a crucial period where several practice and policy changes can be made to help maintain the status of MCC to promote the health and well-being of the PWD and MCC.

Future research should also consider the impact of co-morbidities on the experience of living and dying with dementia, and how this affects caregivers. Goal alignment and decision-making processes around care and treatment near end-of-life should be explored from the perspective of family caregivers as well as HCP who provide support during these difficult times. Given the fact that caregivers of PWD and MCC experience multiple simultaneous transitions at different points in the caregiving trajectory, more research is needed on the best approaches, strategies and interventions to support caregivers through different stages of transitions to facilitate positive outcomes.

Lastly, as the demographic of caregivers continues to change (Public Health Agency of Canada, 2014), there is a necessity to better understand the caregiving experiences of certain subgroups of caregivers such as different genders (particularly male caregivers) as well as adult working caregivers. Again, the experience of dementia caregiving should be considered within the context of MCC as it adds an additional layer of complexity that may influence how different caregivers experience transitions.

The current study provides a more in-depth understanding of the transition experiences of caregivers of PWD and MCC. It highlights key factors that must be considered in this population and how these factors can influence transitions and outcomes of transitions. Future research should consider these findings when developing
interventions, frameworks and services to best support these caregivers through their transitions with the aim of facilitating positive outcomes.

**Strengths and Limitations**

Study strengths include the variety in the sample which includes caregivers at various stages of caregiving (newly diagnosed as well as those caring for someone in the severe stages of the disease) with varied combinations of MCCs. The heterogeneity of experiences is a study strength as it highlights the unique experiences of transitions with this particular group of caregivers. Caregiver participants represented both rural and urban settings across Ontario. The variety in caregiver participants increases the transferability and applicability of results to similar contexts and populations. Another study strength involves the use of multiple strategies to enhance rigour throughout the research process. Multiple sources of data (e.g., caregivers and clinicians) enhances the credibility of the findings in this study. The use of the "thoughtful clinician test" (Thorne, 2016) throughout data collection and analysis enhanced study credibility and not only provided alternative perspectives to the experience of transitions, but also confirmed the experiences of caregiver participants in the study. Clinician participants were also varied in terms of education, background, experience and discipline, thus providing a broad understanding of the experiences of caregivers.

The study is not without its limitations. The majority of study participants were female spousal caregivers and therefore, the transitions identified may not fully represent the experiences of male caregivers and caregivers with other relationships to the PWD. Every effort was made however, to purposively recruit a variety of caregivers with
different demographics. Because this study was a sub-study of a larger mixed-methods study, the researcher was limited during recruitment to: (a) participants who had previously given consent to be contacted for future studies, (b) participants who were in the control group (to prevent co-intervention from the larger study), and (c) participants who resided within Ontario. Participants were originally recruited through the Alzheimer Society, and therefore, volunteer bias may exist within the sample as those interested in the topic may be more willing to participate. Further, because the original sample came from the membership of a caregiver support organization, it is possible that most individuals had already actively accepted and sought sources of social support, thus influencing their experience of transitions and caregiving. Further, the caregivers in the study are predominantly Caucasian and English-speaking. There were more females in the study than males, and a limited number of adult working caregivers. Thus the transferability of their experiences may be limited to other caregivers who fit this demographic profile.
Conclusion

As the population ages, we will continue to see more persons diagnosed with dementia. Among PWD, there is a high prevalence of co-morbid chronic conditions. Dementia itself has a huge impact on a person's ability to engage in health-related tasks and self-manage their own care. As such, caregivers of PWD and MCC are required to take on a complex variety of tasks and responsibilities. Caregivers experience multiple disruptive transitions that affect various aspects of their lives, including their roles and relationships, responsibilities, future plans, social support networks as well as their physical, emotional and mental health and well-being. HCP need to consider the complex interplay between transitions, dementia and MCC when providing care to this population. They should be encouraged to engage in regular communication as well as involve the PWD and their caregivers in the process of decision-making around care and treatment plans from the beginning. By building these strong relationships and including caregivers in the process of care, HCP are able to better understand and support them as they move through multiple transitions in the care trajectory.
REFERENCES


Dunhan, C.C., & Dietz, B.E. (2003). "If I'm not allowed to put my family first": challenges experienced by women who are caregiving for family members with dementia. *Journal of Women and Aging, 15*(1), 55-69.


persons with multi-morbidities, their family physicians and informal caregivers.

*BMC Family Practice, 14*(1), 1-26.


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## APPENDICES

### Appendix A

Qualitative Studies of the Experience of Caring for an Older Person with Multiple Chronic Conditions

<table>
<thead>
<tr>
<th>Study (Country)</th>
<th>Question/Research Topic</th>
<th>Setting and Participants</th>
<th>Methodology</th>
<th>Findings</th>
<th>Critique</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gill et al., 2014 (Canada)</td>
<td>To explore the care challenges experienced by older patients with multimorbidity, their informal caregivers and family physicians.</td>
<td>Toronto, Ontario 27 patient–caregiver–family physician triad interviews; 1.5 hour interviews with patients; 30 minute interviews with caregivers and physicians in the clinic Sampled from one single practice within one family health team in an urban city Interviews in participants' home or clinic</td>
<td>Qualitative description using semi-structured one-on-one interviews Interviews digitally recorded; transcribed verbatim and checked for accuracy by two RA</td>
<td>- System-level challenges identified; lack of efficient and timely information from HCPs and poor communication between care providers - Patient-level frustrations identified; challenges managing MCC and symptoms and adherence to treatment recommendations - Overlapping frustrations from all three perspectives included poor communication from and between care providers, long wait times for appointments and feedback, making decisions about care and managing multiple diseases - Provides insight and understanding on caregiver-related care challenges on a systems and personal level; helps us to understand what processes and services are lacking and that caregivers want and need to help them manage multimorbidity in the patient</td>
<td>Strength: Used an interview guide previously piloted and deemed feasible for use among complex patient populations. Three parallel data sources facilitate more comprehensive understanding of phenomenon. Limitations: Included only one single family practice in an urban setting; predominantly Caucasian, English-speaking sample; limited information on demographics of caregivers and patients to determine transferability.</td>
</tr>
<tr>
<td>Study (Country)</td>
<td>Question/Research Topic</td>
<td>Setting and Participants</td>
<td>Methodology</td>
<td>Findings</td>
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<td>Kuluski et al., (2013) (Canada)</td>
<td>1) To examine patient goals of care from the perspectives of older persons with MCC, their family physicians and informal caregivers. 2) To examine the extent of alignment between these three perspectives.</td>
<td>Ontario, Canada 28 patient-caregiver-family physician triad interviews; 1.5 hour interviews with patient and caregiver; 30 minute interviews with physicians in the clinic Sampled from a single Family Health Team in urban community Interviews in participants' home or clinic</td>
<td>Qualitative description using semi-structured one-on-one interviews Interviews digitally recorded; characteristics analyzed using SPSS version 17; qualitative data thematically analyzed using NVivo9</td>
<td>• Patient goals fell into one of 4 themes; health maintenance, health improvement, behaviour change, preparation for future needs • Caregiver goals fell into one of 6 themes; health maintenance, health improvement/symptom management, preparation for future needs, doing tasks for the patient, keeping patient safe, helping maintain dignity at end of life • Physician goals fell into one of 4 themes; help maintain patient independence; to heal, fix or improve symptoms when possible; mobilize care for patient and caregiver; address safety issues • Provides insight into caregivers' goals for the patient and the focus on future planning as well as maintenance of current status of patient</td>
<td>Strength: Used an interview guide based on a bio-psychosocial model; guide was previously piloted and deemed feasible for use among complex patient populations. Use of open ended questions to elicit the most information possible; examples of questions asked given. Limitations: Included only one single family practice in an urban setting; predominantly Caucasian, English-speaking sample.</td>
</tr>
<tr>
<td>Williams et al., (2016) (Canada)</td>
<td>How does social location influence the experience of family caregivers of older adults with MCC?</td>
<td>Alberta and Ontario, Canada 40 family caregiver interviews; 1 hour interviews Multi-pronged snowball recruitment strategy employed Interviews face-to-face or over the telephone</td>
<td>Thematic analysis of a qualitative subset of participants from a large two-province study; used semi-structured interviews Interviews were audio taped, transcribed verbatim and analyzed using NVivo</td>
<td>• Four key themes were identified: caregiving trajectory (three caregiving phases identified); work, family and caregiving; personal and structural determinants of caregiving, and; finding meaning/self in caregiving • Findings help us understand the importance of social location on family caregiving experiences, including gender, age, education, employment status, ethnicity, and degree of social connectedness</td>
<td>Strength: Provided an extensive and detailed explanation of a three stage analytical process based on Charmaz's Constructivist Grounded Theory method Limitations: Lack of description on how methodological rigor was maintained; limited by recruitment from existing quantitative study</td>
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</table>
Appendix B

Qualitative Studies of the Experience of Caring for an Older Person with Dementia and Multiple Chronic Conditions

<table>
<thead>
<tr>
<th>Study (Country)</th>
<th>Question/Research Topic</th>
<th>Setting and Participants</th>
<th>Methodology</th>
<th>Findings and Relevance</th>
<th>Critique</th>
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</table>
| Bunn et al., 2014 | To scope the extent, range and nature of research activity around dementia and co-morbidity. Looking at: prevalence of co-morbidities in PWD; current systems/structural issues relating to service organization and delivery; and patient, carer and service provider experiences and attitudes towards | International Settings of studies 1) Hospital/outpatient 2) Community 3) Primary care 4) Mixed community 5) Population-based sample Participants 1) PWD (including mild cognitive impairment, cognitive impairment and delirium) 2) Health care professionals 3) Caregivers of PWD | Scoping literature review Included both quantitative and qualitative studies Inclusion criteria and methods for review was peer-reviewed by the National Institute of Health Research | - There is a lack of continuity of health care systems and structures for PWD and MCC.  
- There is little integration and communication between providers. There is little knowledge regarding the views/experiences of PWD and their family caregivers.  
- Found that PWD did not have same access to treatment and monitoring for certain conditions compared to those without dementia.  
- Found that current models of care are focused on single diseases  
- Study reinforces that significant numbers of PWD have co-morbid conditions | Strengths: First review to look at literature on dementia and co-morbidity  
Limitations: Efforts made to look at co-morbidity, however focus was on three single conditions coexisting with dementia (diabetes, stroke, visual impairment). Methodology used means that quality of studies included in the review were not assessed; effectiveness of interventions are unknown and rigor of studies cannot be confirmed |
<table>
<thead>
<tr>
<th>Study (Country)</th>
<th>Question/Research Topic</th>
<th>Setting and Participants</th>
<th>Methodology</th>
<th>Findings and Relevance</th>
<th>Critique</th>
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<tbody>
<tr>
<td>Bunn et al., 2016 (United Kingdom, although the first phase of the study conducted a scoping literature review which included studies similar to Bunn et al., 2014)</td>
<td>To explore the impact of dementia on access to non-dementia services and identify ways of improving the integration of services for this population.</td>
<td>United Kingdom Qualitative portion: 28 PWD and MCC; 33 family caregivers; 56 Health providers (various specialties in primary and secondary care) Patient/Caregiver interviews - Conducted in their homes or at the clinic - Six patients and six caregivers interviewed individually (n=12) - 21 interviews conducted in patient-caregiver dyads (n=42) - Two interviews carried out with pairs of caregivers (n=4) - One interview carried out with one PWD and two caregivers (n=3) - Length of caregiver/patient interviews not specified</td>
<td>Mixed methods study Included: 1) An updated scoping literature review from Bunn et al. (2014); 2) A cross-sectional observational study, using comparative analysis and detailed analysis on two separate longitudinal multicentre population-based studies and; 3) Qualitative interviews/focus groups Interviews digitally recorded; thematic content analysis and constant comparative analysis was used to guide analysis; NVivo 10</td>
<td>From phase I of the scoping literature review • Similar to Bunn et al., (2014) From phase II of the cross-sectional observational phase • PWD and MCC have higher health services use in multiple areas including unpaid care, chiropody, in-patient hospital use • Prevalence: found that 17% of persons with dementia had diabetes, 18% had had a stroke and 17% had some form of visual impairment From phase III of the qualitative interviews and focus groups • Two overarching themes; (a) negotiating continuity of care, and (b) negotiating access to care • Findings reinforced those in the scoping literature review • Found that communication was poor; lack of a standardized approach to sharing patient information and lack of consideration of the interaction between conditions • HCPs acknowledged that family caregivers were vital in health care management, however this did not translate in their routine involvement of family caregivers in decision-making and appointments • Current system structures block access to care for persons with dementia • Pathways and guidelines for dementia, stroke and visual impairment do not address dementia</td>
<td>Scoping literature review Limitations similar to those in Bunn et al., (2014) Cross-sectional secondary analysis Strengths: Large sample size across the UK using existing databases. Strength of using data from longitudinal studies is the ability to show patterns and connections over time Limitations: In original database, all health conditions and service utilization were self-reported by individuals and/or informants, thus results are subject to recall bias Cross sectional design does not allow for determination of causality Authors limited to data collected from primary study and have little control over exposure and methodological decisions; this affected the sample they had to work with</td>
</tr>
<tr>
<td>Study (Country)</td>
<td>Question/Research Topic</td>
<td>Setting and Participants</td>
<td>Methodology</td>
<td>Findings and Relevance</td>
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|                |                         | HCP interviews were in-person or over telephone  
- *Five focus groups (n=29)*  
- Telephone and face-to-face interviews (n=27)  
- 30 mins in length |             |             |                        | Qualitative  
**Strengths:** Large sample size with a variety of caregivers and HCPs from a diversity of backgrounds  
**Limitations:**  
HCP volunteered to take part in study; they may have more knowledge and confidence in management of dementia and MCC to want to participate  
Authors excluded terminally ill/palliative clients who may have more complex medical issues and have different experiences |
<table>
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<tr>
<th>Study (Country)</th>
<th>Question/Research Topic</th>
<th>Setting and Participants</th>
<th>Methodology</th>
<th>Findings and Relevance</th>
<th>Critique</th>
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<tbody>
<tr>
<td>Feil et al., (2011)</td>
<td>To explore caregivers' challenges and quality-of-life issues managing diabetes in patients with dementia.</td>
<td>United States 21 caregivers of PWD and diabetes; six focus groups conducted lasting 90 mins each Recruited from geriatric and primary care clinic at a veterans administration healthcare facility</td>
<td>Qualitative study using focus groups Interviews digitally recorded, transcribed, and translated using a software coding system (ATLAS.ti 5.2.5)</td>
<td>• Results suggest that the management of diabetes in the context of dementia increases caregiver burden and stress • Behavioural and psychological symptoms of dementia are disruptive to diabetes caregiving • Caregivers lacked the tools, knowledge and information to optimally care for and manage both dementia and diabetes • Caregivers expressed wanting more support from family and health care professionals</td>
<td>Strengths: Pre-tested focus group script with small subset of caregivers and modified based on feedback Limitations: Recruitment from one health care facility only. Focus is on one co-morbid condition with dementia only. Lack of congruency in stated methodology, and strategies used to collect and analyze data (state study method as qualitative focus group study but then state that they used grounded theory methodology in their data analysis - not a method of analysis)</td>
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<tr>
<td>Study (Country)</td>
<td>Question/Research Topic</td>
<td>Setting and Participants</td>
<td>Methodology</td>
<td>Findings and Relevance</td>
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<td>Lawrence et al., (2009) (England)</td>
<td>To investigate the experiences and needs of older adults with visual impairment and dementia from the perspective of patients, their family caregivers and their care professionals.</td>
<td>London, England 19 individual case studies with a total of 52 participants (17 PWD and VI; 17 family caregivers; 18 HCPs); 1-hour interviews Recruited via services for older adults with dementia and services for older adults with low vision (e.g., Community Mental Health Teams for Older Adults, voluntary organizations, and statutory health and social care Services)</td>
<td>Qualitative study using in-depth interviews Interviews tape-recorded and transcribed verbatim and analyzed using NVivo 2. Use of constant comparison method during analysis</td>
<td>• Five core themes: (a) safety versus independence; (b) heightened disorientation and distress; (c) visual hallucinations; (d) vulnerability to isolation; (e) difficulty in accepting multiple losses • Found that lack of vision and impaired memory can manifest as disruptive behaviours • Visual impairment in the context of cognitive impairment reduced ability of the older adult to perform activities safely • Caregivers were uncertain about how to manage care for both vision and cognition • Low-vision services felt ill-equipped to manage dementia-related needs, while dementia services felt visual needs were low priority • Study highlights the need for joint collaboration between the two services to meet needs of patients with dementia and visual impairment</td>
<td>Strengths: Interview guide developed in consultation with experts in the field and based on evidence; interview guide developed in consultation with experts in the field and based on evidence; very detailed demographic information providing context on the type of participants and the severity of the patient’s illnesses Limitations: Lack of detail and description of data analysis process and decisions. Relevant, but not a comprehensive background and literature review to support study.</td>
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<td>Study (Country)</td>
<td>Question/Research Topic</td>
<td>Setting and Participants</td>
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<td>Findings and Relevance</td>
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<td>Sanders, 2007 (United States)</td>
<td>The aim of the present study is to examine two main facets of the experience that male caregivers have with their informal support networks: (1) Perceptions of the male caregivers about the willingness of their informal support networks to provide help, and; (2) Willingness of the male caregivers to ask their informal support networks for assistance.</td>
<td>Rural communities of Midwestern region of United States: 20 male caregivers (n=17 husbands; n=3 sons); interviews lasted 60-120 mins. Sampled from geriatric clinics and adult day centres; fliers in daily news column; caregivers from community education programs on Alzheimer’s disease. Interviews in participants’ home or clinic.</td>
<td>Phenomenology using semi-structured one-on-one interviews. Interviews digitally recorded; transcribed verbatim.</td>
<td>• Caregivers views on willingness of support networks to provide caregiving assistance: (a) not involved in care; (b) emergency assistance only; (c) feel free to call if we could be of help; (d) part of the caregiving team. • Also revealed caregiver's willingness to ask for assistance: (a) asked for assistance; (b) felt guilty about asking for help; (c) did not ask for help. • Study illustrates male caregivers' unique experience with relationships with their informal support networks. • While some male caregivers are willing to accept help from others or seek help themselves, not the case for everyone. • Important for rural practitioners to consider issues unique to male caregivers such as patterns for problem-solving behaviour and coping, and gender roles.</td>
<td>Strengths: Interviews completed at two points; captured changes in the caregiving over time and confirmed reliability from first interview; epistemological and theoretical perspective/approach at beginning. Limitations: Predominantly Caucasian male caregivers from rural settings; authors indicate that a lack of prolonged engagement limits their understanding of the caregiving experience.</td>
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<tr>
<td>Study (Country)</td>
<td>Question/Research Topic</td>
<td>Setting and Participants</td>
<td>Methodology</td>
<td>Findings and Relevance</td>
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<td>Sanders &amp; Power, (2009) (United States)</td>
<td>What are the changes in the roles, responsibilities, and relationships that husbands experience as they provide care for their chronically ill wives (who have memory loss and other chronic conditions)?</td>
<td>Rural communities of Midwestern region of United States 17 male spousal caregivers; Interviews in participants' home, in long-term care facility or researcher's office</td>
<td>Phenomenology Interviews digitally recorded; transcribed verbatim.</td>
<td>• First theme focused on adaption of old roles within the marital system to new roles associated with caregiving (includes issues around dignity and self-esteem)  • Second theme is related to changes within relationships between caregiver and care recipient as a result of memory loss and other chronic conditions, resulting in new types of intimacy and coping strategies  • Study shows that male caregivers, like their female counterparts, posses affective qualities when it comes to caregiving  • Caregivers can assist husband caregivers in adjusting to changes in their role and explore how the changes affect relationship status</td>
<td>Strengths: Data analyzed separately then compared; authors found a strong reliability of 0.72. Detailed explanation of data analysis process; use of data triangulation and member checking to maintain rigor. Limitations: Theoretical and philosophical approach not described in detail. Sample is limited to spousal caregivers, Caucasian and those from rural settings.</td>
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Appendix C

Interview Guide for Caregiver Participants

Interview Guide for Caregivers of Persons with Dementia and Multiple Chronic Conditions

1. Tell me what it is like to care for someone with dementia and multiple chronic conditions.

2. How do multiple chronic conditions affect your ability to care for someone with dementia?

3. Many caregivers of persons with dementia and multiple chronic conditions experience transitions, or significant changes in their role as a caregiver. Can you describe some situations where you experienced significant changes as a caregiver of a family member or friend with dementia and multiple chronic conditions?

4. What do you do to help you adapt to/manage these changes as a caregiver?

5. Have you used internet supports to help you with these changes? If yes, what type of Internet supports have you used, and how have they supported you in your transitions? Are there any particular resources that you would like to see on the Internet?
Appendix D

Interview Guide for Clinician Participants

Interview Guide for Clinicians Supporting Caregivers of Persons with Dementia and Multiple Chronic Conditions

1. Tell me what it is like to support a caregiver of a person with dementia and multiple chronic conditions? How do you believe chronic conditions affect the way these caregivers manage dementia?

2. Many caregivers of persons with dementia and multiple chronic conditions experience transitions, or significant changes in their role as a caregiver. Can you describe a situation for me of when you worked with a caregiver and a significant change they experienced?

3. What do you find facilitates, or makes it easy for family caregivers to adapt to/manage these changes? What do you find makes it difficult?

4. Have you shared suggestions for online Internet supports with caregivers? If so, what type of online or internet supports have you shared? What type of online or Internet supports do you find caregivers frequently use? In your experience, what have these caregivers found helpful? What has not been helpful?
Appendix E

Demographic Form for Caregiver Participants

The questions on this form are in reference to you, the caregiver.

1. What is your age? ________________________

2. What is your postal code? (to determine if rural, urban, or suburban) __________________

3. What is your gender?  □ Male  □ Female  □ Transgendered

4. Marital Status:  □ Single  □ Married  □ Widowed  □ Divorced/separated
   □ Other (specify): ____________________________

5. Ethnicity:
   □ Caucasian (White)  □ Southeast Asian
   □ South Asian  □ West Asian
   □ Chinese  □ Korean
   □ Black  □ Japanese
   □ Filipino  □ Other (Specify):__________________________
   □ Latin American
   □ Arab

6. Are you a:  □ Canadian citizen  □ Landed immigrant
   □ Other (specify): ____________________________

7. What is the highest level of education you completed? ____________________________

8. Are you employed?  □ Yes  □ No  If yes, are you self-employed?  □ Yes  □ No
   What do you do for work? ____________________________

9. If employed outside of the home, do you work:  □ Full-time  □ Part-time  □
   Casual  □ Other (specify) ____________________________

10. Do you as a caregiver, live with care recipient?  □ Yes □ No
    If not, where is the person you care for living? ____________________________

11. What is your relationship to care receiver:  □ Husband/wife/life partner  □ Parent
    □ Parent-in-law  □ Son/daughter  □ Sister/brother  □ Other (specify)________________

12. What is the approximate month and year that the caregiving began: ___/___ (mm/yyyy)

13. Do you get formal assistance with caregiving (ie., CCAC)?  □ Yes  □ No
    a. If yes from whom? ____________________________

14. Do you get informal assistance with caregiving (ie., other family members)?  □ Yes  □ No
    a. If yes from whom? ____________________________

15. Do you have any medical conditions?  □ Yes  □ No
    a. If yes what are they? ____________________________
16. **About the person you are caring for:** What is their age? ____ What is their gender? ____

**Data collection of Multiple Chronic Conditions (Adapted from MyTools4Care Study, REB #15-309)**

Now I would like you to tell me about any other health conditions the person you are caring for may have. **For each of the following conditions, please indicate “Yes” if the condition has been confirmed by a doctor, and indicate if this condition has been confirmed in the last 6 months.**

<table>
<thead>
<tr>
<th>Chronic Condition</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td><strong>Cardiovascular</strong></td>
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<tr>
<td>Atrial fibrillation</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
</tr>
<tr>
<td>Hyperlipidemia (high cholesterol)</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
</tr>
<tr>
<td>Coronary artery disease (include ischemic heart disease, angina, previous heart attack)</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
</tr>
<tr>
<td>Congenital malformed valve, valve heart disease or replacement</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
</tr>
<tr>
<td>Hypertension (high blood pressure)</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
</tr>
<tr>
<td>Heart failure (including heart valve disease or replacement)</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
</tr>
<tr>
<td>Peripheral vascular disease (circulatory problem in which narrowed arteries reduce blood flow to your limbs)</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
</tr>
<tr>
<td>Stroke (cerebrovascular accident or transient ischemic attack)</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
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<tr>
<td><strong>Respiratory</strong></td>
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<tr>
<td>Asthma</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
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<tr>
<td>COPD (chronic obstructive pulmonary disorder), chronic bronchitis, emphysema</td>
<td>□ Yes- more than 6 months</td>
<td>□ Yes- less than 6 months</td>
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</table>
### Chronic Condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Pulmonary fibrosis (or bronchiectasis)</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
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<tr>
<td>Other lung conditions (e.g. pulmonary fibrosis cystic fibrosis)</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
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<tr>
<td><strong>Mental/Mood Disorders</strong></td>
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<tr>
<td>Depression</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
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<tr>
<td>Anxiety</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
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<tr>
<td>Schizophrenia or bipolar disease</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
</tr>
<tr>
<td>Anorexia or bulimia</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
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<tr>
<td><strong>Gastrointestinal</strong></td>
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<tr>
<td>Stomach problem (e.g. gastric reflux or peptic ulcer symptoms)</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
</tr>
<tr>
<td>Colon problem (e.g. chronic inflammatory disease, irritable bowel syndrome, or diverticulitis)</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
</tr>
<tr>
<td>Dyspepsia (chronic indigestion or heartburn)</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
</tr>
<tr>
<td>Constipation</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
</tr>
<tr>
<td>Bowel obstruction</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
</tr>
<tr>
<td><strong>Endocrine</strong></td>
<td></td>
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<tr>
<td>Diabetes (type 1 or type 2)</td>
<td><img src="image" alt="Yes - more than 6 months" /></td>
<td><img src="image" alt="Yes - less than 6 months" /></td>
</tr>
<tr>
<td>Chronic Condition</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>------------------------------------------------------------</td>
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</tr>
<tr>
<td>Thyroid disorders</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Chronic liver disease (including chronic hepatitis or cirrhosis)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Liver</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Kidney and Urogenital Disorders</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Chronic kidney disease or failure (including other kidney disease i.e. kidney stones, alport syndrome, kidney leaking, etc.)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Recurrent urinary tract infection</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Bladder problems (including cystitis, prolapse or repair)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Bladder incontinence (does not need to be confirmed by a doctor)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Fecal incontinence (does not need to be confirmed by a doctor)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Gout</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Prostate disorders</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Sexual disorder (including erectile dysfunction)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Hearing and Vision</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Blindness and low vision</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Chronic Condition</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>---------------------------------------------------------</td>
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<td>-------------------------</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>Yes - more than 6 months</td>
<td>Yes - less than 6 months</td>
</tr>
<tr>
<td>Macular degeneration, diabetic retinopathy, Fuchs disease, and other vision disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing loss (hearing problems and vestibular disorders)</td>
<td>Yes - more than 6 months</td>
<td>Yes - less than 6 months</td>
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<tr>
<td>Neurological</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer disease or another form of dementia</td>
<td>Yes - more than 6 months</td>
<td>Yes - less than 6 months</td>
</tr>
<tr>
<td>Peripheral neuropathy (nerve damage)</td>
<td></td>
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</tr>
<tr>
<td>Epilepsy</td>
<td>Yes - more than 6 months</td>
<td>Yes - less than 6 months</td>
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<tr>
<td>Multiple sclerosis</td>
<td></td>
<td></td>
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<tr>
<td>Parkinson’s disease</td>
<td>Yes - more than 6 months</td>
<td>Yes - less than 6 months</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis/ osteoarthritis/ osteoporosis</td>
<td>Yes - more than 6 months</td>
<td>Yes - less than 6 months</td>
</tr>
<tr>
<td>Rheumatoid arthritis, other inflammatory and systemic connective tissue disorders</td>
<td>Yes - more than 6 months</td>
<td>Yes - less than 6 months</td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Painful condition (i.e. chronic back pain, fibromyalgia, tendonitis, bursitis, etc.)</td>
<td>Yes - more than 6 months</td>
<td>Yes - less than 6 months</td>
</tr>
<tr>
<td>Migraine</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

189
<table>
<thead>
<tr>
<th>Chronic Condition</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance abuse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol problems</td>
<td>☐ Yes- more than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>☐ Yes- less than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td>Other substance misuse</td>
<td>☐ Yes- more than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>☐ Yes- less than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td>Infection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic sinusitis</td>
<td>☐ Yes- more than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>☐ Yes- less than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td>HIV</td>
<td>☐ Yes- more than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>☐ Yes- less than 6 months</td>
<td>☐</td>
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<tr>
<td>Other</td>
<td></td>
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<tr>
<td>Cancer in the past 5 years (including melanoma, but not other skin cancers; including precancerous cells)</td>
<td>☐ Yes- more than 6 months</td>
<td>☐</td>
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<tr>
<td></td>
<td>☐ Yes- less than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td>Blood disorders (including anemia and low red blood cell count)</td>
<td>☐ Yes- more than 6 months</td>
<td>☐</td>
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<td></td>
<td>☐ Yes- less than 6 months</td>
<td>☐</td>
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<tr>
<td>Psoriasis or eczema</td>
<td>☐ Yes- more than 6 months</td>
<td>☐</td>
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<tr>
<td></td>
<td>☐ Yes- less than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td>Sleep wake disorders (including insomnia, sleep apnea, narcolepsy)</td>
<td>☐ Yes- more than 6 months</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>☐ Yes- less than 6 months</td>
<td>☐</td>
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<tr>
<td>Other chronic conditions – please specify:</td>
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</table>
Appendix F

Demographic Form for Clinician Participants

Clinician Demographic Form

1. What is your age? ______________________

2. What is your gender? ☐ Male ☐ Female ☐ Transgendered

3. Ethnicity:
   ☐ Caucasian (White) ☐ Southeast Asian
   ☐ South Asian ☐ West Asian
   ☐ Chinese ☐ Korean
   ☐ Black ☐ Japanese
   ☐ Filipino ☐ Other (Specify): _______________________
   ☐ Latin American
   ☐ Arab

4. Are you a: ☐ Canadian citizen ☐ Landed immigrant
   ☐ Other (specify): __________________________________________

5. What is the highest level of education you completed? __________________________

6. What is your current employment status? ☐ Full-time ☐ Part-time ☐ Casual
   ☐ Other (specify) ___________________________________________

7. What is your current position, and how long have you worked in this position?
   __________________________________________________________
   __________________________________________________________

8. Have you had any other positions in the past related to supporting family caregivers of persons with dementia and multiple chronic conditions? Please explain.
   __________________________________________________________
   __________________________________________________________
Appendix G

Consent Form for Caregiver Participants

Information and Consent Form for Caregiver Participants

Study Title: Transition Experiences of Caregivers of Persons with Dementia and Multiple Chronic Conditions: An Interpretive Description

Investigators:

Local Principal Investigator: Dr. Jenny Ploeg, RN, PhD
Professor, School of Nursing
McMaster University
Hamilton, ON, Canada
Phone: (905) 525-9140 ext. 22294
E-mail: ploegj@mcmaster.ca

Student Investigator: Annie Lam, RN, BScN
Student, School of Nursing
McMaster University
Hamilton, ON, Canada
Phone: (289) 808-8654
E-mail: lama36@mcmaster.ca

Funding Source: None

You are invited to take part in a research study conducted by Annie Lam (Masters student) and Dr. Jenny Ploeg from McMaster University. This research study is being done for Masters thesis. You have been asked to participate in this study because you are providing care for a family member or friend who is living in the community and has Alzheimer Disease or a Related Dementia and at least two other chronic health conditions.

WHY IS THIS RESEARCH BEING DONE?

The number of Canadians with Alzheimer Disease or a Related Dementia (ADRD) is growing. Many persons with ADRD also have multiple coexisting chronic conditions that can make it difficult for caregivers to manage alongside the dementia. Family members and friends provide a significant amount of in-home care for persons with ADRD and experience several transitions (changes) to their own physical and mental health, environment, roles, relationships, tasks and responsibilities.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to help us learn about and understand the different transitions (changes) that family caregivers of persons with ADRD and multiple chronic conditions experience. We want to know what kind of changes you experience, how the person with ADRD's chronic conditions affect your experience of dementia caregiving, what supports you in the changes you experience, and your use of online supports. The overall goal of this research is to better understand your experience as a caregiver in order to better support you.
WHAT WILL HAPPEN DURING THIS STUDY?

Approximately 20 caregivers like you will take part in this study. Five clinicians with experience in supporting caregivers will also take part in this study. If you agree to take part in this study, you will be asked to meet and take part in a face to face interview with the student investigator (myself) from McMaster University for about an hour. The time of the interview will be based on your availability and take place at a location most convenient for you (for example, in your home). I will ask you questions about changes you experience as a caregiver, how multiple chronic conditions affect your experience of dementia caregiving, and your use of supports (including Internet supports) to help with changes in your daily life. I will also ask you for some demographic/background information such as your age and gender. During the interviews, with your permission, I will take handwritten notes and our conversation will be audio-taped.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

The risks involved in participating in this study are minimal. It is possible that you may experience some stress or feel upset during the interview when talking about your caregiving experiences. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You are free to stop the interview or stop taking part in the study at any time. If you experience distress during the interview, with your permission, we will provide you with the contact information to the local Alzheimer's Society who will connect you with the appropriate supports and services.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR SOCIETY?

Participation in this research may not benefit you directly. You may however find it helpful to talk about your experiences. It is our hope that this study will help us to better understand the changes and challenges caregiver's face on a daily basis. The findings from this research will also help us determine the best way to help caregivers like you in the future.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Every effort will be made to keep confidential any information that is obtained during this research study. Your participation in this study is confidential. Your name or any information that would allow you to be identified will not be used. No one will know whether you participated unless you choose to tell them. Any of the findings that could identify you will not be published or made available to anyone. Your identity will remain protected in any publications or presentations of the study results.

All information you provide to us will be kept in a locked filing cabinet in the secure Aging, Community and Health Research Unit at McMaster University. Data kept on a laptop will be protected by a password. Once the study is complete, an archive of the data, without identifying information, will be kept for a period of seven years. The audiofiles recorded during the interview will also be erased/destroyed after a period of seven years following completion of the study. The findings will be published in scholarly journals as well as presented at various conferences related to caregiving.

WHAT IF I CHANGE MY MIND ABOUT BEING IN THE STUDY?

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you or your family member/friend with ADRD. You have the option of removing your data from the study at any time. If you do not want to answer some of the questions you do not have to, but you can still be in the study.
IF I HAVE QUESTIONS ABOUT THIS STUDY, WHO SHOULD I CALL?

If you have questions or need more information about the study itself, please contact Annie Lam at:
lama36@mcmaster.ca, (289) 808-8654 or Dr. Jenny Ploeg at ploegj@mcmaster.ca, (905) 525-9140 ext. 22294.

Information about the Study Results: We expect to have this study completed by approximately August 2016. If you would like a brief summary of the results, please let me know how you would like it sent to you.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.
# CONSENT STATEMENT

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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</table>

I have read the information presented in the information letter about a study being conducted by Annie Lam and Dr. Jenny Ploeg of McMaster University.

I understand the benefits and risks involved in taking part in this research study.

I understand the issue of confidentiality and who will have access to my data, including personally identifiable information.

I understand that if I agree to participate in this study, I may withdraw from the study at any time, without having to give a reason.

I will be given a signed copy of this form.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I give permission for the research team to take notes and audio-record our conversations during the interview.

I would like to have more time to consider participating in this study. The best time for a follow-up call would be: __________________________

I agree to participate in the study.

---

**Written consent of research participant:**

<table>
<thead>
<tr>
<th>Name of Participant (Printed)</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

**Consent form explained in-person by:**

<table>
<thead>
<tr>
<th>Name and Role (Printed)</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

**I wish to receive a summary of the study results**

☐ Yes  ☐ No

If Yes, please provide an address or email for which results will be sent to:

___________________________________________________________________________
Appendix H

Consent Form for Clinician Participants

Information and Consent Form for Clinician Participants

Study Title: Transition Experiences of Caregivers of Persons with Dementia and Multiple Chronic Conditions: An Interpretive Description

Investigators:

Local Principal Investigator: Dr. Jenny Ploeg, RN, PhD
Professor, School of Nursing
McMaster University
Hamilton, ON, Canada
Phone: (905) 525-9140 ext. 22294
E-mail: ploegj@mcmaster.ca

Student Investigator: Annie Lam, RN, BScN
Student, School of Nursing
McMaster University
Hamilton, ON, Canada
Phone: (289) 808-8654
E-mail: lama36@mcmaster.ca

Funding Source: None

You are invited to take part in a research study conducted by Annie Lam (Masters student) and Dr. Jenny Ploeg from McMaster University. This research study is being done for a Masters thesis. You have been asked to participate in this study because you have in the past or are currently providing support to informal caregivers (family members or friends) of persons with Alzheimer Disease or a Related Dementia and at least two other chronic health conditions.

WHY IS THIS RESEARCH BEING DONE?

The number of Canadians with Alzheimer Disease or a Related Dementia (ADRD) is growing. Many persons with ADRD also have multiple coexisting chronic conditions that can make it difficult for caregivers to manage alongside dementia. Caregivers provide a significant amount of in-home care for persons with ADRD and experience several transitions (changes) to their physical and mental health, environment, roles and relationships, and tasks and responsibilities. There is currently little understanding of how multiple chronic conditions affects the transition experiences of caregivers of persons with ADRD.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to help us learn about and understand the different transitions (changes) that family caregivers of persons with ADRD and multiple chronic conditions experience. We want to know what kind of changes these caregivers experience, how chronic conditions affect their experience of dementia caregiving, what supports caregivers in the changes they experience, and the types of online supports they use. The overall goal of this research is to better understand the experience of caregivers in order to better support them.
WHAT WILL HAPPEN DURING THIS STUDY?

Approximately five clinicians with experience in supporting family caregivers will take part in this study. Further, 20 caregivers will also take part in this study. If you agree to take part in this study, you will be asked to meet and take part in a face to face interview with the student investigator (myself) from McMaster University for about an hour. The time of the interview will be based on your availability and take place at a location most convenient for you. I will ask you questions about your experience of supporting caregivers who care for individuals with ADRD and multiple chronic conditions, and to describe significant changes that they experience. I will also ask you for some demographic/background information such as your employment and education. During the interviews, with your permission, I will take handwritten notes and our conversation will be audio-taped.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

The risks involved in participating in this study are minimal. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You are free to stop the interview or stop taking part in the study at any time.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR SOCIETY?

Participation in this research may not benefit you directly. You may however find it helpful to talk about your clinical experiences. It is our hope that this study will help us to better understand the changes and challenges caregiver's face on a daily basis. The findings from this research will also help us determine the best way to help caregivers in the future.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Every effort will be made to keep confidential any information that is obtained during this research study. Your participation in this study is confidential. Your name or any information that would allow you to be identified will not be used. No one will know whether you participated unless you choose to tell them. Any of the findings that could identify you will not be published or made available to anyone. Your identity will remain protected in any publications or presentations of the study results.

All information you provide to us will be kept in a locked filing cabinet in the secure Aging, Community and Health Research Unit at McMaster University. Data kept on a laptop will be protected by a password. Once the study is complete, an archive of the data, without identifying information, will be kept for a period of seven years. The audiofiles recorded during the interview will also be erased/destroyed after a period of seven years following completion of the study. The findings will be published in scholarly journals as well as presented at various conferences related to caregiving.

WHAT IF I CHANGE MY MIND ABOUT BEING IN THE STUDY?

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you or your family member/friend with ADRD. You have the option of removing your data from the study at any time. If you do not want to answer some of the questions you do not have to, but you can still be in the study.
IF I HAVE QUESTIONS ABOUT THIS STUDY, WHO SHOULD I CALL?

If you have questions or need more information about the study itself, please contact Annie Lam at: lama36@mcmaster.ca, (289) 808-8654 or Dr. Jenny Ploeg at ploegj@mcmaster.ca, (905) 525-9140 ext. 22294.

Information about the Study Results: We expect to have this study completed by approximately August 2016. If you would like a brief summary of the results, please let me know how you would like it sent to you.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.
**CONSENT STATEMENT**

<table>
<thead>
<tr>
<th>I have read the information presented in the information letter about a study being conducted by Annie Lam and Dr. Jenny Ploeg of McMaster University.</th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>I understand the benefits and risks involved in taking part in this research study.</td>
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<tr>
<td>I understand the issue of confidentiality and who will have access to my data, including personally identifiable information.</td>
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<tr>
<td>I will be given a signed copy of this form.</td>
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<tr>
<td>I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.</td>
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<tr>
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<tr>
<td>I would like to have more time to consider participating in this study. The best time for a follow-up call would be: ______________________________________________</td>
<td></td>
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<tr>
<td>I agree to participate in the study.</td>
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**Written consent of research participant:**

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<tr>
<th>Name of Participant (Printed)</th>
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<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

**I wish to receive a summary of the study results**

- [ ] Yes
- [ ] No

If Yes, please provide an address or email for which results will be sent to:

_____________________________________________________________________________